

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

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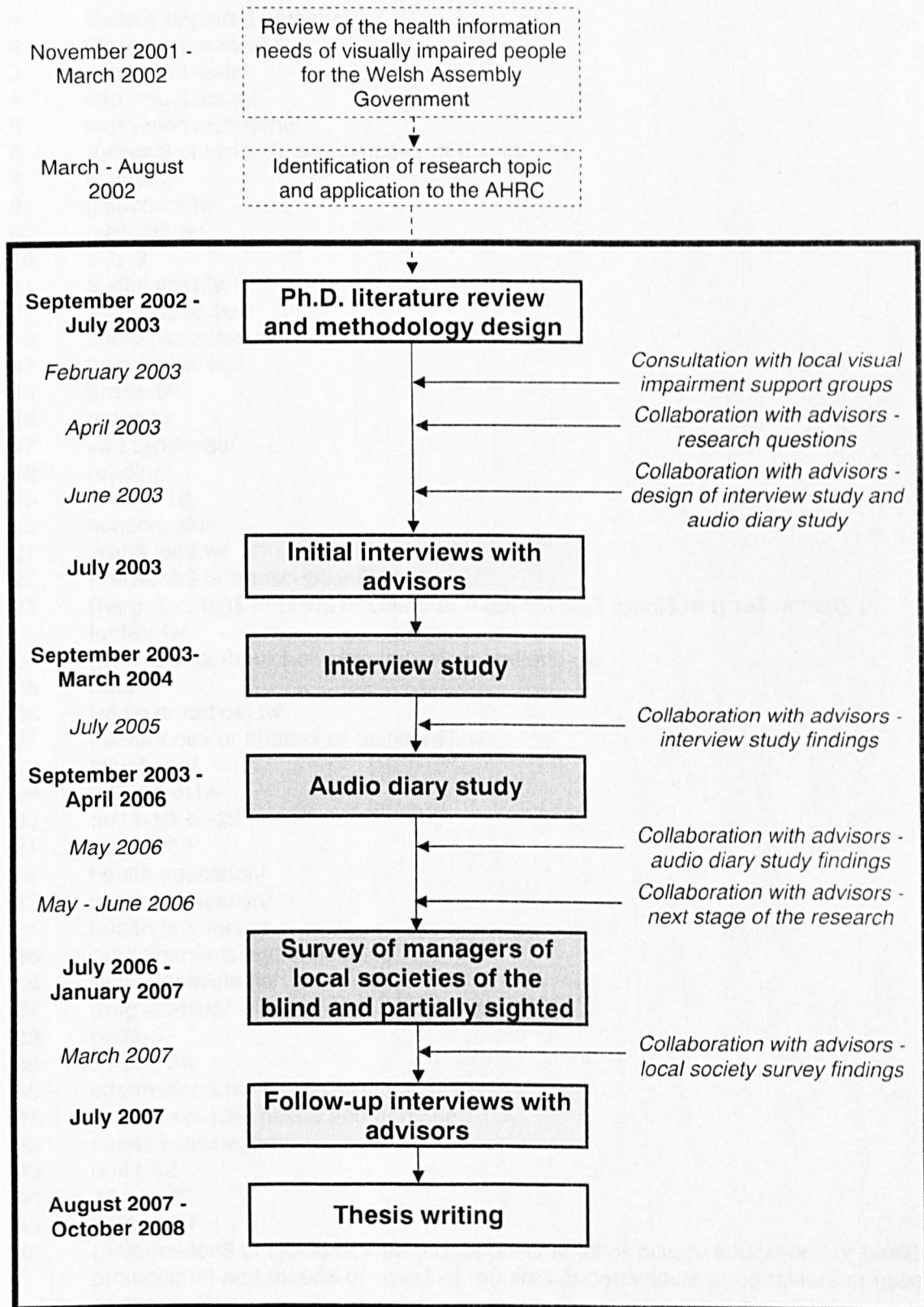
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APPENDICES

Appendix A. Research timeline



Appendix B. Sample search strategy (Ovid Medline)

1 visually impaired persons/
2 exp eye diseases/
3 exp vision tests/
4 exp visual acuity/
5 exp vision disorders/
6 ((visual\$ or vision\$) adj3 (impair\$ or disab\$)).tw
7 sight\$.tw
8 glaucoma.tw
9 macula\$.tw
10 or/1-9
11 audiotape\$.tw
12 audio tape\$.tw
13 audio cassette\$.tw
14 tape recording/
15 braille.tw
16 moon.tw
17 exp blindness/
18 reading/
19 17 and 18
20 sensory aids
21 read\$ aid\$.tw
22 (transcrib\$ or transcription\$).tw
23 ((large\$ or big\$ or bold\$ or clear\$ or magnif\$) adj2 (print\$ or type\$ or text\$ or font\$)).tw
24 (talking adj2 (book\$ or newspaper\$ or leaflet\$)).tw
25 radio/
26 (radio or radios).tw
27 (telephone\$ or phone\$ or helpline\$).tw
28 telephone/
29 nhs direct.tw
30 or/11-16,19-29
31 10 and 30
32 health education/
33 patient education/
34 health promotion/
35 "appointments and schedules"/
36 reminder systems/
37 drug labeling/
38 or/32-37
39 31 and 38
40 information\$.tw
41 "health services needs and demand"/
42 needs assessment/
43 or/41-42
44 40 and 43
45 31 and 44
46 ((information\$ or label\$ or letter\$ or appointment\$ or patient education\$ or health promotion\$) and (need\$ or want\$ or require\$ or behaviour\$ or behavior\$ or usage\$ or service\$)).tw

- 47 41 and 46
- 48 (information\$ and (blind\$ or sight\$ or visual\$ impair\$ or visual\$ disab\$ or visual\$ handicap\$ or braille or large\$ print\$)).ti
- 49 39 or 45 or 47 or 48

Appendix C. Information sheet for potential interview study participants



U N I V E R S I T Y O F S H E F F I E L D

DEPARTMENT OF INFORMATION STUDIES

Postal address: Western Bank, Sheffield S10 2TN

Location: Regent Court, 211 Portobello Street, Sheffield S1 4DP

Tel. (0114) 222 6332 **E-mail:** lip02cab@sheffield.ac.uk

WWW: <http://www.shef.ac.uk/~is/home.html>

INFORMATION SHEET

Title of project:

The health and social care information needs of people with a visual impairment

Investigation:

Interviews with people with a visual impairment (Autumn/ Winter 2003)

Name of researcher:

Catherine Beverley

Department of Information Studies, University of Sheffield, Western Bank, Sheffield, S10 2TN. Tel: 0114 222 6332.

Name of supervisor:

Dr Peter Bath

Department of Information Studies, University of Sheffield, Western Bank, Sheffield, S10 2TN. Tel: 0114 222 2636.

You are being invited to be interviewed as part of the above research project exploring visually impaired people's use and need for health and social care information. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read/ listen to the following information carefully and discuss it with friends, relatives, *etc.* if you wish.

What is the purpose of the study?

The overall aim of this research study is to explore the health and social care information needs of people with a visual impairment. In particular, it will investigate the key sources for people with a visual impairment seeking health and social care information, whether information behaviour varies according to the type and degree of impairment, how current developments in health and social care information provision (*e.g.*, NHS Direct) and information provision in general (*e.g.*, modified Internet user interfaces) can better meet the needs of people with a visual impairment, and how people with visual impairments can be effectively involved in the planning and conduct of research in this field.

What is the purpose of these interviews?

The purpose of these interviews is to explore in-depth with a sample of people with a visual impairment their health and social care information behaviour, *i.e.*, what information you require concerning your health and social care, where you receive and/or seek this information, how useful you find this information, and in what ways the existing provision of information of health and social care information can be improved for people with a visual

impairment. The findings of these interviews will be disseminated both locally and nationally and it is hoped that they will be acted upon by policy-makers.

What will be involved if I agree to take part in the study?

You will be asked several questions relating to the information you have either received or sought in connection with your visual impairment or other aspects of your health and social care. You will also be provided with an opportunity to suggest ways in which the current provision of health and social care information might be improved. In order to help with the analysis of the interviews, you will also be asked a few background questions relating to your visual impairment. The conversation will be tape-recorded, with your permission. You are obviously free to ask for the tape recorder to be stopped at any point.

Do I have to take part in the study?

No. You are free to refuse to be interviewed and may withdraw at any time or choose not to answer certain questions, without giving a reason.

When, where and how will the interview take place?

A face-to-face (or telephone, if preferred) interview will be pre-arranged and is likely to take place in Autumn/ Winter 2003. Where possible, the interview will be conducted in your own home. Alternatively, if you prefer, arrangements can be made to conduct the interview at the University of Sheffield or in a neutral venue, such as the Sheffield Royal Society for the Blind.

Will the information obtained in the study be confidential?

Anything you say will be treated in confidence, no names will be mentioned in any reports of the study, and care will be taken so that you cannot be identified from any reports of the study.

What will happen to the results of the research study?

The interviews will be transcribed and analysed by the lead researcher. The findings will be written up both as a detailed report and as a short "user friendly" briefing. You will be given an opportunity to comment on initial transcripts and reports of the research. Additionally the findings will form the basis of the lead researcher's Ph.D. thesis, and may be used to write articles for publication in relevant journals.

Who is organising and funding the research?

The research is led by a postgraduate student, under the supervision of a Lecturer in Health Informatics, at the Department of Information Studies at the University of Sheffield. It is part-funded by a grant from the Arts and Humanities Research Board (AHRB).

Who has reviewed the study?

The study has been reviewed by the AHRB, the South Sheffield Research Ethics Committee, and the University of Sheffield Department of Information Studies Research Committee.

Who can I contact if I have any outstanding queries?

The lead researcher, Catherine Beverley, can be contacted at the Department of Information Studies, University of Sheffield, Western Bank, Sheffield, S10 2TN, Tel: 0114 222 6332, Mobile: 07956 292487, Email: lip02cab@shef.ac.uk.

What if I wish to complain about the way in which this study has been conducted?

If you have any cause to complain about any aspect of the way in which you have been approached or treated during the course of this study, please contact the lead researcher, Catherine Beverley, Department of Information Studies, University of Sheffield, Western Bank, Sheffield, S10 2TN, Tel: 0114 222 6332, Email: lip02cab@shef.ac.uk, or the supervisor for this study, Dr Peter Bath, Tel: 0114 222 2636, Email: p.a.bath@shef.ac.uk. Alternatively, you can use the University of Sheffield complaints procedure c/o the Research and Consultancy Unit, University of Sheffield, 2/4 Palmerston Road, Sheffield, S10 2TE.

Appendix D. Interview study topic guide

Checks:

- Thank you
- Information sheet
- Reiterate purpose of interview
- Not a test
- Tape recorder
- Consent

1. Background to visual impairment
 - Other health conditions
2. Meaning of health and social care information
3. Contact with different agencies (*e.g.*, RHH, Social Services, SRSB, *etc.*)
4. Information relating to visual impairment
 - Received
 - Sought
 - Acquired
 - Outstanding information needs
5. Information relating to other aspects of health and social care
 - Received
 - Sought
 - Acquired
 - Outstanding information needs
6. Newer sources of information
 - Telephone helplines
 - Internet
 - Touch screens
7. Possible improvements to the provision of health and social care information
8. Demographic information
 - Sex
 - Age
 - Ethnic origin
 - Marital status
 - Living with others
 - Employment status
 - Socio-economic status

Appendix E. Information sheet for potential audio diary participants



U N I V E R S I T Y O F S H E F F I E L D

DEPARTMENT OF INFORMATION STUDIES

Postal address: Western Bank, Sheffield S10 2TN

Location: Regent Court, 211 Portobello Street, Sheffield S1 4DP

Tel. (0114) 222 2636 **E-mail:** lip02cab@sheffield.ac.uk

WWW: <http://www.shef.ac.uk/~is/home.html>

INFORMATION SHEET

Title of project:

The health and social care information needs of people with a visual impairment

Investigation:

Audio diaries with people with a visual impairment

Name of researcher:

Catherine Beverley, Tel: 01228 607113, Email: lip02cab@sheffield.ac.uk.

Name of supervisor:

Dr Peter Bath

Department of Information Studies, University of Sheffield, Western Bank, Sheffield. S10 2TN. Tel: 0114 222 2636.

You are being invited to be interviewed as part of the above research project exploring visually impaired people's use and need for health and social care information. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to listen to the following information carefully and discuss it with friends, relatives, *etc.* if you wish.

What is the purpose of the study?

The overall aim of this research study is to explore the health and social care information needs of people with a visual impairment. In particular, it will investigate the key sources for people with a visual impairment seeking health and social care information, whether information needs vary according to the type and degree of impairment, how current developments in information provision (*e.g.*, NHS Direct and the Internet) can help to meet the needs of people with a visual impairment, as well as how people with visual impairments can be effectively involved in the planning and conduct of research in this field.

What is the purpose of these audio diaries?

The purpose of this particular study is to explore in-depth the real life experiences of a sample of people with a visual impairment in terms of their health and social care information needs, *i.e.*, what information you require concerning your health and social care, where you receive and/or seek this information, how useful you find this information, and in what ways the existing provision of health and social care information can be improved for people with a visual impairment. By asking you to make an audio diary it is hoped that events and behaviours that cannot readily be observed can be investigated,

and that the value of audio diaries as a research method can be further explored. The findings of this study will be disseminated widely and it is hoped that they will be acted upon by policy-makers.

What will be involved if I agree to take part in the study?

The lead researcher will initially meet with you on a one-to-one basis. This will give you an opportunity to learn more about the research study. At the end of the meeting, you will be issued with a tape recorder and a cassette and asked to record any issues that arise during a four week period relating your health and social care information needs. Instructions on making the diary will be provided in your preferred format. You will be requested to make a "live recording", rather than a retrospective account, and, although the diary will remain relatively unstructured, you will be asked to state the date and time before making an entry.

You will be contacted after the first week by the lead researcher to see how you are getting on. Think of this as an opportunity to ask any questions you may have about recording the audio diaries.

Within a month of the four week data collection period you will be interviewed by the lead researcher to clarify comments made in the audio diary, and to gauge your opinions about the audio diary as a research method. This conversation will be tape-recorded, with your permission. You are obviously free to ask for the tape recorder to be stopped at any point.

Do I have to take part in the study?

No. You are free to refuse to participate in the study and may withdraw at any time or choose not to answer certain questions, without giving a reason.

Will the information obtained in the study be confidential?

Anything you say will be treated in confidence, no names will be mentioned in any reports of the study, and care will be taken so that you cannot be identified from any reports of the study.

What will happen to the results of the research study?

The diaries and interviews will be transcribed and analysed by the lead researcher. The findings will be written up both as a detailed report and as a short "user friendly" briefing. You will be given an opportunity to comment on initial transcripts and reports of the research. Additionally the findings will form the basis of the lead researcher's Ph.D. thesis, and may be used to write articles for publication in relevant journals.

Who is organising and funding the research?

The research is led by a postgraduate student, under the supervision of a Senior Lecturer in Health Informatics, at the Department of Information Studies at the University of Sheffield. It is part-funded by a grant from the Arts and Humanities Research Council (AHRC).

Who has reviewed the study?

The study has been reviewed by the AHRC, the South Sheffield Research Ethics Committee, the University of Sheffield Department of Information Studies Research Committee, and Cumbria County Council's Research and Consultation Governance Group.

Who can I contact if I have any outstanding queries?

The lead researcher, Catherine Beverley, can be contacted on Tel: 01228 607113, or by email: lip02cab@shef.ac.uk.

What if I wish to complain about the way in which this study has been conducted?

If you have any cause to complain about any aspect of the way in which you have been approached or treated during the course of this study, please contact either the lead researcher, Catherine Beverley, Tel: 01228 607113, Email: lip02cab@shef.ac.uk, or the supervisor for this study, Dr Peter Bath, Tel: 0114 222 2636, Email: p.a.bath@shef.ac.uk. Alternatively, you can use the University of Sheffield complaints procedure c/o the Research and Consultancy Unit, University of Sheffield, 2/4 Palmerston Road, Sheffield, S10 2TE.

Appendix F. Audio diary guidance notes



UNIVERSITY OF SHEFFIELD DEPARTMENT OF INFORMATION STUDIES

Postal address: Western Bank, Sheffield S10 2TN

Location: Regent Court, 211 Portobello Street, Sheffield S1 4DP

Tel. (0114) 222 2636 **E-mail:** lip02cab@sheffield.ac.uk

WWW: <http://www.shef.ac.uk/~is/home.html>

AUDIO DIARY INSTRUCTIONS

Here are a few guidance notes which should help you to make your audio diary.

What do you want me to record on my diary?

The focus of this research study is on people with a visual impairment and their need for health and social care information. The phrase 'health and social care information' encompasses any aspects of the information (written or verbal) you receive or seek in relation to your health and social care. This, therefore, covers:

- Your interactions with health and social care services, such as your GP, the hospital eye department, pharmacists, your dentist, social services, NHS Direct, *etc.*
- Your interactions concerning your health and social care with local and national organisations, such as local societies for the blind and partially sighted, the Macular Disease Society, the Royal National Institute for the Blind, Action for Blind People, *etc.*
- Information provided by health and social care providers relating to your visual impairment, as well as other aspects of your health and social care, such as health promotion materials, patient information leaflets, drug labels, appointment letters, test results, self-care materials, social security benefit forms, aids and adaptations, *etc.*
- Health and social care information sought independently either by yourself or by friends or relatives, for example, via the Internet.

This is not an exhaustive list, but should prove a useful starting point. If you are in any doubt as to whether something is relevant, please record the details anyway. I am particularly interested in any problems that you encounter and your attempts to overcome these.

How do you want me to make diary entries?

- Please can you start your audio diary by clearly stating your name and giving a brief introduction to yourself and your visual impairment. For example,
 - *"Welcome to the audio diary of John Smith. I am 74 years of age, retired, and live in a first floor flat with my wife in Whitehaven. I was diagnosed with age-related macular degeneration 3 months ago and am in the process of being registered partially sighted."*
- Before making a diary entry, please state the date and time; for example,
 - *"Monday 14th November 2005, 11.15am. My doctor has just put me on a new drug for my arthritis, but I am unsure about the number I need to take each day and am unable to read the label on the bottle. I've also heard that some of these drugs have nasty side effects but do not know what these are. I think I'm*

going to have to ask my daughter for help in seeking out this information. I feel very frustrated having to rely on others to help me out with this sort of thing."

- Where possible, please make a "live recording" rather than a retrospective account of events, *i.e.*, try to make a diary entry as a situation arises because this will enable you to record your thoughts as a problem occurs, rather than your thoughts once the problem has been resolved. For example,
 - *"Wednesday 16th November 2005, 4pm. I've just been speaking to Alan, my neighbour, and he says that I'm eligible for a number of benefits. I've no idea where to find out more about this and whether I need to be registered blind to claim. A few extra pounds a week would come in handy though. It's amazing how much I've had to spend on tapes and things like that since my eyes got worse."*
 - *"Monday 21st November 2005, 2.30pm. A lady from Social Services visited me this afternoon. I mentioned the benefits to her, and she thought I would be eligible, so she will ask someone to visit me to help me fill out some forms. It seems a lot of fuss for a new extra pounds to me, but we'll see what happens!"*
 - *"Thursday 24th November 2005, 5pm. Well, after an hour with Joanne, the forms are now completed. I didn't realise it would take that long, or that I'd have to give out so much personal information. Hopefully it's now all sorted and I'm pleased Joanne was there to explain things to me. These forms would be difficult to complete whether or not I was blind! Joanne has also introduced me to an extremely useful device to help me sign forms."*
- Instead of simply:
 - *"Thursday 24th November 2005, 7pm. I was not sure how to claim social security benefits so I sought help."*
- Please make at least one recording each day for the four week period.
 - If you have nothing to report, simply state the date and time, followed by *"Nothing to report"*.

Who do I contact if I have any questions or encounter any difficulties making the audio diary?

Please contact the lead researcher, Catherine Beverley, Tel: 01228 607113, Email: ljp02cab@shef.ac.uk.

Appendix G. Audio diary follow-up interview topic guide

Checks:

- Thank you
- Reiterate purpose of interview
- Not a test
- Tape recorder
- Consent

1. Clarification of diary entries
2. Previous experience of diaries and audio diaries
3. Guidance notes
 - Read/ listened to?
 - Regularly consulted?
 - Clear about purpose of study?
 - Outstanding questions?
 - Improvements?
4. Overall experience of keeping an audio diary
 - Opinions about the equipment
5. Problems making the audio diary
 - "Live recordings" versus retrospective ones
6. Strengths of audio diaries for collecting data with visually impaired people
7. Weaknesses of audio diaries for collecting data with visually impaired people
8. Personal impact, if any, of participating in this study
9. Other comments

Appendix H. Covering letter to managers of local societies for the blind and partially sighted

03 July 2006



Dear Colleague

Re: University of Sheffield Research Study

NALSVI is supporting a research study led by Catherine Beverley at the University of Sheffield exploring the role of local societies for the blind and partially sighted in meeting the information needs of our users. Further details about the research can be found in the enclosed information sheet.

We would, therefore, really appreciate it if you could spare a few minutes to complete the attached questionnaire and return it to Catherine in the pre-paid envelope by **Friday 28th July 2006.**

If you have any questions about the research or would like the questionnaire in an alternative format (*e.g.*, over the telephone, on tape, or via email), please do not hesitate to contact Catherine on (01228) 607113 or email: lip02cab@shef.ac.uk

Thank you in advance for your help.

Yours sincerely

A handwritten signature in black ink, appearing to read 'S. Hambleton', written over a faint, illegible background.

Steve Hambleton
Chair of NALSVI

CA Beverley

Catherine Beverley
Ph.D. Student

Appendix I. Information sheet for managers of local societies for the blind and partially sighted



U N I V E R S I T Y O F S H E F F I E L D
D E P A R T M E N T O F I N F O R M A T I O N S T U D I E S
Postal address: Western Bank, Sheffield S10 2TN
Location: Regent Court, 211 Portobello Street, Sheffield S1 4DP
Tel. (0114) 222 6332 E-mail: lip02cab@sheffield.ac.uk
WWW: <http://www.shef.ac.uk/~is/home.html>

INFORMATION SHEET

Title of project:

The health and social care information needs of people with a visual impairment.

Investigation:

A survey of information provision and information use by local societies for the blind and partially sighted in Great Britain.

Name of researcher:

Catherine Beverley, Department of Information Studies, University of Sheffield, Western Bank, Sheffield. S10 2TN. Tel: 01228 607113. Email: lip02cab@shef.ac.uk

Name of supervisor:

Dr Peter Bath, Department of Information Studies, University of Sheffield, Western Bank, Sheffield. S10 2TN. Tel: 0114 222 2636. Email: p.a.bath@shef.ac.uk

You are being invited to take part in the above research project exploring information provision and information use by local societies for the blind and partially sighted. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with colleagues if you wish.

1. What is the background to this study?

This survey forms part of a larger scale research study exploring the health and social care information needs of people with a visual impairment. It follows on from a literature review of the health information needs of visually impaired people, a small-scale interview study conducted in Sheffield, and a pilot audio diary study conducted in Sheffield and Cumbria. One particularly interesting finding from the research so far has been the importance of local societies for the blind in providing information to visually impaired people.

2. What is the purpose of this survey?

The main aim of this survey is to build on the interview and audio diary studies and explore in more detail the role of local societies for the blind and partially sighted in meeting the information needs of visually impaired people. The study is designed to answer the following research questions:

1. What information do local societies provide about health and social care matters?
2. Do the local societies provide the information that the interview participants expressed a need for?

3. What information sources do local societies use to seek information about health and social care matters?
4. How many local societies seek health and social care information for their service users via the Internet?
5. What do managers of local societies perceive to be the major barriers and facilitators to greater co-ordination of information between the different health, social care and voluntary agencies?

3. Why have I been chosen?

You have been chosen because you manage one of the local societies for the blind and partially sighted in Great Britain. Managers of all local societies will be invited to take part.

4. Do I have to take part in the study?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you can still withdraw at any time, or choose not to answer certain questions, without giving a reason.

5. What will be involved if I agree to take part in the study?

You will be asked to complete the enclosed questionnaire and return it to the lead researcher. It may be possible that you will also be invited to take part in a telephone interview which will explore in more detail some of the issues raised by respondents to the questionnaire (approximately 20 managers responding to the questionnaire will be contacted).

6. What are the potential disadvantages and/or risks of taking part?

The risks associated with taking part are negligible. If you flag up any issues of immediate concern, these will be referred on to the Chair of NALSVI.

7. What are the possible benefits of taking part?

Whilst the immediate benefits for those people taking part in the survey are negligible, it is hoped that this work will help to improve the provision of information to people with a visual impairment.

8. What if something goes wrong?

If you have any cause to complain about any aspect of the way in which you have been approached or treated during the course of this study, please contact the lead researcher, Catherine Beverley, Department of Information Studies, University of Sheffield, Tel: 01228 607113, Email: lip02cab@shef.ac.uk, or the supervisor for this study, Dr Peter Bath, Tel: 0114 222 2636, Email: p.a.bath@shef.ac.uk. If this does not result in a successful outcome, you can contact the University's 'Registrar and Secretary'.

9. Will my taking part in the research be kept confidential?

Anything you say will be treated in confidence. No names will be mentioned in any reports of the study, and care will be taken so that you cannot be identified from any reports of the study.

By completing and returning the questionnaire you are confirming that:

- You have read and understood this information sheet.
- You understand that your participation is voluntary and that you are free to withdraw at any time, without giving a reason.

- You understand that your responses will be anonymised before analysis and that you give permission for members of the research team to have access to your anonymised responses.
- You agree to take part in the research.

10. What will happen to the results of the research study?

The survey results will be collated and analysed by the lead researcher. The findings will be written up both as a detailed report and as a short “user friendly” briefing which will be circulated to all local societies for the blind and partially sighted, as well as the Chair of NALSVI. Additionally the findings will form the basis of the lead researcher's Ph.D. thesis, and may be used to inform conference presentations and to write articles for publication in relevant journals.

11. Who is organising and funding the research?

The research is led by a postgraduate student, under the supervision of a Senior Lecturer in Health Informatics, at the Department of Information Studies at the University of Sheffield. It is part-funded by a grant from the Arts and Humanities Research Council (AHRC).

12. Who has ethically reviewed the study?

The study has been ethically approved by the Department of Information Studies at the University of Sheffield.

13. Who can I contact if I have any outstanding queries?

Please contact the lead researcher, Catherine Beverley, Tel: 01228 607113, or email: lip02cab@shef.ac.uk.

Appendix J. Questionnaire sent to managers of local societies for the blind and partially sighted

1. Information provided to clients

1.1 Which of the following topics does your local society provide information (written or verbal) to clients about? [PLEASE TICK ALL OPTIONS THAT APPLY]

	<ul style="list-style-type: none"> • Different eye conditions, in particular information about the diagnosis, prognosis, treatment options, and causes.
	<ul style="list-style-type: none"> • The health and social care services and facilities available to visually impaired people.
	<ul style="list-style-type: none"> • Aids, adaptations and equipment available to visually impaired people, such as visual aids; talking books; liquid level indicators, <i>etc.</i>
	<ul style="list-style-type: none"> • General health care, including techniques for administering medications, such as tablets; reading medical information, such as appointment letters, prescriptions, medicine labels, <i>etc.</i>
	<ul style="list-style-type: none"> • Benefits and money.
	<ul style="list-style-type: none"> • Mobility, including using public transport, shopping, eating out, going on holiday, <i>etc.</i>
	<ul style="list-style-type: none"> • Housing and accommodation, including performing household chores, such as cooking and cleaning.
	<ul style="list-style-type: none"> • Employment, education and training.

1.2 In what format do you provide most of the information listed above? [PLEASE TICK ONE OPTION ONLY]

	<ul style="list-style-type: none"> • Verbal (over the telephone)
	<ul style="list-style-type: none"> • Verbal (face-to-face)
	<ul style="list-style-type: none"> • Large print
	<ul style="list-style-type: none"> • Audio cassette
	<ul style="list-style-type: none"> • CD
	<ul style="list-style-type: none"> • Braille
	<ul style="list-style-type: none"> • Moon
	<ul style="list-style-type: none"> • Email
	<ul style="list-style-type: none"> • Local talking newspaper
	<ul style="list-style-type: none"> • Local radio
	<ul style="list-style-type: none"> • Local television
	<ul style="list-style-type: none"> • Web site
	<ul style="list-style-type: none"> • Other (please specify below)

1.3 Do you target information to particular groups of clients?

	<ul style="list-style-type: none"> • Yes
	<ul style="list-style-type: none"> • No

1.3.1 If you do target information, how do you mainly target information?
 [PLEASE TICK ONE OPTION ONLY]

<input type="checkbox"/>	• By eye condition/ diagnosis
<input type="checkbox"/>	• By time since registration
<input type="checkbox"/>	• By age group
<input type="checkbox"/>	• By other means (please describe below)

2. Information sources used by local societies

2.1 Which of the following sources do you or your colleagues at your local society use to seek answers to clients' queries about health and social care matters?
 [PLEASE TICK ALL OPTIONS THAT APPLY]

<input type="checkbox"/>	• The hospital eye department (including the low vision clinic)
<input type="checkbox"/>	• A local optician
<input type="checkbox"/>	• A local general practitioner
<input type="checkbox"/>	• A rehabilitation officer for visual impairment (ROVI)
<input type="checkbox"/>	• A social worker
<input type="checkbox"/>	• Colleagues at other local societies
<input type="checkbox"/>	• National societies (e.g., RNIB, Macular Disease Society)
<input type="checkbox"/>	• The mass media (e.g., newspapers, magazines, television, radio)
<input type="checkbox"/>	• NHS Direct
<input type="checkbox"/>	• The Internet
<input type="checkbox"/>	• Other (please specify below)

2.2 Do you have Internet access at your society?

<input type="checkbox"/>	• Yes
<input type="checkbox"/>	• No

2.2.1 If so, do you or any of your colleagues at your local society use the Internet to answer clients' queries?

<input type="checkbox"/>	• Yes
<input type="checkbox"/>	• No

2.2.2 If so, please can you give an example of the information you sought for a client using the Internet (e.g., for what topic, which web sites you used).

--

2.2.3 Do you have any additional comments you would like to make about the Internet?

--

2.3 Have you heard of NHS Direct?

<input type="checkbox"/>	<input type="checkbox"/> Yes
<input type="checkbox"/>	<input type="checkbox"/> No

2.3.1 If so, have you ever directed any of your clients to use NHS Direct in connection with their eye condition?

<input type="checkbox"/>	<input type="checkbox"/> Yes
<input type="checkbox"/>	<input type="checkbox"/> No

2.3.2 Do you have any additional comments you would like to make about NHS Direct?

--

3. An integrated information service for visually impaired people?

3.1 Which of the following do you think are barriers to providing an integrated information service for visually impaired people across the National Health Service (NHS), social care and voluntary sectors? [PLEASE TICK ALL OPTIONS THAT APPLY]

	1.	Concerns about sharing personal information (e.g., in response to the Data Protection Act)
	2.	Inability to share information due to incompatible information/ computer systems
	3.	Conflicting priorities of different organisations
	4.	Budget constraints
	5.	Separate budgets for each organisation
	6.	Cultural differences
	7.	Differences in terminology used
	8.	Unsuccessful attempts to work together in the past
	9.	Fear of job losses
	10.	Other (please specify below)

3.1.1 From the list above, what do you think is the biggest barrier to providing an integrated information service for visually impaired people? [PLEASE LIST ONE OPTION ONLY, BY INSERTING THE CORRESPONDING NUMBER].

--

3.2 Which of the following do you think are facilitators to providing an integrated information service to visually impaired people across the NHS, social care and voluntary sectors? [PLEASE TICK ALL OPTIONS THAT APPLY]

	1.	Local and/ or regional information sharing protocols/ agreements
	2.	Compatible information/ computer systems
	3.	Local and/or regional strategies for visually impaired people/ visual impairment services
	4.	Existing good relationships with other organisations (e.g., joint meetings and groups)
	5.	Examples of previous successful integrated working
	6.	Shared budgets
	7.	Active involvement of visually impaired people in shaping services
	8.	Other (please specify below)

- 3.2.1 What do you think is the best facilitator to providing an integrated information service to visually impaired people? [PLEASE LIST ONE OPTION ONLY, BY INSERTING THE CORRESPONDING NUMBER].

--

4. Additional comments

- 4.1 Do you have any other comments that you would like to make?

--

5. Declaration

- 5.1 By completing and returning this questionnaire, I agree to participate in this research study.

Signed:

Date:

- 5.2 If selected, I am willing to take part in a follow-up telephone interview.

	<input type="checkbox"/> Yes
	<input type="checkbox"/> No

Appendix K. Follow-up local society manager telephone interview topic guide

Checks:

- Thank you
- Information sheet
- Reiterate purpose of interview:
 - Responses were received from 97 local societies, which equated to a response rate of 84%. Overall, the survey identified similarities and differences between the information provided by local societies, the information sources used by local societies, as well as the barriers and facilitators to providing an integrated information service for visually impaired people across the NHS, social care and voluntary sectors. I would now like to explore with you in more detail some of the differences that were found.
- Not a test
- Tape recorder
- Consent

A. Background to and brief description of local society

- Number of clients
- Geographical area covered
- Number of staff

B. Information provided to clients

1. Comments or observations on finding that the majority of local societies provided information to their clients about:
 - Aids, adaptations and equipment
 - The health and social care services and facilities available to visually impaired people
 - Different eye conditions
2. Role of local societies in providing information to visually impaired people about health and social care matters
3. Provision of information about different eye conditions to clients
 - Source of this information (e.g., RNIB leaflets, Internet)?
 - Reliability and currency of this information
 - New information versus refresher
4. Other comments

C. Information sourced used by local societies

1. Comments or observations on the finding that 91 local societies responding to the survey had Internet access at their local society, and 73 local societies used the

Internet to answer clients' queries. 67 respondents gave an example of the information they had sought for a client using the Internet.

2. Use of the Internet to answer clients' queries

- When used?
- Why?
- Which Internet sites?
- Trustworthiness of information?
- Reasons for not using the Internet

D. An integrated information service for visually impaired people

1. General comments on setting up an integrated information service for visually impaired people across the NHS, social care and voluntary sectors.
2. Comments or observations on the finding that the top three barriers to providing an integrated information service were:
 - Concerns about sharing personal information (*e.g.*, in response to the Data Protection Act)
 - Conflicting priorities of different organisations
 - Budget constraints
- Real versus 'perceived' barriers?
- Interactions with particular organisations and/or individuals?
3. Overcoming barriers
4. Comments or observations on the finding that the top three facilitators to providing an integrated information service were:
 - Local and/or regional strategies for visually impaired people/ visual impairment services
 - Active involvement of visually impaired people in shaping services
 - Existing good relationships with other organisations (*e.g.*, joint meetings and groups)
5. Example(s) of successful joint working between NHS, social care and voluntary organisations
 - Contributing factors?
6. Other comments about how an integrated information service for visually impaired people might work
 - Funding?
 - Location?
7. Other comments

Appendix L. 'Job description' for research advisors

Post	Consumer research advisor
Title of research study	The health and social care information needs of people with a visual impairment
Researcher	<p>Catherine Beverley</p> <p>Part-Time Research Student, Department of Information Studies, University of Sheffield, Western Bank, Sheffield. S10 2TN.</p> <p>Tel: (0114) 222 6332 Email: lip02cab@sheffield.ac.uk</p> <p>Supervisor: Dr Peter Bath, Tel: (0114) 222 2636</p>
Duration of the study	4-5 years (Project start date: 1 st October 2002)
Likely time commitments	Approx. 1-2 hours every 3-4 months
Salary	This is a voluntary post, although any reasonable expenses (<i>e.g.</i> , travel, stationery, telephone charges, <i>etc.</i>) incurred as a result of participating in this study will be reimbursed
Background	<p>In Winter 2000/1 the Centre for Health Information Management Research (CHIMR) at the University of Sheffield undertook a literature review of the health information needs of people with a visual impairment on behalf of the Welsh Assembly Government. This review revealed that very little high quality research had been conducted in this field. People with a visual impairment require information relating to a number of health issues, including for healthy living (such as health promotion materials), about visual impairment itself and coping with an impairment (such as patient information leaflets) and about accessing health services (such as appointment letters, test results and drug labels).</p> <p>The existing literature appears to be based on one of three assumptions: people with a visual impairment have the same health information needs as totally sighted people; they are disadvantaged in terms of the health information they receive because of their impairment, or they simply require the same health information, but in different formats (<i>e.g.</i>, Braille, large print, audio tape). However, I believe that none of these accurately reflect the complex and diverse needs of people with a visual impairment: instead, they have a set of unique health information needs that are worthy of exploration in their own right. The research conducted to date also fails to address a number of issues, such as other aspects of information (<i>e.g.</i>, content,</p>

	<p>packaging, timing and support mechanisms), the range of needs associated with different visual impairments, the sources of health information (e.g., health professionals, social workers, or health libraries or information services, etc.), or the importance of involving people with a visual impairment in the research process.</p> <p>I am, therefore, undertaking this research study to address some of the gaps identified in the literature. In particular, I am interested in investigating:</p> <ul style="list-style-type: none"> • The key information sources for people with a visual impairment seeking health and social care information • Whether the health and social care information needs vary according to the degree of impairment • How current developments in health and social care information provision (e.g., NHS Direct) and information provision in general (e.g., modified Internet user interfaces) can better meet the needs of people with a visual impairment • How people with visual impairments can be effectively involved in the planning and conduct of research in this field <p>The active involvement of consumers (also termed users) as partners in the research process has been shown to result in more relevant, reliable, and useable research.</p>	
<p>Principal responsibilities</p>	<ol style="list-style-type: none"> 1. To provide advice throughout the research study via an agreed mechanism (e.g., telephone, face-to-face meetings, email, etc.), particularly in terms of: <ul style="list-style-type: none"> • The appropriateness of the research questions • The appropriateness of the research methods • Relevant research and researchers in the field • The research reports/briefings produced for people with a visual impairment 2. To assist, where necessary, in the recruitment of participants for the research 3. To collaborate in the dissemination and implementation of the research findings 4. To assist in the evaluation of the 'consumer involvement' elements of the research 	
<p>Person specification</p>	<p><i>Essential attributes</i></p> <ul style="list-style-type: none"> • Possession of a visual impairment • Willingness to familiarise oneself with new terminology • An interest in 'consumer involvement' in research 	<p><i>Desirable attributes</i></p> <ul style="list-style-type: none"> • An understanding of research methods • Good links with networks/ organisations, etc. serving people with a visual impairment

	<ul style="list-style-type: none">• Good communication skills	
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Appendix M. Information sheet for advisor interviews



U N I V E R S I T Y O F S H E F F I E L D
D E P A R T M E N T O F I N F O R M A T I O N S T U D I E S

Postal address: Western Bank, Sheffield S10 2TN

Location: Regent Court, 211 Portobello Street, Sheffield S1 4DP

Tel. (0114) 222 2636 **E-mail:** lip02cab@sheffield.ac.uk

WWW: <http://www.shef.ac.uk/~is/home.html>

INFORMATION SHEET

- Title of project:** The health and social care information needs of people with a visual impairment
- Investigation:** Evaluation of the consumer involvement process – Interviews with consumer research advisors (Summer 2003)
- Name of researcher:** Catherine Beverley
Department of Information Studies, University of Sheffield,
Western Bank, Sheffield. S10 2TN. Tel: 0114 222 6332.
- Name of supervisor:** Dr Peter Bath
Department of Information Studies, University of Sheffield,
Western Bank, Sheffield. S10 2TN. Tel: 0114 222 2636.

You are being invited to be interviewed as part of the above research project to explore your role as an advisor to this study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives, *etc.* if you wish.

What is the purpose of the study?

The overall aim of this research study is to explore the health and social care information needs of people with a visual impairment. In particular, it will investigate the key sources for people with a visual impairment seeking health and social care information, whether the information needs vary according to the type and degree of impairment, how current developments in health and social care information provision (*e.g.*, NHS Direct) and information provision in general (*e.g.*, modified Internet user interfaces) can better meet the needs of people with a visual impairment, and how people with visual impairments can be effectively involved in the planning and conduct of research in this field. Further details about the study can be found in the 'Consumer research advisor' job description which you have already been sent (please let me know if you would like to be sent this again).

What is the purpose of these interviews?

A key feature of this research is the active involvement of people with visual impairments in the design and conduct of the research, rather than simply as research "subjects". I have identified five people with a visual impairment, including yourself, who have kindly agreed to act as advisors to this research study. To help in the evaluation of the consumer

involvement aspects of this research, three of these advisors will be interviewed on an annual basis.

What will be involved if I agree to take part in the study?

You will be asked several questions relating to your involvement in the research study as an advisor. For example, this will cover your reasons for agreeing to act as an advisor to the research, your understanding of your role in the research, what you hope to gain from the experience, what you hope to be able to contribute to the research, and whether you have any outstanding training and development needs. In order to help the analysis of this interview, the conversation will be tape-recorded, with your permission. You are obviously free to ask for the tape recorder to be stopped at any point.

Do I have to take part in the study?

No. You are free to decline to be interviewed and may withdraw at any time or choose not to answer certain questions.

When, where and how will the interview take place?

If you agree to take part, I will be contacting you in the near future to arrange a date for the interview. This interview can be conducted either by telephone or face-to-face in your own home or at the University.

Will the information obtained in the study be confidential?

Anything you say will be treated in confidence, no names will be mentioned in any reports of the study, and care will be taken so that you cannot be identified from details in reports of the results of the study.

Who can I contact if I have any outstanding queries?

Please feel free to contact me at the Department of Information Studies, University of Sheffield, Western Bank, Sheffield, S10 2TN, Tel: 0114 222 6332, Email: lip02cab@shef.ac.uk.

What if I wish to complain about the way in which this study has been conducted?

If you have any cause to complain about any aspect of the way in which you have been approached or treated during the course of this study, please contact either myself, Catherine Beverley, at the Department of Information Studies, University of Sheffield, Western Bank, Sheffield, S10 2TN, Tel: 0114 222 6332, Email: lip02cab@shef.ac.uk, or the supervisor for this study, Dr Peter Bath, Tel: 0114 222 2636, Email: p.a.bath@shef.ac.uk. Alternatively, you can use the University of Sheffield complaints procedure c/o the Research and Consultancy Unit, University of Sheffield, 2/4 Palmerston Road, Sheffield, S10 2TE.

Appendix N. Advisor initial interview topic guide (Summer 2003)

Checks:

- Thank you
- Information sheet
- Reiterate purpose of interview
- Not a test
- Tape recorder
- Consent

1. Background to visual impairment
 - Type of visual impairment (*e.g.*, age-related, *etc.*)
 - Length of visual impairment
 - When were diagnosed as having your visual impairment?
 - Are you registered blind or partially sighted?
 - Do you suffer from any other health conditions?
2. Reasons for agreeing to be an advisor to this research study
3. Perceived role in this research study
4. Understanding of the term 'consumer involvement'
5. Comments about the 'job description'
6. Perceive benefits of being involved in this research study
7. Possible contributions to this research study
8. Outstanding training and development needs
9. Other issues/ comments

Appendix O. Advisor follow-up interview topic guide (Summer 2007)

Checks:

- Thank you
- Information sheet
- Reiterate purpose of interview
- Not a test
- Tape recorder
- Consent

1. Reasons for agreeing to be an advisor
2. Main role in the research
 - More or less than anticipated?
3. Clarity of involvement/ 'job description'
4. Personal gains from being involved in this research
5. Personal contributions to this research
6. Improvements to involvement
7. Other comments