



Accessibility of health information for blind and partially sighted people

Mairi Thurston and Dr Alan Thurston

RNIB
Scotland

supporting blind and
partially sighted people

Compiled by the Centre for Educational and Psychosocial Research for RNIB Scotland by

Mhairi Thurston
Counselling Service
1 Cross Row
University of Dundee
Dundee
DD1 4HN
Email mhairithurston@yahoo.co.uk

Dr Allen Thurston
Institute for Effective Education
University of York
Heslington
York
YO10 5DD
Email at723@york.ac.uk

Clair Henderson
RNIB Scotland
12-14 Hillside Crescent
Edinburgh
EH7 5EA
Email clair.henderson@rnib.org.uk

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1. Overview and executive summary

1.1. Background

This report presents an analysis of the quantitative and qualitative data collected from research carried out for RNIB Scotland into the accessibility of health information for blind and partially sighted people.

'Accessible formats' refers to the different ways that information is published so that it is accessible to blind and partially sighted people eg braille and audio. 'Health information' refers to the many different types of information relating to health or health care, be it personal or general. 'Personal health information' refers to information which is confidential or particular to a patient eg diagnosis, appointments, hospital procedures, test results, medication, etc while 'general health information' refers to more general patient information.

RNIB has previously undertaken a number of surveys and has published reports on the accessibility of health information. Prior to the Disability Discrimination Act of 2005 it was reported that the needs of blind and partially sighted people were not being met (RNIB, 1998). A UK-wide survey of 600 blind and partially sighted people carried out in 2009 found that whilst the vast majority knew that they had a right to receive information in an accessible format. 72 per cent of those surveyed could not read the health information that they were provided with (Sibley, 2009). However 89 per cent of the sample of respondents for that survey was drawn from England. The survey concluded that due to the small number of respondents from Scotland it was not possible to make robust conclusions about the situation in Scotland. Given that health care is a devolved matter to the Scottish Government, and that the Disability Discrimination Act 2005 operates within a legal system distinct from that of the rest of the UK, it was determined that there was a need to develop a more accurate picture of the accessibility of information needs of blind and partially sighted people living in Scotland.

1.2. Aim

The aim of this research was to examine the experiences of people who are blind or partially sighted when accessing health information from various services in Scotland.

1.3. Methodology

RNIB Scotland Members were sent a questionnaire by post which they were invited to complete and return in an addressed envelope which was supplied. Some Members were sent the questionnaire via email, which could be completed electronically and emailed to RNIB. In addition a facility was made available so that questionnaires could be completed by phone.

The questionnaire comprised seven sections:

- A. About you
- B. Your sight
- C. Access to health care services
- D. Communications support
- E. Communicating with staff
- F. Understanding your condition/treatment
- G. Making a complaint

“About you” (Section A) contained five items gathering data on the ethnography of the sample. Section B ‘Your sight’ contained two items categorising sight levels and length of sight deterioration. Section C ‘Access to health care service’ contained four items asking about participant use of health services and how participants made appointments. Section D ‘Communication support’ contained four items asking about alternative reading format requirements and access availability. One item asked about provision of alternative reading formats in response to which participants were expected to respond ‘yes’, ‘no’ or ‘sometimes’ by ticking the appropriate box. One item used the same ‘yes’, ‘no’ or ‘sometimes’ format to ask participants whether they had ever missed appointments because information was not in their preferred reading format. Section E ‘Communicating with staff’ asked whether participants found it difficult to receive information in their preferred formats from health services and participants responded ‘yes’, ‘no’ or ‘sometimes’. Similarly Section F ‘Understanding your condition’ requested ‘yes’, ‘no’ or ‘sometimes’ responses to participants’ understanding of their conditions and mistakes with medication due to lack of availability of preferred reading formatted information. The final section (G) ‘Making a complaint’ asked whether participants had made a complaint and how they had made it.

The questionnaire was structured so that it elicited both quantitative (yes/no/sometimes) responses and qualitative responses (eg give an example of your experience of accessing health information). The participants were not required to complete all the questions. Some participants only completed a proportion of the questionnaire, while others completed it in its entirety and supplied extra information. This complicated the statistical analysis of the data.

1.4. Executive summary of main findings

- Approximately one in ten blind and partially sighted respondents did not know they had a right to receive health information in a format they could read.
- On average only 10 per cent of all communications from health services to blind and partially sighted participants were received in their preferred reading format.
- 91 per cent (213 out of 223) of blind and partially sighted respondents thought they had a right to receive health information in a format they could read.

- 96 per cent (219 out of 228) of blind and partially sighted respondents reported that they had a preferred reading format.
- Blind and partially sighted respondents reported a loss of autonomy and privacy regarding their experience of accessing health care information.
- The majority of blind and partially sighted respondents did not complain when information was received in an inappropriate format.
- Blind and partially sighted respondents reported difficulty identifying and using medication.
- Blind and partially sighted respondents reported difficulty experiencing health care due to a general lack of understanding of their additional needs.
- Blind and partially sighted respondents reported frequently relying on others to help them access health care information
- The effects of not receiving health information in a preferred reading format were reported to be largely buffered by carers and relatives.

1.5. Executive summary of conclusions

- Blind and partially sighted people should have access to health information in accessible formats.
- Health care information in inaccessible formats may have serious consequences for blind and partially sighted people, both practically and emotionally.

1.6. Executive summary of recommendation

- Education and training for health care professionals.
- Accessible health care services for blind and partially sighted patients.
- Further research.

2. Description of survey methods and sample

2.1. Demographics of survey sample

The nature of the survey meant that some participants were not required to answer each section. Therefore the number of reported respondents in each section varies and is dependent upon the number of participants who opted to complete each section. Percentages reported are in relation to the percentage of valid respondents to each question. These are rounded to one decimal place which could mean totals exceed 100 per cent in some cases.

2.2. Gender and age

Questionnaires were returned from 228 subjects. Of these participants, 86 were male and 141 were female (1 participant did not specify their sex). The age distribution and frequencies of age ranges are presented in Table 1. Data indicates that the majority of respondents were over the age of 65. Only one quarter of respondents were below the age of 65.

Table 1: The age distribution of participants (number in sample = 228)

Age range	Number of participants	Percentage of sample
18–24	2	0.9
25–44	7	3.1
45–54	18	7.9
55–64	32	14.0
65–74	44	19.3
75–84	66	28.9
85+	53	23.2
Under 16	3	1.3
Undisclosed age	3	1.3

2.3. Geographic location

Participants responded from all fifteen different health authorities with the greatest contributions coming from Lothian (29.3 per cent), Greater Glasgow (16.4 per cent) and Lanarkshire (13.3. per cent).

2.4. Ethnicity

The respondents were predominantly White Scottish (79.5 per cent) or White British (17 per cent) in ethnicity. However, one respondent self-reported their ethnicity as Pakistani and one reported their ethnicity as African.

2.5. Sight level of respondents

224 of the participants reported the level of their sight. Of these 119 (53.1 per cent) were registered blind and 76 (33.9 per cent) were registered partially sighted, in total 87 per cent registered blind or partially sighted. A further 19 (8.5 per cent) were partially sighted, but not registered as such. The 10 (4.5 per cent) remaining participants reported their sight levels with a variety of other descriptors. The age range at which respondents began to lose their sight is reported in Table 2. Data indicated that nearly three-quarters of the sample lost their sight after the age of 26 and two-thirds of participants lost their sight after the age of 45. However, 11.6 per cent reported sight loss since birth.

2.6. Registration

Registration as blind or partially sighted is significant as this can only be done through access to health services. Therefore, it is a clear indication that within the participant's medical records would have been information indicating that they had a sight problem. The data indicated that the majority of participants had undergone substantive sight loss as adult patients. This has relevance as it indicates a change in the level of their sight that may mean that the preferred format of information provided for participants should be adapted to take account of this change.

Table 2: Age range at which respondents began to lose their sight (number = 224)

Age at beginning of sight loss	Number of participants	Percentage of sample
From birth	26	11.6
0–2	2	0.9
3–5	3	1.3
6–15	4	1.8
16–17	1	0.4
18–25	5	2.2
26–44	30	13.4
45–54	24	10.7
55–64	33	14.8
65–74	49	21.9
75–84	39	17.4
85+	8	3.6

3. Survey results on accessibility of health information

3.1. Preferred reading formats of respondents

219 of the respondents reported that they had a preferred reading format. Of these, 67 participants (28.6 per cent) preferred recorded audio information and 60 (25.6 per cent) preferred large print. An additional 15 (6.4 per cent) participants preferred a combination of large print and recorded audio information. Other participants reported in lower numbers (under 5 per cent of the total sample) that they had preferred formats, or combinations of formats in twenty different combinations.

3.2. Receiving information in preferred reading formats

217 participants responded to the question regarding needing information in a preferred reading format. Of these, 95 (43.8 per cent) stated that they required information in a preferred reading format and 122 (56.2 per cent) stated that they did not. A number who stated that they did not require information in a preferred reading format indicated that they had a carer or relative to help with reading information from health services. More detail is provided on this in the qualitative data section.

Participants indicated that they rarely received information from a range of health care services in their preferred format. Data presented in Table 3 indicated that very few health services ever send out information in alternative formats. On average alternative format information was not sent out to 89.2 per cent of participants, and only 10.8 per cent of participants received information in their preferred reading format.

Table 3: Participants' reported frequencies of receipt of information in their preferred reading format from health services

Health service	Number of respondents from survey	Had information in preferred format		Never had information in preferred format	
		number	%	number	%
GP	202	27	13.4	175	86.6
Practice nurse	182	12	8.8	166	91.2
Hospital outpatient	183	30	16.4	153	83.6
Hospital inpatient	129	12	10.1	117	89.9
Accident and emergency	116	6	6.0	110	94.0
NHS dentist	135	13	9.6	122	90.4

Participants perceived the following reasons as to why they were not provided with information in their preferred reading format. Of the 156 participants who responded to a question on this issue 56 (35.9 per cent) indicated that they did not think that staff knew how to provide information in their preferred format, 17 (11.0 per cent) thought that staff did not know that they required an alternative format, 7 (4.5 per cent) thought it was too short notice to receive information in a preferred format, 60 (38.5 per cent) stated that they did not know that they could ask for information in their preferred format and 16 (10.3 per cent) gave no explanation.

The vast majority thought that they had a right to receive information in a format that they could read (213 out of 223 respondents – 91 per cent). However 9 per cent were not aware that they had a right to receive information in a format that they could read. This finding runs counter to the responses from participants regarding the reasons for not receiving information in their preferred reading formats. However, there appears to be a discrepancy regarding a blind or partially sighted person's knowledge that they should be able to receive information in their preferred formats, but thinking that health services did not need to provide information in the preferred format.

3.3. Implications of not receiving information in a preferred reading format

The qualitative data section reports that the effects of not receiving information in a preferred and accessible reading format are buffered by carers and relatives. The disempowerment that results from this are also discussed in this section. However, despite the buffering effects and help received from carers and relatives, there are still some serious implications for blind and partially sighted people. Data presented in Table 4 indicated that blind and partially sighted people had missed appointments, had difficulty understanding their medical conditions and taken the wrong amount of medication. Whilst these instances are relatively infrequent the potentially serious effects on individuals should not be underestimated.

3.4. The likelihood that blind and partially sighted people will complain about not receiving information in their preferred reading format

101 participants indicated what action they took if they did not receive information in their preferred reading format. Of these, 55 (54.5 per cent) indicated that they did not complain. 35 (34.7 per cent) indicated that they complained to the health service, 6 (6 per cent) stated that they reported the issue to RNIB or another charitable organisation and 5 (5 per cent) reported that they took other action. Therefore, the majority of blind and partially sighted

respondents did not complain when the information they received was in an inappropriate format. More information regarding why participants did not complain is contained in the qualitative data analysis section.

Table 4: The implications of not receiving information in preferred reading format

Health service	Took the wrong amount of medication because information was not in preferred reading format		Missed appointments because information was not in preferred reading format		Came out of appointment not knowing what their condition was because information was not in preferred reading format	
	Number of respondents from survey	%	Number of respondents from survey	%	Number of respondents from survey	%
GP	24	11.7	8	2.5	16	9.4
Practice nurse	4	2.4	5	1.6	13	8.1
Hospital outpatient	8	5	11	6	22	14.1
Pharmacist	Not applicable	–	Not applicable	–	17	11.4
Hospital inpatient	1	0.8	3	2	12	10.4
Accident and emergency	2	1.8	Not applicable	–	10	9.7
NHS dentist	1	0.8	11	7.3	8	6.7

4. Qualitative data analysis on accessibility of health information

The qualitative data were analysed using a methodology informed by grounded theory. Participants were invited to give examples of their experiences of accessing health information. Not all participants responded. Those who did, identified things that were difficult for them to do.

4.1. Taking medication

One of the most commonly reported difficulties involved accessing information about medication. “Not being able to read labels on medication” (participant 43). This included not being able to identify the type of medication.

“For blind people, there are serious problems with different packaging of the same medicine from different suppliers. This is important!! The variable in packaging is a very serious potential calamity for the blind” (participant 158).

“Off-the-shelf medicine instructions are unreadable on both the packaging and the instruction leaflets” (participant 198). Participants reported that they often relied on others to support their use of medication. “If I receive more than one medication at a time, I have to depend on others to give them to me” (participant 223).

4.2. Making appointments

One of the main difficulties reported by participants was appointment availability, “It is difficult getting the appointment to see a doctor in the first place” (participant 6). Waiting list times were also reported as being frustrating, “The waiting time is not acceptable” (participant 172). The location of appointments was reported as being important to participants, because of mobility issues, “I was asked to travel from Edinburgh to Livingston. Eventually, I was given an appointment in Edinburgh” (participant 78). “I could not go to the dentist in Cambeltown as it was up two flights of stairs” (participant 39).

Other health conditions often compounded participants’ difficulties in making appointments, “I have difficulty with hearing” (participant 68). Lack of resources also impacted on participants’ ability to make appointments, “I have difficulty in getting to the surgery because of lack of taxis” (participant 67). Even the most basic of tasks presented a challenge to some of the participants making appointments, “I have difficulty finding the phone numbers and dialling” (participant 46), with many participants describing their reliance on others as a crucial factor in their ability to make appointments, “If I didn’t have my husband it would be a problem” (participant 109). Participants reported some frustration about being unable to see a GP who they knew and trusted, “I am housebound, so I need to request a visit. I am unable to request my own doctor, so I have to take whoever is on duty. They are often rushed and do not know my background and will not discuss more than one issue” (participant 170).

4.3. Visiting hospitals

Several participants reported finding hospital experiences challenging. They reported difficulty with appointment notifications, "All notices of hospital appointments are in ordinary print" (participant 28). The physical environment of the hospital was also reported as being problematic, "Signage in hospitals is not suitable for blind and partially sighted people" (participant 172). Some aspects of outpatient procedures were reported as being problematic. Participants referred specifically to difficulties reading pre-procedural instructions. "I had difficulty reading the instructions on what to do prior to going in for a colonoscopy re sachets etc" (participant 73). They also reported embarrassment at relying on others to read the results of more sensitive procedures, "...sexual health or gynaecological problems" (participant 224). Inpatient treatments were also reported as being problematic, "We once had to write a sign over our son's bed in hospital, 'My name is Matthew. I am blind. Please talk to me and tell me what you were going to do before you do it'. On the whole, ward staff and hospital teams are still very ignorant of visual impairment issues" (participant 154). Participants reported basic care, such as mealtimes, challenging in hospital, "As an inpatient, I was unable to read a food menu" (participant 33). Overall, there was general dissatisfaction with hospitals' ability to cater for blind and partially sighted patients.

4.4. Adopting coping strategies

Participants reported adopting a variety of coping strategies for accessing health information and services. Some relied on low vision aids, "I rewrite the date and time of my appointments using my magnifier" (participant 63) "My family members can access the internet and print off things in large format" (participant 32). Some participants relied only on family support, "My husband reads received information to me" (participant 70). Some participants used a combination of family support and low vision aids as a coping strategy, "I live with a sighted person. I also have a scanning reading machine which reads me any printed material" (participant 87).

4.5. Feeling dissatisfied

Generally, most participants felt there were inadequacies within NHS, "I once had an appointment at the ENT department and I waited a long time to be seen. Eventually I noticed a blackboard, which I stood close in front of and read a chalked message telling outpatients to let it be known if they had not been seen within 30 minutes. I did this and was shown into another waiting area. A blind or partially sighted person could have sat even longer if they did not notice the blackboard. Also if being moved to another waiting room constitutes being seen for the purposes of NHS targets, the procedure is farcical" (participant 211).

Some participants reported inadequacies in internal communications within health centres, “I took part in RNIB’s ‘Losing patients campaign’. I sent a template letter to my local health centre requesting that all future correspondence was sent in my preferred format (audio). I received a call from one of the receptionists saying they could not send me anything in audio as they did not have the equipment. Her solution was that I would be telephoned with any appointments, information and results in future and she would inform all other receptionists that this was to be done. She also said she would have this flagged up on my records that I was registered blind. I understood this had been done five years ago, but obviously not. This tells me that their own communication and recording systems are not working as well as they should” (participant 86).

Despite difficulties accessing health information, a few participants reported satisfaction with NHS, “I have every faith in NHS” (participant 66). “I have never had any problems with GP or hospital information. Recent hospital operation was handled with expertise and professionalism” (participant 48). “My GP, hospital and eye specialist are all excellent and very helpful to me” (participant 72).

4.6. Experiencing negative feelings

Participants reported that not being able to access health information had a negative psychological impact on them. Loss of autonomy was the most commonly reported negative feeling. Having to rely on others was reported as being immensely challenging, “From this comes lack of independence and privacy” (participant 64). Some participants felt generally abandoned by the system. “Once registered partially sighted, you get your visit and a few gizmos (white stick, liquid level measure). After that, there is no follow-up to see if your needs have increased. If not for RNIB, you are ignored” (participant 154).

4.7. Making complaints

Although participants experienced difficulty accessing health information and health services, very few complained. They reported many different reasons for this. The most common reason was “it would be a waste of time” (participant 11). This was coupled with low expectations of change, “They say there is nothing they can do about it” (participant at 13). Some participants were not familiar with complaint procedures, “I did not know the procedure to complain” (participant 214). Other participants reported that they lacked the emotional strength to complain, “I do not need the hassle. I suffer from depression and try to keep on an even keel” (participant 154). Some participants feared that they would be labelled as a troublemaker if they complained, “I don’t want to be labelled as someone who’s always complaining” (participant is 210), while others “didn’t want to be a bother” (participant 93). Some participants were wary about the possible repercussions of

complaining, “I don’t complain, because it usually means you have to go back to the same hospital and face the wrath of someone’s tongue” (participant 73). Some participants were physically unable to complain, “I am unable to put a complaint in writing and my family have busy lives” (participant 12). A few participants reported that their pride prevented them from complaining. They did not want to be perceived as not being able to cope. “I don’t like a stranger to know that I have a problem” (Participant 94).

4.8. Suggesting improvements in practice

Participants had several ideas that might improve their access to health information. Standard use of large print was viewed as being beneficial, “I would like all letters in large print” (participant 19) “All hospital menus could be provided in large print” (participant 35). One participant felt that better collaboration between drug companies and dispensing chemists might result in better access to medication information for blind and partially sighted people, “Chemists should advertise instore that prescription labels may be available in braille or that large print is applicable. The information that comes with all medications, within and on the printed packaging (not chemists’ labels), should be available on computer websites from pharmaceutical companies. This could be printed off by the chemist on request by the client collecting prescriptions in large print” (participant 102). Another participant identified the need for better information provision from clinicians around the time of diagnosis. “More information needs to be provided by opticians. Mine just said, ‘You have macular degeneration and you will lose your sight’. It was left up to me to find out further details” (participant 106).

5. Case studies

This section provides a more in-depth look at the experiences of blind and partially sighted people by providing four case studies. Responses made to different sections of the questionnaire have been collated and presented as case studies. The case studies have been prepared to illustrate the overall experience in respect of accessibility to health information of respondents.

5.1. Marina (participant 128)

Marina is aged between 55 and 64 years old and is registered blind. She has other health issues and is a wheelchair user. Her preferred format of accessing information is through DAISY. Marina discusses her experience of being diagnosed with macular degeneration, along with her experience of using her GP surgery, and her experience of being a patient at her local hospital.

“When I was first diagnosed with macular degeneration, things started to disappear, which was strange. That was the first thing which started to happen. So I said to my GP in passing that something was wrong with my eyes. I am at the doctor’s a lot because of other health conditions, but she didn’t listen at all or check my eyes or refer me on. She said that it was fine. It was my friend who suggested that I would have to go private and have my eyes checked out as it wasn’t normal. Even when I was paying for a service, he did all the tests, sat me down, and told me what I needed done. I said to him, ‘if I don’t get all this done, what will happen?’ And he basically said, ‘You’re going blind anyway, so if you don’t get it done it doesn’t matter’. I didn’t see it coming, because he hadn’t even told me what my eye condition was. I had to send my husband to look it up and explain all my symptoms to him so that he could figure out what was wrong with my eyes. Then I thought it wasn’t so bad, so I went back with a list of questions to ask and said to the eye doctor, ‘Is this macular degeneration?’ He replied, ‘Yes.’ I had to find it out for myself. How awful is that? To send someone away in a complete panic and not even explain anything.

“My GP surgery is absolutely useless. They know I am registered blind, but nothing comes from them in a format I could read. It’s my fault really. I would be more forceful if I didn’t have a husband to depend on. I have a great GP, but it’s the receptionists who are the difficulty. They hate to be told anything, so I don’t even bother. They basically run things and just won’t go out of their way for anyone.

“My dentist was the only one who knew exactly what macular degeneration was! The nurses don’t have a clue. Because you can see something, they just don’t get it. It’s too hard to explain, and they are the medical people so you shouldn’t have to explain all the time. It’s frustrating. You get the feeling that they are really thinking that you can really see!

"I was in hospital in August. I have macular degeneration, and it doesn't look as if I am blind. So to try and say to people, 'look, I can't see what you think I can see' was horrendous. I was in for heart attack. The junior doctor was talking to me and I said that I couldn't see too well. She said, 'Oh, you're partially sighted?' and I said, 'No, I'm registered blind'. She said, 'But you can see?' She actually questioned me over my own sight loss. I had to sit and have a heated discussion about my condition (she didn't even ask what it was called) and justify how I could see certain things and not others. I explained that I really, genuinely couldn't see what she thought I could. She didn't even ask what condition I had and she works in the medical profession. There was nothing to support me over those four days in hospital. I asked to come home because I think I would have had another heart attack had I been left in there! It was awful. I am so independent normally, even though I am in a wheelchair, I just get on with it. For someone who couldn't cope at all, there was no concession at all. That was the hospital I had been registered blind in, so they had it in all in my notes. They had no idea. No clue at all. It was frightening.

"I'm frightened to complain because you feel so vulnerable in hospital. You know that it really isn't a good thing to complain. When I'm in hospital now, I'm terrified to complain or say anything and I just want to get home.

"But as I said before, I am just really lucky that I have my husband to read everything to me. Everything would be easier if it had information in a format you could understand, including medication instructions."

5.2. Elizabeth (participant 133)

Elizabeth is aged between 65 and 74 years old. She is registered blind. Her preferred format of accessing information is audio tape or CD. She talks about the difficulties she has with communication, outpatient visits and medication. She also describes the difficulties facing her during hospital procedures.

"Everything comes by written letter, whether it's a confirmation, a change of appointment, or results. If you ask if there is another way of communicating, they shake their heads! The answer is no. Getting results would be so much better in your own format. At the time, you may not understand or remember, so it would be useful to play it back and then you can go back with questions.

"When you go to the hospital as an outpatient, if your doctor has not written on your notes that you are totally blind, then the staff don't pick up on it. They don't even notice you have a white stick. They call your name and then walk away. They either don't bother or don't understand. Because I don't look blind, they don't seem to think that I could be blind.

They will say, 'Have a seat on that chair,' but I have no idea where the chair is! They just don't understand.

"I don't think there are enough patients with a sight problem, so it's not financially viable (to produce information in alternative formats). I feel comfortable asking, but no one will do it. The biggest issue is medication. Your GP tells you how many and when to take tablets. They write it down for you, but you can't read it and there is a good chance that you will have forgotten what he said. My surgery is doing braille, but I don't read it. There is no choice.... I have my husband who can read instructions, but without him I wouldn't have a hope. All the boxes and tablets feel and look the same so it's really hard.

"My husband puts my appointments in the diary so I know what I have coming up each week and thankfully my memory can still remember these!

"When I visit the hospital, or have a procedure, when I get the results, they never seem to have the time or patience to explain things to you and ask you if you have any questions. They send you out information but that is not helpful. I've come out and thought, I never got the chance to ask this and I will go to my GP and ask him to explain this for us. I've had him for 11 years so he knows me.

"Fortunately, I haven't had anything very complicated, so I am quite good at remembering. I attended the genetic clinic at my hospital to see what kind of retinitis pigmentosa I had. I got a lengthy letter giving me details of all the problems I had and the cause of it. It was followed up by an appointment with a consultant to go over the letter and talk through any questions I had. But with other people, you don't get that follow-up. If I got it on a CD then I could play it back to follow up and understand it more fully or decide what questions I would ask. You could even go to your GP. I didn't raise the issue with them and that they knew I was blind and the condition I had, but they still sent out a letter. It was one of the questions you don't think about at the time. I was so concerned with the results that I wasn't thinking about it. I was so concerned really to get the results as I've been waiting for a long time. Health professionals are not really interested in how you want the information, only in giving it to you and then getting you out the door. It is so difficult when going into hospital for anything to make staff understand that you can't see what they are asking them to do or see, eg are you passing blood? How would I know when I can't see!

"Even if someone was allocated in the hospital or a certain number of people who could assist people with sight loss, just helping answer any questions they may have.

“I have never complained. I was just relieved to get it over and done with. I’m loath to complain as I know what pressure is on these people. They are trying to do the best for you. In the main, they are all nice enough and helpful. They try to do their best and you don’t want to add to their burden.”

5.3. David (participant 135)

David is aged between 55 and 64 years old. He is registered blind. His preferred format of accessing information is large print. He also prefers talking to a health care professional either face-to-face or by phone. He describes the difficulties he has encountered when requesting information in a different format. He talks about the lack of understanding people have about blindness, particularly health care professionals.

“One of the problems you have when you make an appointment by phone and you get through, is using your phone as a keyboard. I hate it.

“... I used to get a large print [statement] out from the bank, but then one day I received a copy of all those people who received large print bank statements. They process them by hand, but they had sent them all to me. I stopped as I didn’t think it was secure. You expose yourself to danger when you do anything out of the ordinary. I cancelled it. This has put me off doing it with health care professionals, because anyone could get access to your information. I have never asked for information in my preferred format. If you do ask, things always go wrong.

“I missed a dental appointment once because they make an appointment six months in advance for a check up. My memory is not that great! What my dentist does now, is they phone me two days before to remind me that I have my appointment. When they make the appointment, I ask them to put a footnote to get them to call me to remind me about it.

“The staff at GP practices don’t understand blindness. The paint handles are yellow and they think that is blind-friendly. They concentrate on a play area for kids, but the toys are always lying around and blind and old people have to negotiate the area. People struggle. I know my way round the surgery now, but at first the reception staff hadn’t a clue about how to guide you. They say, ‘Just go to the waiting area,’ but you can’t see where that is! No one will guide you, or even realise that you are a blind person, despite walking in with a guide dog!

“I have taken the wrong eye drops, because I can’t identify which is which. I have taken the wrong ones. They keep changing them and you are constantly confused.

“I never really ask for my preferred format of information (large print). There are longer delays in getting the information, which is no good. I just give up.”

5.4 Binnie (participant 138)

Binnie is aged between 55 and 64 years old. She is registered blind and has been blind since birth. Her preferred format of accessing information is braille. She talks about the difficulties she has encountered through not being able to access information in her preferred format.

“I prefer alternative formats as I can obtain a clearer overall picture of the instructions and information provided. No department has ever offered me any literature or information in a format I could use! Very recently, I had a new artificial eye made for me and was given a leaflet in large print at the end of the consultation. No alternative format was on offer. I then took the trouble to get a friend to read me the details as I suspected that the instructions for inserting, removing and caring for an artificial eye would not be relevant to people who were blind and could not ‘see’ their artificial eye. I was not mistaken. All references throughout the literature were about the use of a mirror to identify which way up the eye should be and how to hold it in front of the mirror before inserting and removing the eye. It was written for partially sighted people. But it was obvious that no one who was registered blind had been involved in any input.

“After some thought, I contacted the person in my area who has overall responsibility for the production and distribution of leaflets. I found the lady in question most helpful and we did a rewrite between us to provide instructions to assist someone with little or no sight. I found that department very open to suggestions for change and from now on, the leaflet will be available in braille as well as in large print. Partially sighted people who can see to read will be given one leaflet, and those with little or no sight will receive a leaflet with more appropriate information which does not require visual input.

“No alternative formats have ever been offered to me, presumably because it is not the policy of the organisation to provide anything other than print options. The recent availability of medication details in braille is very helpful.

“Communication with staff is often difficult. My name is called, then that person walks away quickly, not always allowing enough time for me and my guide dog to follow. Also, I am not given information about where facilities are such as toilets, etc.

“I have never made a formal complaint, but I find that, even in the eye ward, there is an astonishing lack of understanding about the practical implications of sight loss.”

5.5 Ethics and informed consent

The participants in this report have given permission for their information to be published in this report. Any further use of this information will need to be approved by each participant.

6. Conclusions

6.1. Previous research

The findings of this survey support the findings of previous research into blind and partially sighted people's experience of accessing health information. Nzegwu (2004) explored the experiences of blind and partially sighted users of the NHS and reported the predominance of inaccessible formats of health information along with limited staff awareness of the physical and psychological needs of blind and partially sighted NHS users. Sibley (2009) found that most blind and partially sighted people were not receiving health information in an accessible form. Sibley identified that blind and partially sighted people required health information in a wide range of formats, and that the majority of blind and partially sighted people could not read the health information they received. Sibley also reported that blind and partially sighted people were reluctant to request health information in accessible formats. Thurston (2010) reported that blind and partially sighted people experienced dissatisfaction during their experience of diagnosis of a serious eye condition due to a perceived lack of information from clinicians about their eye condition, and the consequent practical and psychological implications.

6.2. Having a preferred reading format

This survey found that the majority of blind and partially sighted people have a preferred reading format. Most thought they had a right to receive health information in a format they could read. However, one in ten respondents did not realise that they had a right to health information in their preferred format and the majority of blind and partially sighted respondents did not complain about the lack of health information in an inaccessible format.

6.3. Using medication

The survey also revealed that blind and partially sighted people reported particular difficulty identifying and using medication and that they frequently relied on others to help both identify it and administer it.

6.4. Making appointments

Blind and partially sighted respondents reported dissatisfaction with appointment availability and waiting list times in general. The accessibility of location was reported as being important because of mobility issues and reliance on others was a recurring theme.

6.5. Visiting hospitals

The survey revealed that blind and partially sighted people commonly reported having difficulty reading appointment notifications and accessing physical hospital environments.

Both outpatient procedures and inpatient treatments were reported as being problematic due to lack of accessible information. Participants found basic care was compromised due to what they perceived to be a lack of understanding from staff about the additional needs of blind and partially sighted people.

6.6. Adopting coping strategies

The majority of blind and partially sighted participants reported using coping strategies to buffer the effects of receiving information in inaccessible formats. Most interpreted inaccessible information using a combination of low vision aids or assisted technology, along with family, friends or carers.

6.7. Feeling dissatisfied

Generally the participants reported that there were inadequacies within the NHS, regarding the treatment and care of blind and partially sighted people, although some reported that they had received excellent treatment.

6.8. Suggesting improvements in practice

Some participants thought that the standard use of large print in health information might allow more blind and partially sighted people to access health information without requesting a special format and feeling 'different' from society. Some participants thought that there could be better collaboration between drug companies and dispensing chemists regarding provision of accessible formats.

6.9. Experiencing negative feelings

Loss of autonomy was the most commonly reported psychological side effect of receiving health information in an inaccessible format, with blind and partially sighted people reporting that having to rely on others led to a lack of independence and a lack of privacy.

6.10 Making complaints

Despite experiencing difficulty accessing health information and health services, very few of the participants reported that they had complained. The most common reason given for this was that it would be a waste of time. Some participants also reported that they lacked the emotional strength needed to complain, while others reported that they feared being labelled a troublemaker. A few participants reported that pride prevented them from complaining as they did not want to be perceived as not being able to cope.

6.11. Learning from case studies

The case studies support the survey findings and contextualise them within the personal experiences of respondents. The recurring themes within the case studies were:

- Lack of accessible health information for blind and partially sighted people.
- Staff attitudes and perceptions of blindness in health care settings.
- Lack of staff training for those working with blind and partially sighted people within the health service.
- Lack of physical and emotional support for blind and partially sighted people within the health service.
- Lack of recognition of specific additional needs of blind and partially sighted people within the health service.
- Lack of autonomy, independence and privacy for blind and partially sighted people within health care settings.

7. Recommendations

From the findings of this survey, it is possible to make the following recommendations:

7.1. Education and training for health care professionals

- There is a need for enhanced awareness and professional development for health care staff on how to support the needs of blind and partially sighted patients physically and emotionally.
- Health care professionals need to understand that the confidentiality of patients is seriously compromised when health information is not sent in an accessible format.
- There is an identified need for education opportunities for health care staff regarding different types of blindness and the impact that this could have on communications with their patients.

7.2. Accessible health care services for blind and partially sighted patients

- There is an identified need for improved access to health care facilities and information for blind and partially sighted patients.
- Health care providers need to reflect on how they provide information for blind and partially sighted patients to ensure that they have access to their preferred formats for health information, appointments, medication and hospital menus.
- There is a need for further awareness raising and education amongst blind and partially sighted people to ensure that they are aware of their rights regarding receiving health information in their preferred reading format.
- There may be a need to encourage blind and partially sighted people to complain when information is not provided in their preferred reading format in order to highlight the issue to health care professionals.

7.3. Further research

- The results of the survey raise the question as to whether it would be useful to establish focus groups to discuss the results of this survey and the action that should be taken as a result. These focus groups could include blind and partially sighted people, health care professionals, campaigners, politicians, policy makers and representatives from RNIB Scotland.

8. References

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Royal National Institute of Blind People Scotland (RNIB Scotland)
12–14 Hillside Crescent
Edinburgh
EH7 5EA
Telephone 0131 652 3140
Website rnib.org.uk/scotland

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