Risks to Client Confidentiality when Communicating Health Information to Blind and Partially Sighted Persons

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ABSTRACT

Purpose: *This research was carried out to give a more accurate picture of the particular needs of the blind and partially sighted people living in Scotland. It explores the risks to client confidentiality if information is not provided in accessible formats.*

Method: *Data were gathered from a survey of 228 blind and partially sighted persons in 15 Health Authorities across Scotland. The survey reported NHS clients' experiences of receiving health information in accessible reading formats.*

Results: *The data indicated that about 90% of blind and partially sighted persons did not receive communications from various NHS health departments in a format that they could read by themselves.*

Conclusions: *The implications for client privacy, confidentiality and the wider impact on life and healthcare have been highlighted. The implications for professional ethical medical practice and for public policy are discussed, and recommendations for improved practice are made.*

Key words: *client confidentiality, blind and partially sighted persons, NHS, accessible reading formats, communication with clients*

INTRODUCTION

Confidentiality lies at the heart of legislation and professional standards for health practitioners. Under 'Health Care Principle 3' in The Patients Rights (Scotland) Bill 2010, it is stated that the 'Privacy and confidentiality (of patients) are respected' (Scottish Parliament Corporate Body, 2010; p10). The issue of ensuring confidentiality of clients during transfer between health organisations is regulated by Caldicott Guardians. Establishment of mechanisms to protect

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confidentiality is a testament to how seriously the issue of client confidentiality is taken within the National Health Service (NHS) (Department of Health, 2010). The Human Rights Act, which incorporated the European Convention on Human Rights into UK law, recognised the importance of confidentiality. Under Article 8 of the Convention, the right to respect for private and family life stated, 'Everyone has the right to respect for his private and family life, his home and his correspondence.' The Disability Discrimination Act 1995 stated that persons with disabilities should be able to have 'Access to and use a means of communication and have access to information when using services to which the public have access' (Scottish Office, 1995).

The General Medical Council (GMC) advises doctors that 'Patient information (leaflets, posters, etc) and important signage and announcements should be in plain language and accessible to all the main groups served by the healthcare organisation (for example, Braille, audiotape...)' (General Medical Council, 2010a). Paragraph 22 of the 'Good Medical Practice' guide stated that to communicate effectively with clients, doctors should 'share with patients, in a way they can understand, the information they want or need to know about their condition' (General Medical Council, 2006; paragraph 22b). The importance of checking that clients have understood information and treatment options available is emphasised in the GMC guidance on consent (General Medical Council, 2008).

Similarly, the Nursing and Midwifery Council (NMC) codes on standards of professional practice stated that nurses '.. must share with people, in a way they can understand, the information they want or need to know about their health' (Nursing & Midwifery Council, 2008; p3). The NMC has a stated commitment to understanding the individual's communication needs and recognising when there is a need to provide additional assistance (Nursing & Midwifery Council, 2010). The Royal Pharmaceutical Society of Great Britain code of conduct for pharmacy students stated they must 'communicate effectively with them (clients) in a way they can understand' (Royal Pharmaceutical Society of Great Britain, 2009). Therefore, great emphasis is placed within medical ethics on ensuring that information is provided to clients in an accessible format, particularly over issues of consent and confidentiality.

The ethics of establishing confidentiality between client and clinician is identified by the The Confidentiality and Security Advisory Group for Scotland. It was stated in their guidance on client confidentiality that 'The principle of a confidential relationship between a patient and a clinician is an ancient one, shared by many cultures' (The Confidentiality & Security Advisory Group for Scotland, 2002; p8). The General Medical Council publishes explicit advice regarding professional ethics of respecting client confidentiality. Guidance for Doctors stated that confidentiality is central to trust between doctors and clients, and that clients have a right to expect that information will be treated confidentially (General Medical Council, 2009).

Similar codes of ethics surrounding confidentiality are shared by other health professional regulatory bodies. The NMC code on standards of conduct, performance and ethics for nurses and midwives states that nurses and midwives must respect the client's right to confidentiality (Nursing & Midwifery Council, 2008). The Royal Pharmaceutical Society of Great Britain (RPSGB) and Scottish Pharmacy Board state the essential role that confidentiality plays in the professional practice of pharmacists in Scotland. In an open letter to the Scottish Government Minister for Health and Wellbeing, it was stated that 'The RPSGB Code of Ethics governs the practice of pharmacy; patient confidentiality is treated with paramount importance, both by pharmacy practitioners and by their staff' (Parr, 2010). The ethics of confidentiality are extended to reception staff and administrative staff. The NHS in Scotland assured clients of confidentiality from all staff - working, medical and otherwise - within the NHS. Further, breaching client confidentiality is identified as a disciplinary offence for any staff working within the NHS, in section 3.2 of the NHS Code of Practice on Protecting Patient Confidentiality (National Health Service Scotland, 2003).

There is a long established code to ensure client confidentiality within the medical community which dates back to Thomas Percival's code of medical ethics in 1803 (cited in Olsen & Sabin, 2003). It is reported that ensuring confidentiality during communications between the physician and client is central to preserving trust between them (Spielberg, 1998), and leads to full disclosure of medical information. Clear access to health information is reported to enhance trust and increase compliance with treatments (Sadan, 2001). Breach of client confidentiality occurs when 'a person who holds the patient's confidence conveys private information about a patient to another party unauthorised to receive the information' (Berman, 2002).

Privacy was been identified as a concern for clients, in a study of 427 clients in Arizona (Parrot et al, 1989). In a USA emergency room setting, a survey of 440 persons indicated that 48% of conversations were overheard in adjacent rooms and that 36% of the sample felt that their privacy had been compromised. It was concluded that this led to sub-optimal care for clients (Olsen & Sabin, 2003). Findings of a study involving interviews with 51 persons found a number of ways in which client confidentiality was breached during communications. The nature of such breaches of confidentiality had previously received limited empirical, theoretical, or practical attention in terms of research (Brann & Mattson, 2004).

Previous research into blind and partially sighted people's experience of accessing health information in England highlighted that they did not receive health information in accessible formats (RNIB, 1998). The requirement to provide accessible formats of health information under disability legislation has been previously reported (Carter & Markham, 1999). Nzegwu (2004) 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), who found that most blind and partially sighted people in England did not receive health information in an accessible form, reported that they were reluctant to make requests for accessible formats.

Barriers to effective doctor-client communication are recognised in medical literature. Clinicians need to ensure that physical barriers to communication are removed, before they can communicate effectively (Quill, 1989). Vision loss was identified as an issue for clinicians working with older clients. Despite advice on the design of medical facilities and communicating face-to-face with visually impaired clients, no specific consideration was given to communicating confidentially with them (Adelman et al, 2000). The need for accessible format information is highlighted, as blind and partially sighted people are reported to require a stepped approach to receiving information. This could mean that essential information may be required after appointments and diagnoses, in order to allow them to understand their condition (Douglas et al, 2010). People who have a visual impairment and are between 30 and 64 years of age are more likely to be living alone than the general population of the same age (Clements & Douglas, 2009). If health information is not in a readable format, then blind and partially sighted people who live alone may have to ask for help to read it, and client confidentiality could thus be compromised.

The number of published empirical studies on vision impairment, health communication and confidentiality are very low. It is hoped that highlighting these issues can make an effective contribution to the debates surrounding client confidentiality and access to health information for blind and partially sighted persons.

The aim of this research was to examine the experiences of blind or partially sighted persons when accessing health information from various services in Scotland. The following research questions were developed accordingly:

- Are communications from healthcare professionals and organisations to blind and partially sighted persons at risk of breaching client confidentiality?
- What impact does inaccessibility of health information have on the lives and health of blind and partially sighted persons?
- How do blind and partially sighted persons respond when they receive information in an inaccessible format?

Research into the accessibility of health information for blind and partially sighted people was carried out for Royal National Institute for the Blind (RNIB), Scotland. **Accessible formats** refer to formats that blind and partially sighted persons can read for themselves without assistance. **Health information** refers to the many different types of information relating to health or healthcare, be it personal or general. **Personal health information** pertains to information that is confidential or particular to an individual, as for example details on diagnosis, appointments, hospital procedures, test results or prescribed medication. **General health information** refers to more general client information.

METHOD

RNIB Scotland has 322 members who are registered as blind and 173 members who are registered as partially sighted. Questionnaires were posted to 495 of the members who were over 16 years of age. They were requested to return the completed questionnaires to RNIB Scotland, in the addressed envelopes that were supplied. The questionnaire was an adapted version of the instrument used in a previous RNIB survey that took place in England (Sibley, 2009). Information was provided to members as to the aims and scope of the questionnaire. Those who were sent the questionnaire via email could complete it electronically. The questionnaires could also be completed over the phone with questions being read out by a telephonist. The completed questionnaires were then passed on to the authors for collation, and all the received questionnaires were included in the analysis.

The questionnaire was comprised of seven sections: A)About you; B)Your sight; C)Access to healthcare services; D)Communications support; E)Communicating with staff; E)Understanding your condition/treatment; and F)Making a complaint.

'About you' contained five items to gather data on the ethnography of the sample, such as items on age, ethnicity, sex and geographic location. 'Your sight' contained two items categorising sight levels, registration status (blind/partially sighted/not registered) and length of sight deterioration. Age bands were used to collect data, in an attempt to increase the response rate by those who may have been reticent to disclose their actual age, or could not remember the exact date of their diagnosis. Other questions required participants to respond with a 'yes/no' to accessing services. 'Access to healthcare service' contained four items asking about participants' use of health services and how they made appointments. 'Communication support' contained four items asking about alternative reading format requirements and accessing healthcare. 'Communicating with staff' enquired as to whether participants found it difficult to receive information in their preferred formats from health services. 'Understanding your condition' explored participants' understanding of their conditions and mistakes with medication. 'Making a complaint' asked whether participants made a complaint and how it was done.

The questionnaire was structured so that it elicited both quantitative (yes/no) responses and also gave space for more qualitative responses (such as 'Give an example of your experience of accessing health information'). Qualitative data were analysed using a methodology informed by grounded theory (Strauss & Corbin, 1990). This method of analysis identified categories from the interviews, using a method of open coding. It involved reading each transcript and identifying the emergent themes mentioned in the participants' responses. These themes were then collated and grouped into cognate areas and issues. This methodology was previously reported to be an effective means of analysis (Thurston et al, 2010). Data is presented under these themes, accompanied by relevant comments from participants.

The participants were not required to complete all the questions. If an NHS service had not been used in the past year, they would not respond to questions in those sections. Therefore, reported responses in each section varied according to the use of the service.

Note: Percentages reported in the following data are those in relation to the percentage of valid respondents to each question. The denominator therefore changes on the following descriptive data sets. This is because participants only responded to questions about services they had actually used.

RESULTS

Demographics of Survey Sample

Questionnaires were received from 228 subjects (86 male and 141 female; 1 not specified), making the return rate 45.15% (228 out of 505). The ranges of age distribution and frequencies of age are presented in Table 1. Data indicated that the majority (about three-quarters) of the respondents were over 65 years of age. They were predominantly White-Scottish (79.5%) in ethnicity. Participants responded from 15 Health Authorities.

Table 1: The age distribution and frequencies of age ranges of participants

Age	Frequency	Percent
18-24	2	.9
35-44	7	3.1
45-54	18	8
55-64	32	14.2
65-74	44	19.6
75-84	66	29.3
85+	53	23.6
Under 16	3	1.3
Undisclosed age	3	1.3
Total number of participants	228	100

195 of the participants reported the level of their sight. 119 were registered blind and 76 were registered partially sighted. 29 were either not registered or did not report registration status. However, they must have been registered as either blind or partially sighted at some point in the past to have been on the RNIB database. Therefore, 195 of the 228 (85.5%) respondents had medical records that would clearly state they had a visual impairment. In Scotland, registration as blind/partially sighted is at the discretion of an ophthalmologist. The age range at which respondents began to lose their sight is reported in Table 2. More than three-quarters of the sample developed sight complications when they were over 26 years of age.

Table 2: Age range at which respondents began to lose their sight

Age at beginning sight loss	Frequency	Percent
From birth	26	11.6
0 – 2	2	.9
3-5	3	1.3
6 -15	4	1.8
16-17	1	.4
18-25	5	2.2
26-44	30	13.4
45-54	24	10.7
55-64	33	14.7
65-74	49	21.9
75-84	39	17.4
85+	8	3.6
Total	224	100

Preferred Reading Formats

219 (96%) participants indicated that they needed information in a preferred reading format. Among them, 67 participants (30.6%) preferred audio-taped information, 60 (27.4%) preferred large print, and 15 (6.8%) preferred a combination of large print and audio-taped information. Other participants reported in lower numbers (under 5%) that they had combinations of twenty different preferred formats. A number of those 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. Participants indicated that they rarely received information from a range of health- care services in their preferred format (see Table 3). Adapted format information was not sent out to 89.7% of the participants.

Of the 156 participants who responded, 56 (35.9%) thought that the staff did not know how to provide information in their preferred format, 17 (10.9%) thought that staff did not know they required an alternative format, 7 (4.5%) thought it was too short notice to receive information in a preferred format and 60 (38.5%) stated that they did not know that they could ask for information in their preferred format.

The majority of respondents thought that they had a right to receive information in an adapted format (213 of 228 respondents-93.4%). 6.6% were not aware that they had a right to receive information in an adapted format. This finding runs

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

Heath service	Number of respondents from survey (N)	Had information in preferred reading format		Never had information in preferred reading format	
		N	%	N	%
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 & Emergency	117	6	6	110	94

Percentage figures are calculated from the number of respondents who responded to this particular section of the survey (i.e. 27x100/202 for GP; 12x100/182 for Practice Nurse)

counter to the responses from participants regarding the reasons for not receiving information in preferred formats. There appears to be a discrepancy: blind and partially sighted persons' know that they should be able to receive information in their preferred formats, but they think that health services actually had to do this i.e. they did not think that they could ask for information in a preferred format. It was common for respondents to report difficulty in receiving information in their preferred formats. Of the 95 respondents who reported that they found it difficult to receive information in their preferred format, 32 (33.7%) cited difficulty in receiving information from their GP, 30 (31.6%) from the practice nurse, 36 (37.9%) from eye clinic staff, 33 (34.7%) from other hospital departments, 20 (21.1%) from accident and emergency departments and 18 (18.9%) from ambulance staff. Overall findings indicated that 28% of respondents found it difficult to receive information in their preferred formats across the HNS.

Impact on Health and Life

The reported data is from the open responses to questions. Respondents indicated that assistance from carers and relatives mitigated the effects of not receiving information in preferred/accessible formats. In spite of this, there was still evidence of disempowerment for blind and partially sighted people. Data presented in Table 4 indicated that visually impaired persons had missed appointments, had difficulty understanding their medical conditions and had taken the wrong dosage of medication. Though these were infrequent instances, the potentially serious effects should not be underestimated. In each instance where there is reliance on help from others, there is a potential breach of doctor-client confidentiality.

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

Health service	Taken the wrong amount of medication because information not in preferred reading format		Missed appointments because information not in preferred reading format		Have come out of appointment not knowing what their condition was because information not in preferred reading format	
	N	%	N	%	N	%
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	-	17	11.4
Hospital Inpatient	1	0.8	3	2	12	10.4
Accident & Emergency	2	1.8	Not applicable	-	10	9.7

Percentage figures are calculated from the number of respondents who responded to this particular section of the survey (i.e. 24x100/202 for GP; 4x100/182 for Practice Nurse)

Taking medication: One of the most commonly reported difficulties involved accessing information about medication. 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…The variable in packaging is a very serious potential calamity for the blind" (Participant 158);* and not being able to read the instructions on packaging: *"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).*

Making appointments: The most basic of tasks presented a challenge to some of the participants when making appointments: *"I have difficulty finding the phone numbers and dialling"* (Participant 46). Many participants described 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).

Visiting hospitals: Several participants reported that they found hospital experiences challenging. They cited difficulty with appointment notifications: *"All notices of hospital appointments are in ordinary print"* (Participant 28). The physical environment of the hospital was also reported to be problematic: *"Signage in hospitals is not suitable for blind and partially sighted people"* (Participant 172). There was specific reference to difficulties in reading pre-procedural instructions: *"I had difficulty reading the instructions on what to do prior to going in for a colonoscopy, regarding sachets, etc"* (Participant 73). Hospital stays as an inpatient were reported to be difficult too: *"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 are 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).

Adopting coping strategies: Participants reported that they adopted a variety of coping strategies to access health information and services. Some relied on low vision aids: *"I rewrite the date and time of my appointments using my magnifier"* (Participant 63). Some participants relied solely on family support: *"My husband reads information received to me"* (Participant 70).

Experiencing negative feelings: Participants reported that inability to access health information had a negative psychological impact. Loss of autonomy was the most common negative feeling. Reliance on others was reported to be immensely challenging: *"From this comes lack of independence and privacy"* (Participant 64).

Making Complaints

Of the 101 participants who indicated what action they took if they did not receive information in their preferred reading format, 55 (54.5%) stated that they did not complain, 35 (34.7%) indicated that they had complained to the health service, and another 6 (6%) stated that they reported the issue to RNIB or some other charitable organisation. The majority did not complain and gave different reasons for this. The most common reason was that: *"It would be a waste of time"* (Participant 11); coupled with low expectations of change: *"They say there is nothing they can do about it"* (Participant 13). Some participants were not familiar with complaint procedures: *"I did not know the procedure to complain"* (Participant 214). Others 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). A few participants reported that their pride prevented them from complaining. They did not want to be perceived as being unable to cope: *"I don't like strangers to know that I have a problem"* (Participant 94).

Suggesting Improvements in Practice

Participants had several ideas to improve their access to health information. Standard use of large print was viewed as being beneficial: *"Chemists should advertise in store that prescription labels may be available in Braille or large print as 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).

DISCUSSION

This survey found that the majority of blind and partially sighted people did have a preferred reading format but did not receive information in that manner. Though most thought they had the right to receive health information in an adapted format, they had not complained. Many of them had undergone substantive sight loss as adults and needed help in accessing information, which implied that confidentiality was compromised in most of the health communications. This is in direct contradiction to current legislation. The central tenets of The Patient Rights (Scotland) Act 2010 (Scottish Parliament Corporate Body, 2010) and the Disability Discrimination Acts 1995 and 2005 (Scottish Office, 1995; Scottish Government, 2005) appear to be ignored, judging from the experience of the survey sample. It is possible that more specific advice from the General Medical Council may be required to enhance professional standards of doctors and to ensure that the issue is highlighted during professional training. Present advice to doctors (General Medical Council, 2010a, 2010b), although explicit and extensive, does not appear to be making the desired impact. The findings of this survey support the findings of earlier research which had reported inaccessible formats of health information and limited staff awareness about the physical and psychological needs of blind and partially sighted people in the NHS in England (RNIB, 1998; Nzegwu, 2004; Sibley, 2009). It would appear that similar issues pervade the NHS in Scotland.

The survey also revealed that blind and partially sighted people had difficulty identifying and using medication, and frequently relied on others for help. Difficulty in reading appointment notifications and accessing physical environments in hospitals was commonly reported. Outpatient procedures and inpatient treatments were reported to be problematic due to lack of accessible information. Having to ask the location of clinics because of inadequate signage, and needing someone to read the instructions on a prescription label were two areas where the confidentiality of personal health information was breached. This is a stealth breach caused when a person has no choice other than to disclose health information to a third party due to systemic structural deficiencies. Participants reported that 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. It is essential that this issue should now be addressed by NHS Scotland. The standard use of large print in health information might allow more of the blind and partially sighted people to access health information without requesting a special format. There could be better collaboration between drug companies and dispensing chemists regarding provision of accessible formats of drug labels. Accessible format health information was presenting a physical barrier to effective medical care (Quill, 1989). Data concurred with previous findings that breach of confidentiality and privacy resulted in sub-optimal care for clients (Olsen & Sabin, 2003). The need for client-centred practice in eye care has been previously highlighted (Rumney, 1992). However, nearly twenty years and a number of laws later, it appears that something as basic as communicating in a format that a client will be able to read has still not been achieved in all aspects of healthcare in Scotland.

The majority of blind and partially sighted participants reported on the coping strategies they employed to mitigate the effects of receiving information in inaccessible formats. Most used a combination of low vision aids or assisted technology, along with help from family, friends or carers. Loss of autonomy was the most commonly reported psychological side effect of the problem, because having to rely on others led to both lack of independence and privacy. Thurston et al (2010) reported that there was a need for clinicians to be aware of the power differential that may exist between them and a blind or partially sighted person during initial diagnosis. It would appear that communication with clients is another area in which this power differential is manifested.

Despite experiencing difficulty accessing health information and health services, very few of the participants reported that they had complained. The most common reason given was that they thought it would be a waste of time. Some participants also reported that they lacked the emotional strength needed to complain. This highlights the important role that individual representatives, researchers and organisations have in representing the views and needs of blind and partially sighted people. It is imperative that organisations such as RNIB and Guide Dogs for the Blind bring such issues to the forefront of medical debate. In doing so, they can give a voice to the voiceless, and help redress social inequity and promote social inclusion.

CONCLUSION

Accessible and confidential healthcare services for blind and partially sighted clients need to be improved so that there is better access to healthcare facilities. This would include the receipt of appointment information, medication, hospital menus and diagnosis in appropriate reading formats. There may also be a need to educate blind and partially sighted people themselves regarding their right to receive health information in their preferred reading formats. Based on the findings of this survey, it is possible to make the following recommendations:

Recommendation 1: Education and training may be required for healthcare professionals. This would include raising staff awareness on how to support the needs of blind and partially sighted persons, both physically and emotionally.

Recommendation 2: Effective professional development and education for healthcare staff regarding different types of blindness may be required.

Recommendation 3: Hospitals may require resources such as hardware (e.g. Braille printers) and software to ensure information is sent in an accessible format.

The extensive legislative and ethical practice framework within which the health service operates has the required wording and meaning to protect client confidentiality. However, data from this study indicated that professional practice does not currently adhere to either ethical or legal requirements. Further research may be required in this field.

Limitations

Limitations of the research must be acknowledged in respect of the composition of the sample. The survey was drawn from a self-selected sample of RNIB members and therefore there may be bias in sample composition. Government statistics indicate that there are approximately 37,000 blind and partially sighted people in Scotland (Scottish Government, 2010). There are approximately

10,400 RNIB members in the UK, and 495 blind and partially sighted members in Scotland (RNIB, 2009). The membership of RNIB members in Scotland is a smaller proportion of the wider population of blind and partially sighted persons (approximately 13.4%). Based on these figures, the findings must be viewed with some caution. Sample size was sufficient to be representative of the population of RNIB members at 95% accuracy with a margin of error of 5% (minimum sample size of 217 required). However, sample size was too low to allow extrapolation to the Scottish population.

The psychometric properties of the instrument are not discussed in this manuscript and therefore the conclusions drawn must be treated with caution. Future efforts should establish validity and reliability of the tool being used. For this, a larger sample size would be required and Cronbach's alpha calculated for each sub-scale. The relatively low (45.15%) return rate must also be considered when interpreting data. Surveying persons who are visually impaired is problematic for obvious reasons. Although the questionnaire was provided in a preferred reading format, and audio-tape and telephone interviews were also employed, efforts to enhance return rates should be considered. This could be done by conducting more telephone interviews or by visiting RNIB members at their place of work or homes.

A final limitation of the data derives from the lives of the researchers. Grounded theory was used to analyse emergent themes. It should be noted that one of the researchers is registered legally blind and has therefore been affected by many of the issues reported. There is a risk that without reflexivity the researchers would look for their own answers in the emergent data set. However, the researcher is also a trained Psychotherapist and during professional practice she is accustomed to examining the place of the 'self' in framing and interpreting events. Careful supervision during data analysis and coding by each researcher tried to minimise the risk of biased data selection. In addition, data presented included verbatim quotations from participants. This adds authenticity to the themes and allows the reader to assess the trustworthiness, credibility, coherence and dependability of the analysis presented.

However, despite these limitations, with 90% of the survey sample reporting their experiences of breach of confidentiality, the research has identified what may be an important issue for blind and partially sighted people. A wider survey may indicate the true extent of the problem in the larger population. Findings are in line with those found for England (RNIB, 1998; Nzegwu, 2004; Sibley, 2009).

Given that the issue identified by this survey has been identified much earlier, it is surprising that improvements to services have not already taken place. One explanation for this may be that previous surveys have reported results embedded within the context of effective service provision. Data from this survey is presented within the context of medical confidentiality. Within this framework, it is hoped that health professionals will modify their behaviour and professional practice on seeing the ethical dilemma that communication with blind and partially sighted clients presents. It is important to recognise that there are many people involved in the chain of communication between health services and clients. This includes doctors, pharmacists, nurses, receptionists and administrators. However, all of the people in the chain ultimately convey information that is integral to the doctor-client relationship. Doctors must identify deficiencies in communications made by other personnel, and take responsibility for managing these communications effectively. In addition, there may be a need to undertake further research to assess the emotional and societal impact of receiving healthcare information in inaccessible formats. Finally, it is important that lawmakers recognise the potential risks involved in breaches of client confidentiality. The authors of this manuscript gave evidence to the Scottish Parliamentary Health and Sport Committee considering the Patients Rights Bill (Scotland) 2010, as a result of which an amendment to the Bill was included that specifically referred to the use of appropriate communication formats with blind and partially sighted persons. This has enshrined the right to accessible health information in the legislative framework of Scotland. However, without substantive changes to professional practice, the issue highlighted by this research may persist and the risk of breached client confidentiality will continue.

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