Towards an inclusive health service: a research report into the availability of health information for blind and partially sighted people

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1. Executive summary

1.1. Introduction

This report presents the results of research into the accessibility of health information for blind and partially sighted people.

RNIB commissioned this research to fill a gap in current research on the availability of accessible health information for blind and partially sighted people. RNIB’s aim is for all blind and partially sighted people to live in a world where they have the same rights and responsibilities as the rest of society and they can live independently. Receiving health information in a format people can read themselves is regarded as one such right. Receiving inaccessible health information can have serious consequences for blind and partially sighted people, including the loss of privacy and independence, potential risks to personal safety and the loss of patient choice.

Ten years ago, RNIB published a report, Ill Informed (RNIB, 1998), showing that the health information needs of blind and partially sighted people were not being met. Since Ill Informed, there have been policy and legal changes, which should have led to improvements. A further reason for this research, therefore, was to understand the extent to which any changes have been made.

1.2. Objectives

The primary objectives of the research were to:

- Explore blind and partially sighted people’s health information needs and experiences
- Explore policies and processes that health services have in place to meet the health information needs of blind and partially sighted people
1. Find out whether blind and partially sighted people’s views and experiences reflect the policies and processes of healthcare organisations

2. Compare the current provision of health information with the situation 10 years ago, when Ill Informed was published by RNIB.

1.3. Methodology

Research was carried out in two phases. Phase 1 involved qualitative research, which included depth interviews with twelve blind and partially sighted people and as well as seven telephone discussion groups. An online forum was also held with twelve healthcare professionals to gain their perspective on providing healthcare information to blind and partially sighted people.

Phase 2 involved three quantitative surveys: a telephone survey of 600 blind and partially sighted people, a telephone survey of 500 healthcare professionals and a postal survey of health boards and primary care trusts. The research spanned England, Northern Ireland, Scotland and Wales.

1.4. Main findings

1.4.1. Importance of providing health information in accessible formats

- Research suggests that there is a clear demand for people to read health information: the overwhelming majority of blind and partially sighted people (97 per cent) believe they have a right to accessible information, and a further 95 per cent want to receive accessible health information themselves. The vast majority of healthcare professionals (91 per cent) also agreed that it is important to provide accessible health information.
GPs and the internet were highlighted as the most important sources of health information for blind and partially sighted people.

Blind and partially sighted people require information in a range of different formats.

1.4.2. Most blind and partially sighted people are unable to access health information for themselves

The majority of blind and partially sighted people could not read the health information they received. For example, 72 per cent of the blind and partially sighted people who were surveyed could not read the personal health information given to them by their GPs.

The majority of blind and partially sighted people are not asked about their information needs: 95 per cent of those given personal health information by their GPs were not asked which reading format they required it in.

Although they received inaccessible information, blind and partially sighted people felt that their healthcare professionals were aware of their sight problems.

Blind and partially sighted people who were able to access print, either by reading large print or via assistive technology, such as speech software, are more likely to be able to read the health information they were given than those who could not access any printed material.

1.4.3. Inaccessible information has serious consequences

Receiving health information in inaccessible formats compromises patients’ privacy because, in order to access it, they are forced to ask others to read it to them.

Having to rely on others to read health information to them means a loss of independence for blind and partially sighted people.
● When health information is delivered verbally, too much responsibility is placed on the patient to remember important information accurately. This can lead to patient safety issues, for example when taking prescribed medicines.

● Inaccessible information can cause missed appointments. Over a fifth of blind and partially sighted respondents (22 per cent) said they had missed an appointment due to information being sent in a format they could not read themselves.

1.4.4. Barriers to the provision of health information

There are attitudinal, educational and organisational barriers to health information being provided in accessible formats. Some themes emerge in terms of overcoming these barriers:

The importance of blind and partially sighted people requesting accessible health information

Blind and partially sighted people are not asking for their health information to be provided in formats they can read for themselves, which may reinforce the perception of healthcare professionals that it is not required. The reasons for not requesting information are varied:

● Asking takes too much effort.

● Blind and partially sighted people are often unaware of the full range of formats available to them (most people are aware of just two formats) and are not informed enough to ask for anything other than the inaccessible information they receive.

● The majority of blind and partially sighted people (65 per cent) had not heard of any legislation designed to protect them from discrimination in the provision of health information. As a result, people are unable to confidently challenge the provision of inaccessible information. The research found that there is a need
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to increase awareness of the Disability Discrimination Act among particular groups, namely females; those who are not in work; those in lower socioeconomic groups; and those aged over 60.

● Around a tenth of blind and partially sighted people (11 per cent) said they do not want to receive health information in accessible formats because they do not want to be labelled as being different. This conflict highlights the need for service providers to present accessible information as a mainstream element of their service and of patient choice, rather than a special provision.

The fact that blind and partially sighted people are not asking for health information in accessible formats may reinforce healthcare professionals’ belief that they do not want it (more on this to follow).

The importance of healthcare professionals asking about individual accessibility preference for health information

● The study found that healthcare professionals rely on other people, most often non-professionals such as relatives and carers, to relay health information to blind and partially sighted people they are treating; 28 per cent wrongly believed that blind and partially sighted people preferred to receive information this way.

● The majority of healthcare professionals (73 per cent) said that either their organisation does not have a clear policy on meeting the information needs of blind and partially sighted people, or that they did not know whether it did or not.

● The majority of healthcare professionals felt they lacked sufficient training on the information needs of blind and partially sighted people (71 per cent) and did not have the means to produce accessible information (62 per cent).
The importance of communication with service providers by primary care trusts and health boards

- Very few primary care trusts or health boards contractually require service providers to promote equal access to health information for blind and partially sighted people. So there is no compulsion on service providers to meet their health information needs.

- Although the majority of primary care trusts and health boards do provide some support and guidance for service providers, the majority of healthcare professionals surveyed were unaware of it. This suggests poor communication between primary care trusts and health boards on the one hand and healthcare professionals on the other.

1.4.5. Little has improved in 10 years

- Findings from the current research suggest that there has been little headway in meeting the recommendations made by Ill Informed (RNIB, 1998) and that the Disability Discrimination Act has failed to ensure that blind and partially sighted people using health services receive personal and general information for themselves.

- It is difficult to make a direct comparison with the situation described in Ill Informed, because that report centred on a survey of health authorities. These no longer exist because the structure of the NHS has changed in the past 10 years. Furthermore, although Ill informed did report on the experiences of blind and partially sighted people, it did not include an extensive survey of blind and partially sighted service users.

- However, in spite of these difficulties, it is clear that now, as in 1998, the majority of blind and partially sighted people are not being asked for their individual reading needs and are not receiving health information in accessible formats, let alone their preferred reading formats. The recommendations made in the Ill Informed report have not been implemented.
1.5. Conclusions and recommendations

The research suggests that several interventions are required to overcome the barriers to accessible health information, to translate good intentions into action. These should focus on three main areas:

● Education, raising awareness and challenging perceptions
● Empowerment
● Organisational change and service development.

The study suggests that there are three target groups for interventions: blind and partially sighted people, healthcare professionals, and commissioners of primary care trusts and health boards.

Blind and partially sighted people

● Blind and partially sighted people need to feel empowered to make the link between accessible information and the ability to make personal, confidential decisions about their own healthcare. Access to information is a right, not a privilege.

● Blind and partially sighted people need to be facilitated in improving their knowledge of the range of accessible formats, the rights and options open to them, and their health literacy. They should be given practical support in asking for health information.

● Accessible health information should be presented as a mainstream element of patient choice, not a special provision.

Healthcare professionals

● To fill the current information gap and to dispel misleading myths, healthcare professionals need training on the consequences of inaccessible health information and the information needs and preferences of blind and partially sighted people.
All healthcare professionals need to carry out individual needs assessments, record individual reading requirements and implement systems for planning resources and delivering accessible health information.

Commissioners working for primary care trusts and health boards

Commissioners working for primary care trusts and health boards need to:

- Have a clear policy that specifically sets out how the health information needs of blind and partially sighted people will be met (pan-disability policies are not specific enough to translate into action).

- Contractually oblige service providers to meet health information requirements of blind and partially sighted people and assess them against specific objectives (e.g. investigating and recording individual requirements and providing staff training on giving accessible health information).

- Provide, circulate and promote guidance on how to meet the information needs of blind and partially sighted people.

- Improve lines of communication with frontline providers, so that they are aware of policies, processes, systems and support for meeting the health information requirements of blind and partially sighted people.
2. Introduction and objectives

2.1. Introduction

This report presents the results of qualitative and quantitative research into the availability of health information in accessible formats for blind and partially sighted people.

‘Accessible formats’ are ones that blind and partially sighted people can read themselves, without assistance. ‘Health information’ covers a wide range of different types of information relating to health and healthcare and can either be personal or general.

Personal health information is either confidential or vital to a patient. It includes information on treatment, aftercare, test results, medication, instructions and information about appointments. General health information includes patient and other health promotional information, such as the benefits of giving up smoking, advice on how to live a healthy lifestyle and/or general advice on living with a health condition.

2.1.1. The need for research

RNIB commissioned this study to fill a gap in current research into the availability of accessible health information to blind and partially sighted people. A literature review concluded that there were no recent, comprehensive studies investigating the accessibility of health information for blind and partially sighted people. Existing studies were either of a limited scope or they were published before recent legislative and policy developments.

RNIB’s aim is for all blind and partially sighted people to receive all health information in a format they can read themselves. Receiving health information in inaccessible formats has serious consequences for blind and partially sighted people. These include loss of privacy and independence, serious risks to personal safety (for example,
through not being able to read prescription information), worsening health inequalities, and not being able to make informed choices about healthcare.

In 1998, RNIB published Ill Informed, a report showing that the NHS was not meeting the health information needs of blind and partially sighted people, and that it did not have the policies, processes or systems in place to do so.

Since Ill Informed, there have been legislative and policy changes that should guarantee the right of blind and partially sighted people to receive health information in formats they can read themselves. However, RNIB is concerned that, despite these changes, the NHS is still not meeting the health information needs of blind and partially sighted people. Research published since Ill Informed, although not comprehensive, seems to support that view.

Given the research gap, as well as the serious consequences of receiving health information in inaccessible formats and the indication that the information needs of blind and partially sighted people are still not being met, there was a clear need for further research.

RNIB therefore commissioned this study to provide a clear and comprehensive understanding of the current situation in the UK. The study involves blind and partially sighted people, healthcare professionals, primary care trusts and health boards across England, Northern Ireland, Scotland and Wales.

2.2. Objectives

The primary objectives of the research were to:

● Explore blind and partially sighted people’s health information needs and experiences
Introduction and objectives

• Explore the policies and processes that health services have put in place to meet the health information needs of blind and partially sighted people

• Find out whether blind and partially sighted people’s views and experiences reflect the policies and processes of healthcare organisations

• Compare the current provision of health information with the situation reported in Ill Informed, published by RNIB in 1998.
3. Background

3.1. Ill Informed

In 1998, RNIB published a report, Ill Informed (RNIB, 1998), showing that the health information needs of blind and partially sighted people were not being met.

Ill Informed described a situation in which:

● Few hospital trusts contractually required service providers to give information in accessible formats

● Few attempted to identify blind or partially sighted people

● Most hospital trusts had no clear procedures or guidelines for staff to follow in terms of ensuring that blind and partially sighted people received health information in accessible formats.

The report also made a number of recommendations for the provision of health information to blind and partially sighted people:

● Personal and general health information should be made available in a person’s preferred format.

● All health services should consult with local groups of blind and partially sighted people when developing specifications for health information services.

● Policies should be developed to ensure that the information requirements of visually impaired patients (and/or their carers) are recorded.

● All printed information should be as accessible as possible.

● All healthcare professionals should receive training in the Disability Discrimination Act 1995.
Healthcare organisations should develop and monitor internal policy regarding the provision of accessible information.

3.1.1. Limitations

Despite its usefulness as a point of comparison, it must be noted that although Ill Informed did report on the experiences of blind and partially sighted people, it did not include an extensive survey of blind and partially sighted service users. It is also difficult to make a direct comparison with the situation at the time of the Ill Informed report in 1998 because the structure of the NHS has changed. This means we cannot make a direct comparison with responses to the survey of health organisations.

However, the information that was gathered for the 1998 report allows us to better understand the situation facing the majority of blind and partially sighted people ten years ago. It therefore provides us with a valuable means of comparison.

3.2 Legislative context

At the time of Ill Informed, the duties of the Disability Discrimination Act 1995 were already in force. Under the Disability Discrimination Act 1995, all disabled people have a right to equal access to NHS services. As made clear by the Disability Rights Commission, this includes the right to health information.[Footnote 1] Since 1999, all service providers have been under a duty to make reasonable adjustments in order to meet the needs of disabled users. This includes making reasonable adjustments to meet the health information needs of blind and partially sighted people.

The Disability Discrimination Act 2005 introduced new duties on public bodies, including the Disability Equality Duty, which came into force in December 2006. This Duty reinforces those under the Disability Discrimination Act 1995, as well as adding a new duty on public bodies
to promote disability equality. The Disability Equality Duty has two parts:

1. **General disability duty**, which requires all public bodies to actively promote disability equality. Under this duty, public bodies must (among other things):

   a. Promote equality of opportunity between disabled people and other people.
   
   b. Eliminate discrimination that is unlawful under the Disability Discrimination Act.
   
   c. Promote positive attitudes towards disabled people.
   
   d. Make steps to take account of a disabled person’s disability, even where that involves treating them more favourably than other people.

2. **Specific disability duty**, which places a requirement on certain public bodies to:

   a. Produce and publish a disability equality scheme and action plan setting out how the organisation will promote disability equality.
   
   b. Involve disabled people in producing the scheme and action plan.
   
   c. Demonstrate that they have taken the actions outlined in the scheme and achieved appropriate outcomes.
   
   d. Report on progress and review and revise the scheme in order to promote disability equality.

3.3. Policy context

Prior to designing the qualitative and quantitative research, a policy review was conducted to:

- Understand the legislative and policy context in which provision of accessible health information to blind and partially sighted people should be understood.

- Assess what evidence there is for healthcare services developing policies and guidance that will help identify blind and partially sighted patients’ information needs and address them effectively.

In the context of health information for blind and partially sighted people, there are two strands of policy that are particularly relevant. The first is policy designed to ensure implementation of duties and responsibilities under the Disability Discrimination Acts. Policy in this area has been developed by government, public bodies, trade associations and the NHS. The second strand is policy designed to increase patient choice in the NHS, which, in order to be effective, requires access to health information.

3.3.1. Policy on implementation of the Disability Discrimination Act 2005

National and local government policy

Several governmental bodies have drafted policy documents to help public bodies understand their obligations under the Disability Discrimination Act 2005. Policy documents uncovered by the policy review were:


Disability Rights Commission (2004): You Can Make a Difference


These governmental policy documents act as general, pan-disability guides. They are therefore of limited use in helping healthcare organisations understand how the Disability Discrimination Act translates into a duty to provide accessible health information. The policy review did not uncover any policy documents, produced by governmental bodies, which focus specifically on meeting the needs (either general or health information) of blind and partially sighted people. Those that mentioned the general or health information needs of blind and partially sighted people did so only briefly and in general terms.

Policy produced by trade associations and charities

The policy review uncovered some policy documents produced by trade associations and charities, looking at how public organisations (sometimes specifically health organisations) can meet their obligations under the Disability Discrimination Act. Trade association and charity policy documents found in the policy review were:


Both documents focus on meeting the needs of disabled patients in the context of GP surgeries. The British Medical Association report is a pan-disability policy report, providing guidance to GPs on how to meet their general obligations under the Disability Discrimination Act 2005. Unlike the government policy papers, the British Medical Association report focuses in more detail on different disabilities and briefly considers the communication needs of blind and partially sighted patients. However, it provides little practical guidance in terms of how to meet duties towards blind and partially sighted patients.

The Guide Dogs for the Blind paper builds on research by Nzegwu (2004, see below), which suggested that very few blind and partially sighted patients were being provided with accessible health information. The policy paper provides detailed guidelines and action points to support GP practices in providing health information to patients who are blind or partially sighted. It is unclear, however, how widely circulated the Guide Dogs for the Blind document is.

**Policy produced by primary care trusts and health boards**

The policy review found very few policy documents on accessible health information had been produced by healthcare organisations themselves. However, one primary care trust, Liverpool Central Primary Care Trust, published a policy document – Accessible Health Information: Project Report.[2]

Accessible Health Information outlines recommendations for meeting the requirements of the Disability Discrimination Act 1995. For blind and partially sighted patients, these include:

- Ensuring that health information is available in large print and braille, on computer disk, audiotape/CD, and accessible websites

Ensuring alternative reading formats are publicised on the front cover of all leaflets

Ensuring that alternative formats are available in hospitals, waiting rooms, libraries and other public buildings

Producing a catalogue listing every health information leaflet and the formats that it is recorded in

Recording patients’ health information access needs using electronic healthcare records.

Conclusion

Overall, existing policy documents aimed at the implementation of the Disability Discrimination Act 2005 are too broad to provide practical, actionable guidance on meeting the health information requirements of blind and partially sighted people. The policy review suggests a need for more detailed guidance on implementation.

3.3.2. Patient choice

The current national policy trend in health services is to increase patient choice. Following the Department of Health’s 2006 White Paper, Our Health, Our Care, Our Say, patient choice has increasingly been introduced into NHS services. Patients can now choose the time and place for many elective (pre-planned) hospital treatments.

In his influential report, High Quality Care for All: NHS Next Stage Review, Lord Darzi makes clear that patient choice will remain a central feature of the NHS going forward and sets out his intention for patient choice to be entrenched in the NHS constitution:

“We believe that choice should become a defining feature of the service. A health service without freedom of choice is not personalised. So the right to choice will now be part of the NHS Constitution, ensuring that people become more clearly aware of it.”[3]
In order to make effective choices, patients need access to good quality health information in a format that meets their individual needs. This is highlighted (in the context of social care services) by Baxter, Glendenning and Clarke (2008):

“To make informed choices, people need information. The process of finding and using information has costs for individuals in terms of effort, time and material resources. These costs are different for different people and impact on their use of information in different ways. Thus the accessibility of information is important in ensuring those people who need to make choices can do so in an informed way.”[4]

Baxter et al. make clear the importance of access to health information for patients when they both expect and are expected to make choices about their healthcare and treatment plans.

3.4. Review of existing research

Alongside the policy review, a literature review was also conducted. This was to assess the existing research into the provision of health information. Furthermore, it was to examine the following:

● Whether healthcare organisations are developing policies and guidance for staff, to enable them to identify and address the health information needs of blind and partially sighted patients and;

● The availability of accessible health information to blind and partially sighted people in a range of different health settings.

The literature review found that there was very limited research into whether healthcare organisations are developing policies and guidance for staff. The staff need this information to enable them to identify and address the needs of blind and partially sighted people. Research identified by the review fell into two broad categories:

- Limited scope and/or less recent research into the availability of accessible health information to blind and partially sighted people.
- Studies reviewing existing research into the health information needs of blind and partially sighted people (these suggested a need for further research into the health information needs of blind and partially sighted people).

3.4.1. Research into the availability of health information to people who are blind or partially sighted

All studies looking at the accessibility of health information to people who are blind or partially sighted found that blind and partially sighted people are not receiving health information and/or that health information is not widely available in accessible formats.

Nzegwu (2003) found that “...insufficient information and awareness about the needs of blind and partially sighted people currently exist within the NHS”. [5]. She surveyed 832 blind and partially sighted people to explore recent experiences of GP primary care, hospital outpatient services and hospital inpatient services.

Nzegwu found that, among those who had used GP services (percentage unknown), the majority (95 per cent) had never received personal or general health information in their preferred reading format, and 89 per cent had never asked to receive it in this format. Nzegwu also found that 97 per cent had never received or asked to receive braille or large print prescriptions and that 95 per cent had never received or asked to receive large print medicine labels.

For hospital inpatient and outpatient services, Nzegwu reports on personal health information and forms but not general health information. Among those who had used hospital outpatient services (percentage unknown), 90 per cent had never received “appointment letters and all other related correspondence” (personal health information) in their preferred format. Six per cent had asked for this information in their preferred format but did not receive it (overall percentage of those requesting this information unreported).

Among those who had used hospital inpatient services (percentage unknown), 96 per cent had never received any “letters of admission or other documents relating to their stay in hospital” (personal health information) in their preferred reading format (percentage of those requesting this information unreported); 35 per cent had been asked to fill in forms as part of the admission process. Of these, 76 per cent could not read the forms themselves.

For the purposes of this research project, Nzegwu’s study is limited in a number of respects. First, her research was carried out prior to the introduction of the Disability Discrimination Act 2005 and the Disability Equality Duty. Therefore, it does not pick up any potential change in practice following the introduction of this legislation. Second, its scope is limited to blind and partially sighted people themselves. It does not include healthcare organisations or healthcare professionals. Third, there are no reported quotas for age ranges, gender, type of sight condition, reading needs, socioeconomic group or geographic location. This means
that experiences cannot be segmented according to demographic characteristics. Fourth, her study does not include urgent care or community pharmacy settings. Finally, since the scope of her study is “experiences in general” rather than experiences of access to health information, there is no in-depth study of access to health information.

In a review of health information leaflets, Cryer (2008) found that just seven per cent of the 103 leaflets included in the review explicitly stated that they were available in alternative formats. The leaflets were sourced from the NHS, governmental departments, pharmacies, health governing bodies, private healthcare providers and pharmaceutical/health supplies companies. The leaflets covered a range of different health issues, based on National Service Frameworks (national standards set to improve services for high priority health issues). The majority of those that explicitly stated they were available in alternative formats were produced by public bodies (the NHS and other government bodies). Cryer’s study, though indicative of a lack of generally accessible health information, was restricted to a review of health information leaflets and, therefore, is not a comprehensive study of the accessibility of health information.

In a consultation carried out for RNIB on equality for disabled people, Stapleton (2007) found concern among blind and partially sighted participants about their difficulties in accessing health information. The consultation, “The Future of Equality for Disabled People”, involved 36 blind and partially sighted people, across five telephone consultation groups. Participants discussed a range of issues facing blind and partially sighted people in the UK and spontaneously raised issues relating to health information. These issues included not being able to read information about prescriptions, frustration at a lack of centralised information on patients’ reading needs (leading to the need to repeatedly inform healthcare professionals of their reading needs) and long waiting times for receiving health information in accessible formats.
Stapleton’s study is indicative of inadequate provision of accessible health information. However, access to health information was not explored systematically and differences in experiences of different socioeconomic groups were not explored. Participants were recruited from a pool of 600 RNIB members, who were invited to participate in the consultation. Participants were not screened and there were no quotas for gender, age range, geographic location, ethnic group, or type of sight loss.

Beverly, Bath and Booth (2003), in a systematic review of literature on the health information needs of blind and partially sighted people, found that, although “access to and provision of information is key to reducing health inequalities in health and social care”, such “information is not always accessible and does not always meet the needs of specific groups. One such group is people who are visually impaired.”[6]

Clark (2002), in a review of barriers to accessing health information, found that there are “many ways in which the National Health Service is currently not complying with the Disability Discrimination Act, regarding the accessibility of information”.[7] Clark’s report, however, was published before the introduction of the Disability Discrimination Act 2005 and was based on research carried out prior to 2000: Cawthra (1999), RNIB (1998a), RNIB (1998b) and Deaton (1993). Therefore, it does not provide a picture of access to health information after the introduction of the Disability Discrimination Act 2005.

[7] Ibid., p.77.
In a survey of 1,076 people with ‘uncorrectable’ sight impairments, Bruce and Baker (2001) found that 30 per cent could not “read the labels and instructions on medicines or small print letters from the doctor or hospital”. Forty per cent said that they found it difficult. Bruce and Baker’s study, however, was published prior to the introduction of the Disability Discrimination Act 2005. Furthermore, it focuses on the experiences of blind and partially sighted people themselves and does not look at the attitudes, behaviour or policies of healthcare professionals, primary care trusts or health boards.

Many past studies of access to health information for blind and partially sighted people have focused on particular areas of health information, such as information on healthy living or sexual health. Hall et al. (2000) found that blind and partially sighted people miss out on health promotion campaigns due to inaccessible information. They recommended that health promotion campaigns should involve promotion of information through talking newspapers and that general health information should be available in accessible formats. Hayes (1999), in a study of information about sexual health, found that information about sexual health is not accessible to blind and partially sighted people. While these studies raise concerns about the availability of accessible general health information, they are limited in two senses. First, they do not provide a comprehensive picture of access to health information for blind and partially sighted people across a range of different health settings. Second, they were carried out prior to the introduction of the Disability Discrimination Act 2005.

3.4.2. Studies reviewing existing research into the health information needs of blind and partially sighted people

Studies focusing on existing research into the health information needs of blind and partially sighted people have found that there is a lack of such research.
Background

Baxter and Glendenning (2008) found that there is “no government-related or other recent research evidence on the specific information needs for some user groups and services”. Furthermore, they found that “there are surprisingly few empirical studies examining the unique health information needs of [blind and partially sighted people]”. [8] They found that much existing research is of poor quality and argued that further research, combining qualitative and quantitative methods, is necessary to fill the gap.

Moore (2000) found that research into the health information needs of blind and partially sighted people is “patchy”, but argued even so that it shows a clear picture of unmet need.

In a study whose primary focus was the related field of social care information, Beverley and Bath (2004) found that there are “surprisingly few empirical studies which have examined the health information needs of [blind and partially sighted people]”. [9]


3.4.3. Conclusions

Neither any individual study nor the studies taken as a whole, provide a complete enough picture of the accessibility of health information to meet the objectives of this research programme (see objectives above).

Key limitations of the existing research:

- The studies are limited in the type of healthcare setting reviewed. They do not (either individually or collectively) provide sufficient information to build up a robust picture of access to health information across a broad range of different healthcare settings.

● The studies are limited in the type of health information reviewed. They do not (either individually or collectively) provide sufficient information to understand whether, for example, general health information is more readily available in accessible formats than personal health information.

● The studies are limited in terms of the population surveyed: the focus is on experiences of blind and partially sighted people (not segmented by age, gender, reading needs, socioeconomic group or geographic location). There is very little information on the policies and processes of healthcare organisations or healthcare professionals.

● There is insufficient data to segment experiences of blind and partially sighted people by geographic location, gender, age, or reading preference.

● There is insufficient data to segment experiences by type of healthcare professional or their geographical location.

● There are no recent comprehensive studies, allowing for comparison with the situation in 1998, as reported in Ill Informed.
4. Methodology

4.1. Multi-method approach

This comprehensive study adopted a multi-method approach, combining qualitative and quantitative methods. These included in-depth interviews, telephone discussion groups, online forums, and postal, telephone and online surveys. Research was conducted with blind and partially sighted people, healthcare professionals and commissioning organisations (health boards and primary care trusts) and spanned England, Scotland, Wales and Northern Ireland.

Primary research was divided into two phases: qualitative and quantitative. These were preceded by a review of existing research, to ensure that this study contributed to the existing body of knowledge. The qualitative phase was used to gain in-depth insight into the views and experiences of blind and partially sighted people and healthcare professionals. It was also used to provide a framework for the quantitative research, through scoping out the range of issues to be investigated and the likely range of responses.

The second, quantitative phase involved surveys of blind and partially sighted people, healthcare professionals, health boards and primary care trusts. This phase was used to gain a clear picture of behaviours and attitudes within each of these broad audiences, and to provide robust evidence to allow comparison between different demographic or professional groups. Findings from the qualitative research were used to help interpret quantitative results.

An expert panel consisting of eight blind and partially sighted people involved in campaigning and policy development was convened at various stages throughout the research. The panel helped to steer the direction of the research and provided insight to aid interpretation of research findings.
Using a multi-method approach and conducting research with different audiences allowed us to validate the research findings and provide a fuller picture of the provision of health information to blind and partially sighted people.

**4.2. Phase 1: qualitative research**

**4.2.1. Blind and partially sighted people**

Twelve individual in-depth interviews and seven group telephone forums (comprising a total of 48 participants) were carried out with blind and partially sighted people. All participants had used health services in the past 12 months. Participants were screened during recruitment to ensure a mix of people for different genders, age ranges, geographic locations, sight conditions, reading needs and health settings or contexts experienced in the 12 months before the study started.

RNIB had anecdotal evidence to suggest that differences in people’s experiences of accessing health information would be driven by age and whether or not they could read print (including large print and clear print). Therefore group forums were divided according to these criteria. The interviews and forums explored experiences of and attitudes towards receiving health information in the following settings or contexts: GP primary care, hospital outpatient departments, hospital inpatient departments, urgent care and prescribed medicines.

**4.2.2. Healthcare professionals**

An online forum was held with 12 healthcare professionals to gain their perspective on providing healthcare information to blind and partially sighted people. This method was chosen in recognition of the difficulties in getting professionals together in one place for a focus group, and was particularly useful for obtaining the views and experiences of a diverse range of professionals across a wide geographic spread. The forum enabled participants to respond to threads in
their own time over 48 hours. Participants were drawn from England, Northern Ireland, Scotland and Wales. They work in a range of different community and hospital settings, and provide – or are responsible for providing – healthcare information.

The forum was used to explore how information is provided to blind and partially sighted patients, barriers to providing accessible health information, and policies, processes and systems for providing accessible health information.

4.3. Phase 2: quantitative research

4.3.1. Survey of blind and partially sighted people

Quantitative research with blind and partially sighted people was carried out via a telephone survey of 600 people. The survey was conducted by RNIB’s telemarketing team over September and October 2008.

The sample of 600 respondents was recruited from a pool of 10,000 blind and partially sighted people, selected at random from an RNIB database. The database holds details of all people who have contacted RNIB to use one of their 60 services and had given their consent to be contacted for research purposes. The majority are not members of RNIB.

Potential respondents were screened during recruitment to achieve quotas for gender, age, geographic location, reading ability and socioeconomic group. This was to ensure a large enough sample of blind and partially sighted people to generate robust findings and allow comparison between different demographic groups. Table 1 shows the quotas set and the final sample achieved.
Table 1. Quotas and sample for the survey of blind and partially sighted people

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Quotas</th>
<th>Sample achieved: n=600</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>300 female, 300 male</td>
<td>300 female, 300 male</td>
</tr>
<tr>
<td>Age</td>
<td>300 aged 16-44, 300 aged 45+</td>
<td>300 aged 16-44, 300 aged 45+</td>
</tr>
<tr>
<td>Geographic location</td>
<td>350 England, 150 Scotland, 75 Northern Ireland, 75 Wales</td>
<td>350 England, 150 Scotland, 75 Northern Ireland, 75 Wales</td>
</tr>
<tr>
<td>Reading Ability</td>
<td>300 print readers, 300 not print readers</td>
<td>300 print readers, 300 not print readers</td>
</tr>
<tr>
<td>Socioeconomic group</td>
<td>300 ABC1, 300 C2DE</td>
<td>270 ABC1, 315 C2DE</td>
</tr>
</tbody>
</table>

4.3.2. Survey of healthcare professionals

Quantitative research with 500 healthcare professionals was carried out through an online survey, using an established ‘omnibus’. The omnibus survey was conducted with members of a panel of healthcare professionals from across England, Northern Ireland, Scotland and Wales.

Quotas were set to ensure a large enough sample of respondents from different professional groups to be able to generate robust findings for each group and allow comparisons to be drawn between them. Table 2, next page, shows the quotas set and the final sample achieved.
### Table 2. Quotas and sample for the survey of healthcare professionals

<table>
<thead>
<tr>
<th>Professional group</th>
<th>Quotas</th>
<th>Sample achieved: n=500</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Practice nurses</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Hospital physicians</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Hospital nurses</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Community pharmacists</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Using the omnibus survey, it was not possible to set quotas for different geographic regions. The majority of professionals were located in England (88 per cent). However, there was a good geographic spread within England and there were participants from Scotland (7 per cent), Wales (4 per cent) and Northern Ireland (less than 1 per cent).

### 4.3.3. Survey of primary care trusts and health boards

Quantitative research with primary care trusts and health boards was carried out via a postal survey. Two copies of the survey (postal and electronic) were sent to each primary care trust in England and each health board in Scotland, Northern Ireland and Wales.

Postal surveys typically have a response rate of between 10 per cent and 20 per cent. To increase the response rate, each primary care trust and health board was given two follow-up telephone calls. The final sample achieved was 47 (a 25 per cent response rate).
4.4. Demographics of the sample achieved

4.4.1. Survey of blind and partially sighted people

The total sample achieved was 600. The quotas set for gender, age, geographic location and reading ability were met. There was a small deviation from the quota set for socioeconomic group, with 45 per cent of respondents being from groups A, B or C1, and 55 per cent being from groups C2, D or E.

Gender and age

The age profile for female respondents was slightly older than for male respondents, with women more likely than men to be aged over 60. This age difference may explain some differences in male and female responses to the survey.

Geographic location

The age profile of Scotland, Northern Ireland and Wales was slightly higher than that of England. The average age of respondents from England was 41, whereas in Scotland it was 57 and in Northern Ireland and Wales it was 54. Respondents from Scotland, Northern Ireland and Wales were also more likely than those from England to be aged over 60. This age difference may explain some variation in responses between those from different countries.

Reading ability and sight condition

Respondents were asked to define their own sight condition. Sixty per cent described themselves as being blind and 40 per cent as being partially sighted. Since 50 per cent of respondents could read print, this means that at least some people who defined themselves as blind could actually read print. One possible explanation for this is that they have access to assistive technology (such as scanners), which allows them to convert print into readable formats. This was the case for several participants in the qualitative research.
“If I get anything at all, I get sighted letters, but I’ve got a computer so I just scan and read [them]. I have to say I’m quite happy getting letters now that I’ve got a computer and I can scan and read and save whatever the documentation is.”

Focus group participant, male, aged 18-44, blind

Socioeconomic group and working status

Overall, 23 per cent of respondents were in work (either full or part time). Those who worked were more likely to be able to read print, more likely to be male than female and more likely to be from socioeconomic groups A, B or C1 than C2, D or E.

Ethnicity

The majority of respondents to the survey reported being White UK (93 per cent), with 6 per cent being black or minority ethnic. According to the 2001 census, 92 per cent of the UK population as a whole is White UK.

4.4.2. Survey of healthcare professionals

The total sample achieved was 500. Quotas for the types of professional were met.

Gender

It was not possible to set quotas for gender using the omnibus survey. There were slightly more men than women in the overall sample (56 per cent male, 44 per cent female). The majority of GPs, hospital physicians and community pharmacists were male. By contrast, the majority of practice nurses and hospital nurses were female.
Region

It was not possible to set quotas for the regions. The majority of respondents were from England (89 per cent). However, there was a good spread of respondents from regions across England. Given the small sample of respondents from Scotland, Northern Ireland and Wales, it is not possible to make robust comparisons between responses of professionals from different geographic regions.

Management role

Respondents were asked whether they were in a management role in which they had influence over decisions regarding personnel administration, finance, IT and/or strategic planning. This was in order to see whether they were likely to have responsibility for decisions regarding the systems, policies and processes for providing health information to blind and partially sighted patients. Forty-one per cent of respondents were in such a managerial role, and 59 per cent were not.

4.4.3. Survey of primary care trusts and health boards

There were 47 respondents to the postal survey of primary care trusts and health boards. This represents 25 per cent of the total number of health boards and primary care trusts in the UK.

The majority of respondents to this survey were primary care trusts and therefore based in England. However, there was a good geographic spread within England and there were responses from health boards in Northern Ireland, Scotland and Wales. Table 3 on page 41 shows the breakdown of respondents by region.
Table 3. Geographic spread of respondents to primary care trust and health board survey

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of trusts and health boards responding to survey responding</td>
<td>29</td>
<td>5</td>
<td>3</td>
<td>10</td>
<td>47</td>
</tr>
<tr>
<td>Per cent of total trusts/boards responding to survey [14]</td>
<td>62 per cent</td>
<td>11 per cent</td>
<td>6 per cent</td>
<td>21 per cent</td>
<td>100 per cent</td>
</tr>
<tr>
<td>Per cent of total trusts/boards in region (e.g. in England)</td>
<td>19 per cent</td>
<td>36 per cent</td>
<td>75 per cent</td>
<td>48 per cent</td>
<td>-</td>
</tr>
</tbody>
</table>

[14] n(total primary care trusts and health boards)=190.
5. People need health information they can read

Blind and partially sighted people both want and need health information in formats that they can read themselves. The consequences of not receiving readable health information are serious. This chapter explains:

● The strong demand for accessible health information
● What the health information requirements are for different blind and partially sighted people and where they most commonly seek health information
● The consequences of people receiving health information in formats they cannot read themselves.

5.1. Ninety-five per cent want accessible formats

Findings suggest a strong demand for accessible health information among blind and partially sighted people. Respondents to the survey thought accessible health information was a right and the overwhelming majority wanted to receive accessible health information themselves. This contradicts the belief, held by many healthcare professionals (28 per cent), that blind and partially sighted people are content – or even prefer – to rely on relatives, partners, carers or friends to manage their health information.

The overwhelming majority of survey respondents (97 per cent) agreed or strongly agreed that blind and partially sighted people have a right to receive health information in a format that they can read themselves (2 per cent neither agreed nor disagreed and 1 per cent either disagreed or strongly disagreed).[15]

[15] \( n(\text{all blind and partially sighted})=600.\)
People need health information they can read

The vast majority (95 per cent) also either agreed or strongly agreed that they themselves want to receive health information in accessible formats (3 per cent neither agreed nor disagreed and 2 per cent either disagreed or strongly disagreed).

These views were echoed by healthcare professionals, the majority of who (91 per cent) either agreed or strongly agreed that it is important to provide health information in accessible formats (7 per cent neither agreed nor disagreed and 2 per cent either disagreed or strongly disagreed).[16]

Some healthcare professionals were more likely than others to agree that it is important to provide health information in accessible formats. Pharmacists and hospital nurses were more likely than GPs to think that it is important (94 per cent of pharmacists and 94 per cent of hospital nurses, compared with 85 per cent of GPs).

5.2. GPs and the internet are important sources of health information

The most commonly used services among survey respondents were those provided by GPs. The majority (86 per cent) had used GP services in the past year. When asked where they would go to find health information, by far the most popular choice was going to a GP (68 per cent overall).[17]. This means that there is a particularly strong need for GP services to provide accessible health information. For many, the GP is the first port of call for any health difficulties. This is an important finding given that GPs were least likely of all the professional groups to agree that it was important to provide information in accessible formats.

[16] n(all healthcare professionals).
[17] n(all blind and partially sighted)=600.
The second most popular source of health information was the internet (31 per cent). This suggests a possibility for developing information provision to blind and partially sighted people using new technologies. However, this will not be suitable for all demographic groups. As expected, it is less suitable for people aged over 60, those from lower socioeconomic groups and those who are not in work:

- Respondents aged over 60 were far less likely to use the internet as a source of health information than those aged under 60 (6 per cent of those aged over 60, compared with 39 per cent aged 16-29, 42 per cent aged 30-44 and 32 per cent aged 45-49).

- Respondents from lower socioeconomic groups (C2DE) were less likely than those from higher groups (ABC1) to use the internet as a source for health information (21 per cent of those from groups C2DE, compared with 41 per cent of those from groups ABC1).

- Respondents not in work were less likely to use the internet as a source of health information than those in work (24 per cent of those not in work, compared with 52 per cent of those in work).

This suggests that, although the internet could be an important and useful source of health information for some groups of blind and partially sighted people, it will not meet the needs of others.

5.3. People have different needs

Blind and partially sighted respondents to the survey were asked what format(s) they would need health information to be in for them to be able to read it themselves. This question was asked for each different health setting or context they had used in the past 12 months.

Respondents were given a list of different possible formats from which to choose. This list included some formats not involving reading (face to face from a healthcare professional, over the phone from a healthcare professional, and via a relative or carer). This was so that we could fully
People need health information they can read

explore people’s own perceptions of how they needed to receive health information.

The same list of options was given for all the different health settings and contexts investigated, to allow direct comparison between settings. This list necessarily included some options that may not have been relevant or suitable in all contexts (e.g. text messages or handwritten cards). Where participants gave more than one response, they were interpreted as being able to read more than one format, rather than as requiring both.

Different socio-demographic groups had different health information requirements and preferences. However, requirements varied little between different health settings. Therefore, discussion here centres on the needs of different demographic groups, rather than requirements in different settings.

This report focuses on health information requirements as reported by respondents who had used GP services in the past 12 months (hereafter ‘GP users’), because the majority of respondents had used these services.

5.3.1. The most needed formats are audio and large print

Overall, the most commonly needed formats for health information are audiotape/CD and large print. Blind people were more likely to say they need audiotape/CD than partially sighted people. Partially sighted people were more likely to say they need large print than blind people.

There was a wide gap between the formats that people said they require and the formats that they receive (this is discussed further in section 6):
People need health information they can read

- Audiotape/CD: 42 per cent of GP users said they need audiotape. This compares with 1 per cent who receive personal health information in this format.[18]

- Large print: 41 per cent said they need large print. This compares with 3 per cent who receive personal health information in this format.[19]

- Face to face (from a healthcare professional): 25 per cent of respondents said they need information to be given to them face to face.[20]

- Phone call (from a healthcare professional): 21 per cent of respondents said they need personal health information to be provided over the phone.[21]

- Email: 20 per cent of respondents said they need personal health information by email. This compares with less than 1 per cent who said they had received it in email format in the past.[22]

- Braille: 15 per cent of respondents said they need personal health information in braille. This compares with just 1 per cent who said they had received it in this format in the past.[23]

5.3.2. Face to face and over the phone are not preferred options

Although a significant minority of people said that they need health information face to face or over the telephone from a healthcare professional, few actually prefer these options. Respondents who had used GP services were asked for their single preferred format for receiving health information. The most popular formats were large print (36 per cent) and audiotape/CD (25 per cent). Just 4 per cent preferred information face to face from a healthcare professional, and just 1 per cent preferred information over the telephone.

[18], [19], [20], [21], [22], [23] n(GP users)=518.
Receiving health information via a carer was similarly unpopular, with just 1 per cent preferring this option. This is shown in table 4, below. Verbal means of communication (face to face, over the phone and via a relative or carer) were included, even though they are not reading formats, to provide a fuller picture of blind and partially sighted people’s preferences. As explained below (section 5.4.), verbal means of communication are generally inappropriate for receiving health information.

Table 4. The single preferred reading formats of blind and partially sighted respondents

<table>
<thead>
<tr>
<th>Reading format</th>
<th>Per cent of respondents saying it is their preferred format [24]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Large print</td>
<td>36 per cent</td>
</tr>
<tr>
<td>Audiotape/CD</td>
<td>25 per cent</td>
</tr>
<tr>
<td>Email</td>
<td>15 per cent</td>
</tr>
<tr>
<td>Braille</td>
<td>10 per cent</td>
</tr>
<tr>
<td>Standard print</td>
<td>5 per cent</td>
</tr>
<tr>
<td>Face to face from a healthcare professional</td>
<td>4 per cent</td>
</tr>
<tr>
<td>Phone call from a healthcare professional</td>
<td>1 per cent</td>
</tr>
<tr>
<td>Text message</td>
<td>1 per cent</td>
</tr>
<tr>
<td>Via relative/carer</td>
<td>1 per cent</td>
</tr>
<tr>
<td>Handwritten card</td>
<td>0 per cent</td>
</tr>
</tbody>
</table>

NB: Two per cent of respondents either did not answer this question or said they do not know their preferred format.

5.3.3. One format does not fit all

Different socio-demographic groups in the survey of blind and partially sighted people had different requirements and preferences. This suggests that a variety of formats are needed and that one size does not fit all. Looking at the responses of GP users gives a good indication of the variety of formats required by different socio-demographic groups. The pattern of needs for the different demographic groups (presented below) remained constant across the other healthcare settings and contexts investigated.

Audiotape/CD

GP users were more likely to say they need information on audiotape/CD if they were blind, could not read print, were over 45 years old or lived in Scotland:

- Audiotape/CD was the most popular format among blind GP users, with 51 per cent saying they need personal health information to be in this format.[25]
- Blind GP users were more likely to say they need personal health information in audio format than partially sighted GP users (51 per cent of blind respondents, compared with 30 per cent of partially sighted respondents).[26]
- GP users who could not read print were more likely to say they need the audiotape/CD format than GP users who could read print (64 per cent of those unable to read print, compared with 21 per cent of print readers).[27]

[25] n(blind GP users)=309; n(partially sighted GP users)=209.
[26] n(blind GP users)=309; n(partially sighted GP users)=209.
[27] n(print-reading GP users)=263; n(non-print-reading GP users)=255.
People need health information they can read

- GP users aged over 45 were more likely to say they need audiotape/CD than those aged under 45 (51 per cent of those aged 45-59, compared with 39 per cent aged 30-44 and 26 per cent aged 16-29). [28]

- Audiotape/CD was also more popular among respondents from Scotland (60 per cent) than those from England (38 per cent) or Northern Ireland (30 per cent). [29]

Large print

GP users were more likely to say that they need personal health information in large print format if they were partially sighted, could read print, or were female:

- Large print was the most popular format among partially sighted GP users, with 61 per cent saying they need personal health information in this format. [30]

- Partially sighted GP users were more likely than blind GP users to say they need information in large print format (61 per cent of partially sighted GP users, compared with 28 per cent of blind GP users). [31]

- Women were more likely than men to say that they need personal health information in large print (45 per cent of female GP users, compared with 36 per cent of male GP users). [32]

[28] n(45-59 GP users)=148; n(30-44 GP users)=211; n(16-29 GP users)=43.
[29] n(Welsh GP users)=67; n(Scottish GP users)=92; n(English GP users)=296; n(Northern Irish GP users)=63.
[31] n(blind GP users)=309; n(partially sighted GP users)=209.
[32] n(female GP users)=271; n(male GP users)=247.
People need health information they can read

Face to face

GP users who could not read print were more likely than those that could read print to say they need face-to-face personal health information (32 per cent of those unable to read print, compared with 19 per cent of print readers).[33]

Phone call

Blind GP users, or those who could not read print, were more likely to say they need personal health information by phone call:

- 25 per cent of blind GP users said they need personal health information over the phone,
- compared with 16 per cent of partially sighted GP users.[34]
- 29 per cent of GP users who could not read print said they need personal health information in this format, compared with 14 per cent of people who could read print.[35]

[33] n(print-reading GP users)=263; n(non-print-reading GP users)=255.
[34] n(blind GP users)=309; n(partially sighted GP users)=209.
[35] n(print-reading GP users)=263; n(non-print-reading GP users)=255.
Email

Email was a more popular format among GP users who were blind, had lived with their sight condition for more than five years, and were born with their sight condition, aged under 60, came from England, and were in work or in socioeconomic groups A, B or C1. There was some crossover between these groups, as respondents in work were more likely to be in socioeconomic groups ABC1 than C2DE, and respondents who were blind were more likely to have been born with their sight condition.

- Blind GP users were more likely to say they need information in email format than partially sighted GP users (28 per cent of blind compared with 9 per cent of partially sighted GP users).[36]

- Those who had lived with their sight condition for more than five years, or who were born with it, were more likely to say they need the email format than those diagnosed in the past five years (29 per cent of those born with the condition and 21 per cent of those diagnosed more than five years ago, compared with 4 per cent of those diagnosed in the past five years).[37]

- GP users who could not read print were almost twice as likely as those who could read print to say they require information in email format (27 per cent and 14 per cent respectively).[38]

- GP users in England were much more likely to say they need the email format than those from Scotland, Northern Ireland or Wales (26 per cent of GP users in England, compared with 14 per cent in Scotland, 10 per cent in Northern Ireland and 13 per cent in Wales).[39]

[36] n(blind GP users)=309; n(partially sighted GP users)=209.
[37] n(GP users born with)=112; n(GP users over five years)=335; n(GP users up to five years)=71.
[38] n(print-reading GP users)=263; n(non-print-reading GP users)=255.
[39] n(Welsh GP users)=67; n(Scottish GP users)=92; n(English GP users)=296; n(Northern Irish GP users)=63.
• GP users who were in employment were more likely to say they need the email format than those not in work (44 per cent of those working, compared with 14 per cent of those not in work).[40]

• GP users from higher socioeconomic groups were more likely to say they need the email format than those in lower socioeconomic groups (25 per cent of ABC1 compared with 17 per cent of C2DE GP users).[41]

• GP users aged over 60 were much less likely than those aged under 60 to say they need the email format (4 per cent of GP users aged over 60, compared with 22 per cent aged 45-59, 29 per cent aged 30-44 and 16 per cent aged 16-29).[42]

[40] n(working GP users)=112; n(GP users not in work)=385.
[41] n(ABC1 GP users)=234; n(C2DE GP users)=272.
[42] n(45-59 GP users)=148; n(30-44 GP users)=211; n(16-29 GP users)=43.
People need health information they can read

Braille

GP users were more likely to say they need braille if they were blind, were born with their sight condition, were unable to read print or were under 60:

- 24 per cent of blind GP users, compared with 3 per cent of partially sighted GP users, said they need personal health information to be in braille.[43]

- 30 per cent of GP users who were born with their sight condition, compared with 13 per cent of those diagnosed more than five years ago and 0 per cent of those diagnosed in the past five years, said they need personal health information to be in braille.[44]

- Respondents aged over 60 were less likely to say they need braille than those aged under 60 (just 6 per cent of those aged over 60, compared with 19 per cent aged 45-59, 17 per cent aged 30-44 and 19 per cent aged 16-29).[45]

The research shows that, although certain formats seem to be more appropriate for some demographic groups than others, healthcare professionals should not treat everyone with sight loss as having the same access requirements. Individual needs vary depending on various factors including their level of eyesight, their awareness of alternative reading formats and their media literacy skills.

[43] n(blind GP users)=309; n(partially sighted GP users)=209.
[44] n(GP users born with)=112; n(GP users over five years)=335; n(GP users up to five years)=71.
[45] n(45-59 GP users)=148; n(30-44 GP users)=211; n(16-29 GP users)=43.
People need health information they can read

This is illustrated by the experiences of blind and partially sighted participants in the qualitative research. Some participants had been offered information in a format other than standard print (generally large print) but were not given a range of options from which to choose. So if this format was not accessible to them, they did not have any alternative.

“Sometimes people offer me large print, and I say not to bother because large print is more of a nuisance than anything else to me.”

Telephone forum participant, aged over 45, print reader

5.4. Inaccessible health information can have serious consequences

Failure to provide health information in a format that people can read themselves can lead to serious consequences, including health information being missed or lost all together, loss of personal privacy and independence, and various implications on patient safety. As explained below, providing information face to face or over the telephone does not always meet people’s information needs reliably.

5.4.1. Inaccessible information is a barrier to patient choice

As highlighted earlier, patient choice is central to the NHS agenda. Lord Darzi’s recent report, High Quality Care for All: NHS Next Stage Review, indicates that it will remain so.

Enabling choice for blind and partially sighted service users in health and social care can only happen when information is provided in accessible formats as standard. To exercise choice effectively, on a par with sighted users, patients need robust health information in an accessible format that they can read and refer back to themselves (see section 3.3., above).
People need health information they can read

Communicating information about patient choices though purely verbal methods (whether face to face, over the phone or via a relative or carer) is unlikely to empower blind and partially sighted people in a way that is comparable with their sighted counterparts.

5.4.2. “Too much to remember”

When information is delivered face to face or over the phone, too much responsibility is placed on the patient to remember important information accurately. This can lead to patient safety issues, such as when taking prescription medicines, or to missed appointments (and therefore delayed treatment) or inappropriate preparation for treatments.

Several respondents in the qualitative research talked about the safety risks of not being able to read information about prescriptions or labels on medication. Without written information to refer back to, some rely on the shape and colour of tablets or packaging to tell them which ones to take. If and when the shape or design changes, this can lead to taking inappropriate medication, posing a threat to their health.

“How [do] I know what units I’m doing? [It’s] always done verbally or, as I leave the inpatient care, it’ll be done in the standard form on a letter, with the doses, the medications themselves, the contraindications, when you take the medication...[but these] are too small to read even for most people, let alone someone with sight problems.”

Focus group participant, female, aged 18-45, partially sighted

“Recently, there’s been a breakdown in communications. I’ve been on two tablets I shouldn’t – one shouldn’t be taken with the other. There’s something on that to say ‘do not take with’ for the major contraindications of medication [but I can’t read it].”

Focus group participant, female, aged 18-45, partially sighted
One young participant in the qualitative research said that he attends regular, six-monthly appointments to check up on his diabetes and said that he receives verbal information about the next appointment at the end of each appointment. At the end of one appointment, he was told that he would be having a blood test at his next appointment and that he should not eat anything for 12 hours beforehand. However, as he was concentrating so hard on remembering the date and time of the next appointment, he was unable to remember this detail. Therefore, having arrived at the appointment unprepared, he could not be tested.

“They usually just tell me when I’m there when my next appointment is and I try to remember, but the last time I was there I was supposed to fast and I forgot to fast because I was trying to remember the day and the date and the time and all that.”

Focus group participant, male, aged 18-45, blind

5.4.3. Inaccessible information compromises privacy

Receiving health information in inaccessible formats compromises patients’ privacy. When health information is given in a format that the recipient cannot read themselves, their only option, if they are to access this information, is to ask someone else to read it to them. This compromises personal privacy. Participants in the qualitative research all talked about having to get others to read their personal health information to them. Many said they would rather read this private information themselves.

“If it came to it, you’d actually prefer not for someone else to read it [personal health information].”

In-depth interview participant, female, aged 35, blind

It is understood by RNIB, through general feedback, that providing information over the phone or via a relative or carer can also lead to loss of privacy. If messages are left on answer-phones then there is a danger that they will be heard by other members of the
People need health information they can read

household. If health information is passed on via a relative or carer, then there is a necessary loss of privacy.

5.4.4. Inaccessible information means loss of independence

When health information is provided in inaccessible formats, blind and partially sighted people are forced to rely on friends, family and carers to read the information to them. Some participants in the qualitative research felt that this put a strain on their relationships with others:

“You feel like all you do with your friends is ask them for help with things, while I’d rather have a friendship [based] on friendship, do you know what I mean?”

In-depth interview participant, male, aged under 45, blind

Reliance on others to read health information can become particularly frustrating when an important healthcare decision has to be made and information has to be revisited time and time again:

“There are decisions that you have to make yourself. Nobody else can make [them] for you. So you need...the wherewithal, you need all the information, all the papers to read yourself. If [it’s in an inaccessible format, then], if you want to read it over again [you have to get someone to repeat it]. Obviously my family...[will] do that, but at least if I’ve got it in braille, I can just say ‘I want to read it over again’, you know? That gives you that little bit of independence.”

In-depth interview participant, male, aged over 45, blind

Many participants in the qualitative research were still relying on their parents to provide them with health information, even though they were well into adulthood. For example, one participant in the qualitative research, aged 60, still relied on his mother, now 85, to read his health information to him. Heavy reliance on family and friends becomes more problematic as they themselves become older or develop health problems. Another participant, aged 35 and married but still living with
and heavily dependent on her parents, recognised that it was becoming more difficult for them to support her:

“[My] parents are getting on a little bit and they’ve got their own health problems. So it would be nice to be a bit more independent.”

**In-depth interview participant, female, aged under 45, blind**

### 5.4.5. Inaccessible information can cause missed appointments

Blind and partially sighted survey respondents were asked whether they had ever missed a medical appointment due to information being sent in a format they could not read. Over a fifth of respondents (22 per cent) overall said that they had missed an appointment in this way. [46] Respondents were more likely to have missed an appointment if they were blind than if they were partially sighted: 27 per cent of blind respondents compared with 15 per cent of partially sighted respondents had missed an appointment in this way. [47] Similarly, respondents who could not read print were more likely to have missed an appointment than those who could (28 per cent of respondents who could not read print, compared with 17 per cent of respondents who could). [48]

---

[46] n(all blind and partially sighted)=600.
[47] n(blind)=359; n(partially sighted)=241.
[48] n(print readers)=300; n(non-print-readers)=300.
The majority of information needs are not being met

6. The majority of information needs are not being met

6.1. The majority of blind and partially sighted people cannot read the health information they are given

6.1.1. Accessibility of health information overall

It is clear from the research that healthcare professionals, health boards and primary care trusts do think it is important to provide blind and partially sighted people with health information in formats they can read. There is, therefore, a will to provide accessible health information.

However, across all health contexts and settings investigated, the majority of blind and partially sighted patients could not read any health information they are provided with themselves. This is highlighted in table 5, below, which shows the proportion of respondents who are provided with health information in a format that they cannot read themselves. Only patients who receive information in a potentially readable format were asked whether it is a format they can read themselves. In this context, ‘readable’ means information in a format that people can go back to again and again. Therefore audiotape/CD was included, but information given face to face and over the phone was excluded.
### Table 5. Accessibility of health information by context

<table>
<thead>
<tr>
<th>Health care setting/context</th>
<th>GP services [49]</th>
<th>Hospital outpatients [50]</th>
<th>Hospital inpatients (appointment information) [51]</th>
<th>Urgent care [52]</th>
<th>Community pharmacists [53]</th>
<th>Information about prescriptions [54]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Per cent receiving a format they cannot read</td>
<td>72 per cent</td>
<td>74 per cent</td>
<td>77 per cent</td>
<td>80 per cent</td>
<td>69 per cent</td>
<td>81 per cent</td>
</tr>
</tbody>
</table>

#### 6.1.2. Accessibility of health information to different demographic groups

Across health settings, respondents who were partially sighted or who could read print were more likely to be able to read the health information they are provided with than those who were blind or could not read print. This is demonstrated by the experiences of respondents who had used GP services and/or outpatient services in the past 12 months.

[49] n(GP users given non-verbal personal health info)=382.
[50] n(hospital outpatient users given non-verbal personal health info)=170.
[51] n(hospital inpatient users given appointment info in non-verbal format)=102.
[52] n(A&E users given non-verbal info)=30.
[53] n(provided with general health info in non-verbal format)=26.
[54] n(provided with prescription info in non-verbal format)=283.
The majority of information needs are not being met

**GP users**

Some GP users were more likely than others to be able to access health information themselves. Partially sighted GP users were more likely than those who were blind to be able to read the information they are given. GP users who could read print were more likely to be able to read it than those who could not read print:

- 41 per cent of partially sighted GP users receive information in a format they can read themselves, compared with 17 per cent of blind GP users.[55]
- 45 per cent of print-reading GP users receive information in a format they can read themselves, compared with 9 per cent of those unable to read print.[56]

However, partially sighted GP users were no more likely than blind GP users to be asked what format they would like to receive health information in, and neither group was more likely to receive information in their preferred format. This suggests that people who can gain some level of access to print are simply better able to adapt to what they are given, and that it is the patients who are bearing the cost of adjustment.

[55] n(blind GP users given personal info in non-verbal format)=281; n(partially sighted print readers given personal info in non-verbal format)=186.
[56] n(print-reading GP users given personal info in non-verbal format)=199; n(non-print-reading GP users given personal info in non-verbal format)=183.
Outpatient users

Among outpatient users, again, partially sighted respondents and respondents who could read print were more likely to receive personal health information in an accessible format than blind respondents or those unable to read print:

- 90 per cent of blind outpatient users provided with non-verbal health information, compared with 51 per cent of those partially sighted, said it is not in a format they can read themselves.[57]

- 92 per cent of those unable to read print, compared with 61 per cent of those able to read print, said that it is not in a format they can read themselves.[58]

[57] n(blind outpatient users provided with non-verbal personal health info)=75; n(partially sighted outpatient users provided with non-verbal personal health info)=56.

[58] n(print-reading outpatients provided with non-verbal personal health info)=68; n(nonprint-reading outpatients provided with non-verbal personal health info)=63.
The majority of information needs are not being met

6.1.3. How well are individual needs being met? Reports of blind and partially sighted respondents

Across all health settings and contexts investigated, there was a discrepancy between the reading formats that respondents said they need and the formats that they are given. For example, among respondents who had taken prescription medicine in the past 12 months (86 per cent), the most commonly needed formats for information were large print and audiotape/CD.[59] However, the most commonly received formats for prescription information were standard print and face to face. This is shown in table 6 below, which contrasts the formats people said they need with the formats they actually receive.

The findings in table 6 suggest underuse of particular formats, such as audiotape/CD and large print. They also suggest that far greater use could be made of email (a relatively cost-efficient means of providing information) and braille. However, it should be remembered that needs differ by demographic group and that it is important to offer a choice of different formats to meet individual needs.
Table 6. Formats in which respondents need prescription information and the formats they actually received (respondents could choose more than one format).

<table>
<thead>
<tr>
<th>Format</th>
<th>Per cent saying they need this format [60]</th>
<th>Per cent saying they are given need this format [61]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Large print</td>
<td>40 per cent</td>
<td>1 per cent</td>
</tr>
<tr>
<td>Audiotape/CD</td>
<td>36 per cent</td>
<td>less than 1 per cent</td>
</tr>
<tr>
<td>Face to face from a healthcare professional</td>
<td>24 per cent</td>
<td>57 per cent</td>
</tr>
<tr>
<td>Email</td>
<td>19 per cent</td>
<td>less than 1 per cent</td>
</tr>
<tr>
<td>Braille</td>
<td>16 per cent</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Phone call from a healthcare professional</td>
<td>13 per cent</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Standard print</td>
<td>7 per cent</td>
<td>45 per cent</td>
</tr>
<tr>
<td>Text message</td>
<td>6 per cent</td>
<td>0 per cent</td>
</tr>
<tr>
<td>Via relative/carer</td>
<td>2 per cent</td>
<td>2 per cent</td>
</tr>
<tr>
<td>Handwritten card</td>
<td>less than 1 per cent</td>
<td>less than 1 per cent</td>
</tr>
</tbody>
</table>

[59] n(all blind and partially sighted)=600.
[60] n(taken prescribed medicine in last 12 months)=518.
[61] n(taken prescribed medicine in last 12 months)=518.
The majority of information needs are not being met

Table 6 shows that a quarter of respondents (24 per cent) taking prescription medicine said they need prescription information face to face, and that 13 per cent said they need it over the phone.[62] However, as noted, these forms of communication lead to reliance on memory, which can have potentially serious consequences, such as taking incorrect doses or medicines. Such consequences had been experienced by participants in the qualitative research. Therefore, their responses provide further support for the idea that blind and partially sighted people either lack awareness of or do not want to impose their health information needs.

6.1.4. How well are individual needs being met? Reports of healthcare professionals

The picture of individual needs not being met is reinforced by findings from the survey of healthcare professionals. Healthcare professionals were asked what formats they use to provide both personal and general health information to blind and partially sighted patients.

The most popular means of providing personal health information to blind and partially sighted patients were:

● Face to face (69 per cent of healthcare professionals)
● Passing information via a relative or carer (52 per cent)
● By phone (64 per cent)
● Standard print (39 per cent)
● Large print (36 per cent).

[62] n(prescription medicine takers)=518.
There was a discrepancy between what healthcare professionals said and the experiences of blind and partially sighted respondents. For each of the health settings investigated, less than 5 per cent of blind and partially sighted respondents reported having received health information in large print format. However, 36 per cent of healthcare professionals said they provide information in large print. As possible explanations for this discrepancy, the healthcare professionals in the sample may be atypical, they may have inaccurately described their provision of accessible formats or, while they do provide information in large print, they may do so infrequently.

The picture was very similar for provision of general health information. Here the most popular ways of providing health information were:

- Face to face (72 per cent)
- Via a relative or carer (56 per cent)
- By phone (54 per cent)
- Standard print (47 per cent)
- Large print (36 per cent).

The responses of professionals suggest they rely significantly on verbal methods of communication (which, as noted, do not always adequately meet the information needs of blind and partially sighted patients) and on passing on information via relatives or carers (which results in loss of independence and privacy). The under-use of braille, audiotape and email is also apparent, with just 7 per cent providing information on audiotape/CD, 7 per cent in braille and only 5 per cent by email.[63]

[63] n(all healthcare professionals)=500.
The majority of information needs are not being met

6.2. Individuals are not being asked which format they need

6.2.1. What blind and partially sighted respondents say

The research shows that there is a clear need for healthcare professionals to ask individuals with a sight impairment how they would prefer to receive information. While the overall preferences of the different demographic groups may be used as a guide to help plan resources, individual needs vary. To ensure that these individual needs are met, it is important to investigate them and offer patients a choice of different reading formats.

Responses to the survey of blind and partially sighted people suggest that healthcare professionals are not asking them about their individual needs. For example, the majority of those using GP services (85 per cent), hospital outpatient services (92 per cent) or hospital inpatient services (80 per cent) are not asked about their individual reading needs. However, the majority of blind and partially sighted people said they believe staff know about their sight condition (shown in table 7, below). This suggests that, even when staff know about patients’ sight conditions, they do not take steps to ensure that information needs are met.
The majority of information needs are not being met

Table 7. The percentage of blind and partially sighted respondents who are asked about their reading needs and the percentage who said that staff are aware of their sight condition.

<table>
<thead>
<tr>
<th>Health setting or context</th>
<th>GP services [64]</th>
<th>Hospital outpatient services [65]</th>
<th>Hospital inpatient services [66]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Per cent saying they are not asked about their reading needs</td>
<td>95 per cent</td>
<td>92 per cent</td>
<td>80 per cent</td>
</tr>
<tr>
<td>Per cent saying that healthcare professionals are aware of their sight condition</td>
<td>87 per cent</td>
<td>79 per cent</td>
<td>93 per cent</td>
</tr>
</tbody>
</table>

There were exceptions to this situation. Case study 1 (appendix 1) describes one man’s experience of being asked about his individual reading requirements and the difference this has made to his ability to manage his health condition.

[64] n(GP users)=518.
[65] n(outpatient-users given personal health information)=181.
[66] n(inpatient users given personal health information)=71.
The majority of information needs are not being met

6.2.2. What healthcare professionals say

Healthcare professionals were questioned on whether they ask blind and partially sighted patients about their individual reading needs, and, if so, how frequently. Overall, the majority of healthcare professionals reported asking at least some of the time:

- 21 per cent of healthcare professionals said that they ask all the time.
- 32 per cent said that they ask some of the time.
- 24 per cent said that they do ask, but only rarely.[67]

There was an apparent discrepancy between the responses of healthcare professionals and the experiences of blind and partially sighted survey respondents. However, two points should be taken into account when interpreting the responses of healthcare professionals.

First, studies have shown that, when asked (for the purposes of research) to say how frequently they perform a desired or required behaviour, interviewees overestimate how well they perform. For example, Tibballs (1996) found that healthcare professionals overestimated their rate of handwashing when asked by a researcher. Covert observation revealed that their actual rates of handwashing were much lower than predicted. This overestimation effect should be taken into account when reading healthcare professionals’ responses. Trunnell and White (2005) concluded that this overestimation is in many cases due to self-deception about performance. Self-deception, they argue, makes behaviour change more difficult.

Second, the most frequently used healthcare service among blind and partially sighted respondents were GP services and community pharmacists. The breakdown in table 8 shows that just 12 per cent of

[67] n(all healthcare professionals)=500.
GPs and 17 per cent of community pharmacists interviewed said that they ask blind and partially sighted patients for their individual reading needs all of the time.

Table 8. Healthcare professionals’ responses to the question: “Do you normally ask patients who are blind or partially sighted what format they require to access personal information for themselves?”

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, always</td>
<td>21 per cent</td>
<td>12 per cent</td>
<td>10 per cent</td>
<td>17 per cent</td>
<td>24 per cent</td>
<td>43 per cent</td>
</tr>
<tr>
<td>Yes, some of the time</td>
<td>32 per cent</td>
<td>30 per cent</td>
<td>41 per cent</td>
<td>29 per cent</td>
<td>35 per cent</td>
<td>27 per cent</td>
</tr>
<tr>
<td>Yes, but rarely</td>
<td>24 per cent</td>
<td>25 per cent</td>
<td>25 per cent</td>
<td>25 per cent</td>
<td>20 per cent</td>
<td>14 per cent</td>
</tr>
<tr>
<td>No, never</td>
<td>17 per cent</td>
<td>22 per cent</td>
<td>20 per cent</td>
<td>17 per cent</td>
<td>19 per cent</td>
<td>7 per cent</td>
</tr>
<tr>
<td>Have not treated blind or partially sighted patients</td>
<td>6 per cent</td>
<td>1 per cent</td>
<td>4 per cent</td>
<td>12 per cent</td>
<td>2 per cent</td>
<td>9 per cent</td>
</tr>
</tbody>
</table>

[68] n(all healthcare professionals)=500.
[69] n(GPs)=100.
[70] n(hospital physicians)=100.
[71] n(pharmacists)=100.
[72] n(practice nurses)=100.
[73] n(hospital nurses)=100.
6.3. Requests for accessible information are not being delivered

The majority of blind and partially sighted respondents to the survey said they do not ask to receive health information in accessible formats. However, even when they do ask, many do not receive information in these formats. Healthcare professionals and organisations therefore do not respond to their needs, even when made explicit.

The majority of GP users (85 per cent) said that they do not asked to receive personal information from their GP in an accessible format.[74] There was no statistically significant variation between different socio-demographic groups in terms of how likely they were to ask. Of those who do ask to receive health information in their required formats, 57 per cent said that they receive them but a significant minority (43 per cent) said that they do not.[75]

As with GP users, most outpatient users do not ask to receive personal health information in accessible formats. Eighty-five per cent of those provided with personal health information in outpatient departments do not ask to receive this information in formats they can read themselves. [76] There was no statistically significant variation between different respondent types in terms of how likely they were to ask. Of those respondents who do ask to receive personal health information in accessible formats (14 per cent), 62 per cent said that they do not receive the information in the requested formats.[77]

These findings are supported by the experiences of participants in qualitative research. For example, one male participant asked his GP practice to send him information about appointments and prescriptions by email but was told that they did not offer this service. Another participant asked her GP practice to phone her with any information about appointments or test results. At first this was done but, when the staff at her GP practice changed, her needs were not passed on to
the new staff and now she receives information in standard print again. These difficulties made participants feel frustrated or angry.

“I’ve asked my GP to give me information in an accessible format and they can’t seem to do it!”

**In-depth interview participant, male, blind**

There were exceptions to this situation. Some participants reported very positive experiences. For example, one said that, following a transplant operation, she asked her hospital to write information about prescribed medicines on dynotape, and that this was done. This meant that she was able to manage her prescription safely and independently.

[74] \( n(\text{GP users}) = 518 \).
[75] \( n(\text{GP users asked to receive info in accessible format}) = 76 \).
[76] \( n(\text{outpatient users provided with personal health information}) = 181 \).
[77] \( n(\text{outpatient users, asked to receive in accessible formats}) = 26 \).
7. Barriers to health information reaching people who need it

As explained in chapter 6, findings from research with blind and partially sighted people suggest that the majority of health information needs are not being met. This chapter explains some of the factors that may be preventing health information from being provided in accessible formats.

7.1. A culture in which health professionals do not ask patients for their individual reading needs

Well over a quarter of healthcare professionals surveyed (28 per cent) either agreed or strongly agreed that most blind and partially sighted people prefer to receive health information via a relative or carer, rather than reading it themselves.[78] Over half of the healthcare professionals surveyed (56 per cent) said that they pass health information to blind and partially sighted patients via a relative or carer. Participants in the online forum of healthcare professionals also suggested widespread reliance on relatives and carers. When asked what barriers they face in providing health information to blind and partially sighted people, many replied that there are none because they can pass information via relatives and carers. The implication is that relying on relatives and carers is an adequate solution.

“None [I don’t face any barriers]. The patient usually has someone else who can read the letter or information to them.”

**Online forum participant, healthcare professional**

Some healthcare professionals thought it is good practice to ask relatives or carers to help manage any health information and to attend health appointments:

[78] n(all healthcare professionals)=500.
“[I would] discuss with [the] person if there are any family or friends they wish to help [them] with the information.”

**Online forum participant, healthcare professional**

Taking into account the 95 per cent of blind and partially sighted respondents who want to receive health information in accessible formats, it seems clear that this is not true.[79]

### 7.2. A culture in which blind and partially sighted people are not asking for accessible information

Part of the reason why professionals think that patients prefer carers to read information to them may be because the majority of blind and partially sighted people (across all health contexts investigated) do not ask to receive health information in accessible formats. For example, 85 per cent of those visiting a GP do not ask for personal health information to be provided in their required reading format.[80] This is despite the fact that the overwhelming majority of respondents (95 per cent) overall said they want to receive health information in an accessible format.[81]

There are a number of factors that could explain why people say they want information that they can read themselves but accept a situation in which they do not get it. These include low expectations linked to repeated failures of healthcare organisations to provide healthcare information in accessible formats (even when asked) and a circle of dependence on relatives or carers.

[79] n(blind and partially sighted)=600.
[80] n(GP users)=813.
[81] n(all blind and partially sighted)=600.
There are, of course, exceptions to the culture of blind and partially sighted people not asking to receive health information in accessible formats. Case study 2 (appendix 1) describes the experiences of one woman who has decided to change her approach to health information and ask for it to be provided in an accessible format in the future.

7.2.1. “It’s too much effort”

Almost half of blind and partially sighted respondents (48 per cent) agreed that currently it takes too much effort to obtain information in accessible formats. Furthermore, among respondents to the qualitative research, the most common response to receiving health information in formats they cannot read is a general acceptance that ‘that’s just how it is’. The fact that many people are not provided with health information when they do ask for it may help to explain this finding.

7.2.2. Fear of stigma is a barrier to asking for accessible information

One in 10 blind and partially sighted respondents (11 per cent) either agreed or strongly agreed that they do not want to receive health information in accessible formats for fear of being labelled as needing special treatment.[82] There was no statistically significant difference between different demographic groups.

This view is illustrated by the response of a participant in the qualitative research. Although she felt that it would be easier to manage her health issues by receiving health information in large print, she did not want to be singled out for special treatment.

“I don’t want to be treated differently to anyone else. I suppose I find it hard to accept that I am partially sighted.”

In-depth interview, female, aged 26, partially sighted

[82] n(all blind and partially sighted)=600.
Offering a range of formats as a mainstream provision, and routinely asking patients about their individual needs, may help to overcome these feelings of stigmatisation.

7.2.3. Low awareness of the available reading formats

Among blind and partially sighted people there was relatively low awareness of the range of different accessible formats available. While most respondents to the survey were aware of at least one accessible reading format, 9 per cent were either unaware of any or did not respond to the question. On average, respondents were aware of just two different accessible formats.[83]

Low awareness of the available options may contribute to blind and partially sighted people relying on options that are not best suited to meeting their needs. It may also mean that cost-effective and time-efficient means of providing health information (for example, email, text messages or the internet) are not fully exploited, due to lack of demand.

Some differences in awareness were found between demographic groups. Respondents who were over 60, had been diagnosed with their sight condition more recently, were partially sighted, were from lower socioeconomic groups or who did not work, were generally aware of fewer accessible formats. There may, therefore, be a particular need to ensure that people in these demographic groups are fully informed about their options.

7.2.4. People are unaware they have legal rights

There was a gap in knowledge among blind and partially sighted people about their own health information rights. This may contribute to a lack of confidence in asking for health information in accessible formats or challenging the provision of information in formats that they cannot read.

[83] n(all blind and partially sighted)=600.
Barriers to health information reaching people who need it

Nearly two thirds of survey respondents (65 per cent) had not heard of any legislation or policies designed to protect them from discrimination in receiving health information.[84] A third of respondents (33 per cent), however, had heard of the Disability Discrimination Act.

Respondents were less likely to have heard of the Disability Discrimination Act if they were female, not in work, from lower socioeconomic classes, aged over 60 or from Wales. There may, therefore, be a particular need to ensure that people from these demographic groups are educated about their rights.

- 28 per cent of female respondents, compared with 37 per cent of male respondents, had heard of the Disability Discrimination Act.[85]
- 27 per cent of respondents out of work, compared with 53 per cent of respondents in work, had heard of the Disability Discrimination Act. [86]
- 24 per cent of respondents from groups C2DE, compared with 43 per cent of those from groups ABC1, had heard of the Disability Discrimination Act.[87]
- 17 per cent of Welsh respondents had heard of the Disability Discrimination Act, compared with 39 per cent of Northern Irish respondents, 35 per cent of English respondents and 31 per cent of Scottish respondents.[88]
- 13 per cent of respondents aged over 60 had heard of the Disability Discrimination Act, compared with 36 per cent of those aged 45-59, 41 per cent of those aged 30-44 and 33 per cent of those aged 16-29.

[84] n(all respondents)=600.
[85] n(male)=300; n(female)=300.
[86] n(in work)=135; n(not in work)=438.
[87] n(ABC1)=270; n(C2DE)=315.
[88] n(Wales)=75; n(Northern Ireland)=75; n(England)=350; n(Scotland)=100.
7.3. Organisational barriers preventing change

7.3.1. Lack of policies, systems and processes for providing health information

Healthcare professionals reported a lack of knowledge, policies, processes or systems in place to support them in providing health information to blind and partially sighted patients.

The majority of healthcare professionals who responded to the survey (73 per cent) said either that their organisation does not have a clear policy designed to ensure that blind and partially sighted people receive health information in accessible formats (31 per cent) or that they did not know whether there is such a policy or not (42 per cent).[89]

They also reported a lack of training. The majority (71 per cent) either disagreed or strongly disagreed with the statement: “I have been given all the training I need to ensure that I understand the needs of blind and partially sighted people in terms of accessing health information.”[90]

A smaller majority (62 per cent) either agreed or strongly agreed that they face barriers in providing personal health information to patients who are blind or partially sighted because they do not have the means to produce it.[91]

This picture was reflected by findings from the qualitative research. Many respondents reported either that they do not have, or did not know whether they have, policies designed to promote equal access to health information for blind and partially sighted people.

[89] n(all healthcare professionals)=500.
[90] n(all healthcare professionals)=500.
[91] n(all healthcare professionals)=500.
"I am not aware of any policies – that’s not to say that there are none."

**Online forum participant, healthcare professional**

### 7.3.2. Lack of contractual requirements for service providers

In order to ensure that service providers meet the health information needs of blind and partially sighted people, commissioners (health boards and primary care trusts) need either to incentivise or contractually require them to take action.[92]

However, the majority of participating trusts reported that they do not include an explicit requirement for service providers to promote equal access to health information for blind and partially sighted people. Only three trusts (6 per cent) reported that they include such a requirement. More trusts (but still a minority) reported including a requirement to promote equal access to health information, which does not expressly refer to the needs of blind and partially sighted service users (18 trusts, 38 per cent). However, as it is unspecific, this requirement is unlikely to be translated into action.[93]

Similarly, while most trusts (41 trusts, 81 per cent) include a requirement to promote independence and equality of access for disabled people, this again is not specific enough to translate into a requirement to meet the health information needs of blind and partially sighted people.

[92] This is evidenced by extensive research carried out by Dr Foster Intelligence for the National Institute for Health and Clinical Excellence into barriers to healthcare professionals enforcing public health interventions.

[93] n(all primary care trusts and health boards)=47.
Few trusts include requirements to proactively identify blind and partially sighted people (eight trusts, 17 per cent), record individual reading needs (eight trusts, 17 per cent) or ensure that staff have visual awareness training (eight trusts, 17 per cent).[94]

Furthermore, very few trusts (three trusts, 6 per cent) reported assessing service providers’ performance against requirements to give accessible information to blind and partially sighted people.[95]

There were some exceptions.[96] Fifteen trusts (32 per cent) said that their contracts with service providers include a requirement to record the reading needs of blind and partially sighted patients. Twenty-five trusts (53 per cent) said that they contractually require service providers to have policies, processes and systems in place to provide general health information in accessible formats. However, as reported above, the majority of healthcare professionals surveyed reported either that their organisations do not have such measures in place or that they did not know whether they do or not.[97]

7.3.3. Lack of guidance for service providers

There was a lack of guidance circulated by primary care trusts and health boards to support and empower service providers to give accessible health information. Primary care trusts and health boards were asked what guidelines, if any, they give to service providers to support them in meeting the health information needs of blind and partially sighted people.

[94] n(all primary care trusts and health boards)=47.
[95] n(all primary care trusts and health boards)=47.
[96] Case study 3 (appendix 1) shows the measures taken by one Welsh health board to address the needs of blind and partially sighted people.
[97] n(all primary care trusts and health boards)=47.
The majority of trusts (29 trusts, 62 per cent) reported circulating at least some guidance on meeting the health information needs of blind and partially sighted people. However, the level of guidance circulated to service providers varies. Importantly, very few trusts circulate guidance on ensuring that individual reading needs of blind and partially sighted people are met (nine trusts, 19 per cent), how to take proactive steps to identify blind and partially sighted patients, or the types of visual awareness training that staff should receive.[98]

7.3.4. Gaps in support for service providers

Primary care trusts and health boards were asked whether they provide any facilities or training to support service providers in meeting the health information needs of blind and partially sighted patients.

The majority reported providing some support. However, there were gaps in this support. Perhaps the most important gap was for staff training, with just nine trusts (19 per cent) providing visual awareness training for staff of contracted service providers.[99]

7.3.5. Poor communication with service providers by primary care trusts and health boards

There appeared to be a lack of communication between primary care trusts and health boards and service providers, so that healthcare professionals were not always aware of the available support.

The majority of participating primary care trusts and health boards reported providing at least some practical support to service providers in terms of accessible health information (39 trusts, 83 per cent).

[98] n(all primary care trusts and health boards)=47.
[99] n(all primary care trusts and health boards)=47.
This includes support in producing information in accessible formats. For example, 36 trusts (77 per cent) provide facilities for producing information in large print and 31 trusts (66 per cent) provide facilities for braille production.[100]

Several trusts reported providing a telephone information line to address patients’ health information needs (22 trusts, 47 per cent). However, it is unclear whether these are designed to provide health information over the telephone (which would not meet the needs of blind and partially sighted patients) or whether they are designed to signpost people to accessible information.[101]

While many of the primary care trusts and health boards reported providing facilities to support service providers, the majority of healthcare professionals said that they lack facilities or resources to give personal and general health information to blind and partially sighted people. This suggests either that they are unaware of the available facilities or that they are not extensive enough to meet the needs of healthcare professionals. We did not investigate the experiences of healthcare professionals by primary care trust or health board. Therefore we cannot directly compare responses of primary care trusts or health boards with those of healthcare professionals. However, the indication is that, where primary care trusts and health boards do offer support, it is not being communicated effectively to healthcare professionals.

[99] n(all primary care trusts and health boards)=47.
[100] n(all primary care trusts and health boards)=47.
[101] n(all primary care trusts and health boards)=47.
8. Conclusions

Both healthcare professionals and blind and partially sighted people recognise that it is important to provide accessible health information. However, health information needs are not currently being met. There are attitudinal, educational and organisational barriers to change. Interventions and organisational changes are needed to translate good intentions into action. Fourteen years on from the introduction of the Disability Discrimination Act 1995 and more than three years since the Disability Equalities Duty (2005), most blind and partially sighted people still rely on others to pass on health information to them.

Since RNIB’s report, Ill Informed (1998), showed that the health information needs of blind and partially sighted people were not being met, the findings from the current programme of research suggests that little headway has been made in the intervening decade. Although there have been policy and legal changes during this time, which should have led to improvements, it is clear that now, as in 1998, the majority of blind and partially sighted people:

- Are not receiving health information in accessible formats
- Are not being asked for their individual reading needs
- Are not receiving health information in their preferred formats.

The research has revealed a culture in which healthcare professionals rarely ask blind and partially sighted patients about their individual needs. Furthermore, it has revealed that a significant proportion of healthcare professionals believe that patients are content for relatives or carers to read information on their behalf. This research challenges these assumptions and shows that most blind and partially sighted people would prefer to be able to read information themselves. In addition, it indicates that formats such as email and large print, which are relatively easy to produce, are being underused.
The research has also revealed that blind and partially sighted people are not asking to be given health information in formats they can read themselves, and are not challenging the situations where they are given inaccessible information. The research suggests several possible reasons for this. First, there is low awareness among blind and partially sighted people of the Disability Discrimination Act legislation and their rights of access to information. Second, findings suggest that some blind and partially sighted people feel they are inconveniencing healthcare professionals by asking. Finally, a significant proportion of blind and partially sighted people feel that asking for accessible health information requires too much effort. Combined with the fact that many who do ask are not given such information, as well as the fear of being singled out and low awareness of available formats, it is perhaps unsurprising that blind and partially sighted people are not asking.
9. Recommendations

These recommendations suggest an approach for overcoming barriers to accessible health information.

9.1. Main strands for interventions

Findings from the research suggest a need for three main strands of intervention:

- Education, raising awareness and challenging perceptions
- Empowering health professionals and blind and partially sighted people
- Organisational change and service development.

Attempts to facilitate blind and partially sighted people in asking for health information in accessible formats cannot succeed unless policies, processes and systems are in place to meet those needs. Therefore this facilitation needs to be accompanied by service change.

9.2. Target audiences

The research suggests three main target audiences for interventions:

- Blind and partially sighted people
- Service providers (healthcare professionals)
- Commissioners and managers of healthcare services (including primary care trusts and health boards).

It may also be necessary to work with relatives and carers of blind and partially sighted people. Research suggests that relatives and carers are routinely asked to read information on behalf of blind and partially sighted people. This practice may need to be challenged where it is
in direct conflict with an individual’s right to personal privacy and independence.

9.3. Blind and partially sighted people

● Blind and partially sighted people need to be facilitated in making the link between accessible information and the ability to make personal and confidential decisions to manage their health.

● There is a need to raise awareness of the full range of different accessible formats so that blind and partially sighted people can make an informed decision about which formats best meet their health information needs. There is a particular need to raise awareness among people who are over 60, have been diagnosed with their sight condition more recently, are partially sighted, are from lower socioeconomic groups or who don’t work.

● Blind and partially sighted people should be facilitated in understanding the importance of asking for accessible formats as a way of challenging healthcare professionals’ assumptions about their health information requirements. They should be given practical support in asking for health information in accessible formats.

● There is a need to raise awareness of legislation designed to protect blind and partially sighted people’s rights. Women, people not in work or from lower socioeconomic groups or aged over 60 require particular attention, since awareness is lower among these groups.

9.4. Commissioners and managers

Commissioners working for primary care trusts and health boards need to:

● Have a clear policy that specifically sets out how the health information needs of blind and partially sighted people will be met (pan-disability policies are not specific enough to translate into action)
Recommendations

- Contractually oblige service providers to meet the health information needs of blind and partially sighted people and to assess them against specific objectives (e.g. investigating individual access requirements, recording these details on patient information systems and providing appropriate staff training)

- Provide, circulate and promote guidance on how to meet the information requirements of blind and partially sighted people

- Improve lines of communication with frontline providers, so that they are aware of policies, processes, systems and support for meeting the health information requirements of blind and partially sighted people

- Promote proactive provision of accessible health information, rather than relying on blind and partially sighted people to ask for it themselves

- Promote accessible information as a mainstream element of patient choice rather than a special provision, in order to combat fears about stigmatisation expressed by blind and partially sighted people.

9.5. Healthcare professionals

To translate good intentions into action, healthcare professionals need to be empowered to provide information in accessible formats. This means:

- Training them about the health information needs of blind and partially sighted people and the consequences of inaccessible information

- Ensuring there are clear policies, processes and systems for assessing individual needs and then meeting them

- Ensuring there are clear routes for obtaining the resources needed to provide accessible information
Dispelling myths about the health information requirements and preferences of blind and partially sighted people.

All healthcare professionals need to carry out individual needs assessments, to record individual reading requirements and to ensure that accessible information is delivered by implementing systems and planning resources. For example, this may mean:

- In GP practices, carrying out a needs assessment upon registration of any new blind or partially sighted patient, logging their needs on internal computer systems, and ensuring that there is an electronic prompt to consider health information needs whenever a patient’s file is opened or a referral is being made.

- Using ‘choice architecture’ (a social marketing technique) to prompt healthcare professionals to ask patients about their reading needs. Examples include electronic prompts, providing incentives, or assessing healthcare professionals to encourage them to ask patients about their reading needs.
Appendix 1: Case studies

Case study 1: Independence and informed choice: John’s experience

John, aged 49, has renal failure and has been registered blind since birth.[102] He recently attended a dialysis unit, where he was provided with information about his condition and treatment.

John’s positive experience at the dialysis unit and his responses to it highlight both the value of receiving health information in accessible formats and the rarity of individual needs being investigated.

Appreciating the need for alternative formats

The dialysis unit normally provides information about dialysis in a standard print leaflet. However, individual staff on the ward recognised that this leaflet was not accessible to John and saw the importance of providing the information in a format that he could read himself.

John was surprised that the staff appreciated that standard print information would not be good enough. This surprise reflects his poor experiences with regard to health information in general.

“The sister on the ward is very good about it...[There’s a booklet that they give people about their dialysis] and the sister said, ‘We need to get this done so that you can read it for yourself.’ And she had the presence of mind to actually say that to me, rather than giving me a print one.”

[102] John is not his real name.
Exploring and providing for individual needs

John was asked which format he wanted the information to be provided in, and requested braille. The hospital did not have its own braille production facilities on site, but the ward sister was proactive and arranged for the information to be transcribed using a local RNIB service. This meant that John received the information relatively promptly.

“It got done quite quickly. I live in Glasgow, so they sent it to [the] RNIB transcription service, which is in West Glasgow, and they did it.”

This contrasts with John’s poor experience at his local GP surgery, where he has been refused information in braille in the past, despite requesting it:

“I just say [to staff at my GP practice], ‘Could you do it in braille?’ And the ladies say, ‘Well no, we haven’t got it in braille, but if you can get somebody to read it out to you...’ It’s not right.”

As well as providing John with information in braille, staff on the dialysis ward recognised that his family would like to read about and understand his condition and treatment, and that they would need information in standard print.

“She gave me a print one for my family because obviously they’re interested in what’s happened.”

This meant that both John and his family were able to read about his condition themselves.

Independence and informed choice

John feels strongly that it is important to receive health information in accessible formats, because without this it is impossible for him to make informed choices about his healthcare or manage his condition independently. As John puts it:
“There are decisions that you have to make yourself, that nobody else can make...for you. So you need all the wherewithal, you need all the information, the papers to read yourself.”

Receiving information verbally, either from a healthcare professional or from his family, does not meet John’s requirements because he needs to be able to return to the information again, and does not want to rely on his family for this:

“If you want to read it over and over again, you need it in a format that you can read yourself. If I’ve got it in braille, I can just say, ‘I want to read it over again’, you know. That gives you that little bit of independence.”

The issue of informed choice will become even more important in the context of the national policy for increasing patient choice. Following Lord Darzi’s recent report, High Quality Care for All: NHS Next Stage Review, this looks set to remain central to the government’s health policy agenda.[103]

**Change**

Individual staff in the dialysis unit recognised that there was a need to ensure that patients who are blind or partially sighted are provided with health information in formats that they can read themselves. John is hopeful that this will lead to change in the dialysis unit’s policies:

“I said, ‘Could we get it in braille?’ and she said, ‘Oh yes, we really need to do something about that, not just for yourself but all our people that are blind that are on dialysis.’”

Unlike the majority of blind and partially sighted respondents to the survey, John normally asks whether he can receive health information in a format that is accessible to him (braille). In the majority of cases, he is told that this is not possible.

John makes the benefits of change to this situation manifestly apparent:

● Decreased dependence on relations
● Independent management of health issues
● Ability to make informed decisions about his healthcare, decisions which he recognises that only he can make.

**Case study 2: Taking responsibility for accessible information**

Lucy is 35 years old and has been registered blind for 10 years. [104] She lives in Northern Ireland, with her husband and parents.

Having relied on her family to manage her health issues since losing her sight at the age of 19, Lucy now wants to regain independence. She feels that blind and partially sighted people should take more responsibility themselves for ensuring that they receive health information in accessible formats.

Lucy’s experiences highlight the fact that a number of different factors – family habits, the behaviour of healthcare professionals and the attitudes of blind and partially sighted people themselves – all collude in holding up progress in providing health information.

**Reliance on her parents and husband**

Since losing her sight, Lucy has relied heavily on her parents to help her manage her health issues. She is in frequent contact with healthcare professionals and organisations, as she has a renal condition that requires regular checkups at an outpatient department. Since she first lost her sight, all Lucy’s health information has been read to her by her mother. This situation has continued even now that she is married:

[104] Lucy is not her real name.
“Well, I’ve always lived here with my mum. You know, from when I first lost my sight...my mum has been opening the letters [from my GP or clinic] and she just reads them to me.”

Lucy has relied on her father to help her find her way around the clinic she visits for checkups, since there is no accessible signposting:

“My Dad always takes me down to the clinic...I wouldn’t be able to get around it by myself. I’d get lost. I just wouldn’t know where to go.”

Wanting to regain independence

Before losing her sight, Lucy was an independent young woman, who confidently managed her health issues herself:

“I didn’t lose my sight until I was 19 and, before then, I would say [to myself] you can manage all those things yourself.”

As her parents have grown older, Lucy has begun to think about the importance of becoming more independent and beginning to manage her health issues herself:

“[My] parents are getting on a little bit and they’ve got their own health problems. So it would be nice to be more independent.”

Aside from the health concerns of her ageing parents, Lucy sees other benefits of managing her health issues herself. For example, she would prefer not to have to rely on other people to read personal health information to her:

“If it came to it, you’d actually prefer not for someone else to read it [personal health information].”

The role of blind and partially sighted people

Lucy feels strongly that blind and partially sighted people have a right to receive health information in accessible formats:
“It would be nice if they had different sources of information, like audio or some other format. I think I should have as much right to know about a condition [as sighted people].”

She feels that healthcare professionals rely too much on relatives and carers to pass health information to blind and partially sighted people, and that this situation needs to change. At her kidney clinic, for example, staff pass any information to her parents and expect them to read it to her:

“You know, they’ll give [any health information] to your family or friends. If you didn’t have them with you, you probably wouldn’t get it... They rely on your family or friends that are with you.”

Although Lucy feels that healthcare professionals need to change their behaviour, she also thinks that blind and partially sighted people themselves need to take some responsibility for changing the current situation. She recognises that, through remaining dependent on her family and not asking to receive health information in accessible formats, she has contributed to the issue of healthcare professionals relying on her family:

“I didn’t lose my sight until I was 19 and before then I would say [to myself], ‘You can manage all those things yourself.’ When you’ve always been blind, you tend to be a little bit more independent, but when you lose your sight later on I think you are more dependent.

But it’s partly my own fault too...I haven’t been offered any sort of formats but, as I say, maybe part of that is my own problem. I’m reliant on other people as well. Maybe if I asked the clinic if there was any format they could send me other than letters.”

Lucy has determined that, in future, she will take more responsibility for asking for health information in accessible formats. She hopes that this will contribute to a change in her situation, away from reliance on her family and towards greater independence in managing her health issues.
Case study 3: Meeting the duties of the Disability Discrimination Act: assessing service providers against explicit policies

1. Background: the Disability Discrimination Act 2005

The Disability Discrimination Act 2005 established a Disability Equality Duty, which requires all public bodies to:

- Promote equality of opportunity between disabled and non-disabled service users
- Take steps to take account of disabled persons’ disabilities, even where that involves treating them more favourably than non-disabled people.

One consequence of the Disability Equality Duty is that health organisations are under a legal obligation to promote equal access to health information and to tackle discrimination against blind and partially sighted people in the provision of health information.

Under the Disability Discrimination Act 2005, public bodies also have a duty to produce and publish a disability equality scheme and action plan setting out how the organisation will promote disability equality.

2. Meeting the duty: explicit policies for promoting equal access to health information

Disability equality schemes that make no explicit reference to the information needs of blind and partially sighted people are of limited use in meeting the duty to provide accessible health information. Such pan-disability schemes lack the specificity needed to translate into practical changes for blind and partially sighted people. The majority of primary care trusts and local health boards surveyed in this research have no explicit policy promoting equal access to health information for blind and partially sighted people. There are, however, some exceptions.
One local health board in Wales (referred to here as Local Health Board A) has drawn up a disability equality scheme which:

- Explicitly addresses the health information needs of blind and partially sighted people
- Sets out the measures needed to meet these information needs
- Incorporates these measures in a clear action plan, which identifies action points, the groups responsible for implementing them, dates by which they must be implemented and mechanisms for reviewing progress.

**Excerpt from Local Health Board A’s disability equality scheme:**

“Patients with a visual impairment have expressed a desire to see their chosen format for information displayed within their health records... Information can be made available in larger print readily in-house. We will ensure that key documents are also offered in braille or tape on request...the local health board (LHB) will promote a culture internally whereby staff developing public information will take these issues on board. This is already covered within our communication strategy.”

**Examples of action points from Local Health Board A’s disability equality action plan:**

- “Raise awareness of the difficulties encountered by those with sensory and physical impairments...”
- “Encourage the availability of larger print information – or braille or tape where necessary by identifying the needs of individuals within their records and passing this information to other professionals.”
- “Ensure that the commissioning framework identifies that these [access and communication] issues are addressed by providers.”
3. Meeting the duty: ensuring that consultation leads to action

The Disability Equality Duty places a requirement on health organisations to consult with disabled people in the development of their disability equality scheme. One issue with consultation exercises is that, unless there are clear processes in place for considering and acting upon the views of participants, they do not always feed into change.

In developing their disability equality scheme, Local Health Board A worked closely with blind and partially sighted service users. They were keen to ensure that the consultation was meaningful and that its findings would be translated into practice. Therefore, they developed an involvement process to ensure accessibility, transparency and influence:

“In order to be fully effective, the involvement process was:

**focused** – the process was clear about where the LHB has scope to make changes, and what resources are available

used accessible mechanisms – it was possible for a wide range of disabled people to participate, e.g. transport was provided through RNIB to ensure the safety of those with visual impairments attending the focus group...

**proportionate** – the approach taken was commensurate with the size of the LHB

**influential** – people outside the organisation will be able to see how the involvement has affected the LHB’s plans

**transparent** – to maintain ongoing commitment and involvement by disabled people, they need to know that their involvement has been influential, not merely tokenistic. This requires providing feedback and information on the scheme to those who gave of their time and emotion in its development.”
Blind and partially sighted service users were involved in an initial focus group to identify issues affecting them, and will be reconvened to review and assess the development and implementation of the disability equality scheme.

Local Health Board A’s disability equality action plan included a requirement for the executive team and board to “create a meaningful action plan reflecting, as far as is practicably possible, the needs of the local population as identified within the involvement process”.

4. Meeting the duty: contracts with service providers

Even where health authorities have explicit policies on promoting equal access to health information to blind and partially sighted people, these are not always translated into practice. Local Health Board A was concerned to ensure that their policies for the provision of accessible health information were translated into practice by service providers. To this end, it includes specific requirements to ensure equal access to health information in its contracts with certain service providers. Currently, these requirements are only included in GP contracts, but the scheme has the potential to be rolled out to contracts with other service providers.

Requirements included in Local Health Board A’s contracts with GPs include:

● Taking proactive steps to identify blind and partially sighted patients

● Ensuring that the health information needs of individual patients who are blind or partially sighted are recorded (this draws on Local Health Board A’s finding that blind and partially sighted patients wanted their reading needs to be recorded in their patient records)

● Having policies, processes and systems in place for the provision of both personal and general health information in accessible formats
• Publicising their healthcare services in formats that are accessible to people who are blind or partially sighted
• Ensuring that staff undergo visual awareness training
• Ensuring that all written material is produced in line with RNIB’s ‘see it right’ guidelines, or similar.

GPs working for Local Health Board A are, therefore, contractually obliged to take steps to identify blind and partially sighted patients, record their reading needs and take steps to ensure their health information needs are met.

5. Meeting the duty: assessing performance of service providers

To further guarantee that policies are translated into practice, Local Health Board A assesses the performance of service providers against targets for ensuring equal access to health information for blind and partially sighted people.

Again, this is currently restricted to GPs, who are assessed against their contractual requirements. However, the model could be rolled out to other service providers.
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