

Chapter 4: Collecting data from people with sight loss

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Introduction

This chapter highlights some practical considerations that research teams may wish to keep in mind in advance of, and when carrying out, data collection with people with sight loss. The overarching message is that everybody's needs will differ and must be considered on an individual basis. It is always best to ask rather than assume, as what suits one person will not suit another.

This chapter has been informed by researchers who have previously undertaken research with Pocklington and by people with sight loss. If there is something you think should be included or amended, please let us know.

The messages in this chapter can be applied to any means of data collection, such as consultation, interviews and focus groups. They should also be consulted when organising Project Advisory Group meetings or, where applicable, an event at which research teams present findings to participants.

Simple tips

The following are commonly cited visual awareness tips:

- **Use names.** Identify yourself when entering and exiting a room. If talking directly to someone, use your name and theirs, for example 'Hi Dan, it's Jo'. If someone joins a meeting late, it is worth pausing and repeating the introductions, so that everyone is on an equal footing and knows who is in the room.

- **Vocabulary.** Feel free to use words that relate to vision during a conversation, such as 'see', 'watch' and 'look'.
- **Eye contact.** Maintain eye contact and speak directly to the person rather than through an intermediary.
- **Voice.** Use a natural conversational tone, speed and volume.
- **Peripheral vision.** The level of sight loss and the area affected varies from one person to another, which may influence the way people look around them. For example, if someone has better peripheral vision than central vision, they may prefer to look from the side.
- **Low vision aids.** Participants may bring low vision aids such as signature guides, magnifiers and talking watches. These help people make the most of their remaining sight. It is best to ask before touching them.
- **Change and variation.** Eye sight can change during the day according to stress, tiredness and lighting. Two people with the same eye condition will see differently; two people with the same level of sight will have varying levels of independence, confidence and mobility.

In advance of data collection

Understanding access needs

It is likely that during your first conversation with a prospective research participant, you will be required to gain an understanding of their needs – especially if you wish to meet at a specific location or send them further information. The participants are the experts here, and know best if there is anything you can do to ensure that they are able to contribute fully. Some questions might include:

- Are there any particular accessibility issues you would like us to be aware of?
- Would you like to meet at the station / at the front entrance?
- What format would you prefer to receive this document in? What is your preferred reading format?
- What can we do to ensure that you feel comfortable to participate fully?
- What terminology do you prefer? For example, one person may describe themselves as 'blind' and another – with the same level of sight – as having 'poor sight'. While many people will not mind

which phrase is used, this question gives them the option to say if there is a particular term they like or dislike.

- Is there anything else you think I should know?
- Will you be bringing a personal assistant / support worker / family member / friend / guide dog?

Booking assistance

An attendee may wish to be accompanied by someone.

Assistance comes in different forms depending on the specific requirements of the individual.

- Personal assistants can help people with physical disabilities or sensory impairments with getting from place to place, with drinks and food, going to the toilet, taking notes or minutes, turning pages and holding things.[1]
- Communication professionals include sign language interpreters, lip-speakers and note-takers. If the meeting will involve specific terminology, this should be specified when booking. The work that communication supporters do is tiring so ensure that you factor regular breaks into the agenda.

Some may like to bring their own assistant and others may ask for it to be arranged for them. They should be booked as early as possible (preferably four to six weeks in advance).

On the day, remember to direct questions and comments to the participant rather than to the assistant.

For more information on the different types of communication support and booking procedures, see:

Action on Hearing Loss, Communication Support
www.actiononhearingloss.org.uk/supporting-you/communication-support.aspx [last accessed July 2014].

Consider the impact

It is possible that the research will touch upon issues that immediately affect the lives of the participants. If so, it is good

1 Social Care Institute for Excellence (2005), Accessibility guidelines for events. Social Care Institute for Excellence, London p.4.

practice to have at hand some knowledge or resources to direct participants to in case they ask for further information.

For example, a research team that carried out a project to evaluate how changes to the benefit system affect people with sensory impairment anticipated that it would prompt participants to ask how they could go about navigating these changes. The research team therefore sought out contact details of people who might be able to offer advice, such as the RNIB helpline and the Citizens Advice Bureau.

Arranging the time

- Do not assume that the research participants will be free to meet/ attend an event during working hours, as they may be in employment or have caring responsibilities.
- Depending on the location, it may be worth considering the feasibility of avoiding rush hour, as public transport can be difficult to navigate and it might be difficult to get a taxi at this time.
- A Freedom Pass will offer free public transport after 9:30am on weekdays. This varies across the UK and the type of transport such as bus, tram, tube or train.

Choosing the location

Distance

The meeting place/ event should be held no more than a 5 to 10 minute walk from a major transport link. If it is more than this, research teams should offer to organise or provide transport by taxis.

Lighting

The majority of people with sight loss have some vision or light perception, so it is worth thinking about the level and position of lighting when choosing and setting up the room. Lighting is very individual and will affect everyone differently. Be aware that someone may prefer to sit in a particular place depending on how helpful the available light is for them.

Research teams may wish to check that:

- There is an even distribution of light in the room.
- There are no dark corners.

- Researchers and participants have the ability to control daylight with a blind or something similar.
- The main speaker is not standing in front of a window as they will be in silhouette and the glare may cause discomfort.
- Bright lights can be very uncomfortable. Ask the person if they would prefer to sit with their back to the window.
- A sudden change in lighting, such as moving from a dark corridor into a bright room, might cause someone to feel disorientated. Allow time for the person to adjust.

For more information on lighting and its effect on sight, see:

Macular Society (2013), Lighting. Macular Society, Andover. A PDF version leaflet can be downloaded at www.actiononhearingloss.org.uk/supporting-you/communication-support.aspx [last accessed July 2014].

Boyce, P., Matching lighting to sight loss. Thomas Pocklington Trust, London. A PDF or Word document version of the Research Discussion Paper can be downloaded from www.pocklington-trust.org.uk/researchandknowledge/latest/rdp5 [last accessed July 2014].

Colour contrast

If you know the colour of the room, dress to offer some colour contrast. Avoid wearing black if it is a dark room or in red if there are red curtains. This way the person has a better chance of tracking where you are.

Background noise

If possible, choose a room or building that is free from background noise such as heating and ventilation systems or background music.

Consider multiple disabilities

A participant might feel that it is not their sight loss that acts as a barrier to maximum participation and comfort, but another condition such as their arthritis, hearing loss or diabetes. For this reason, it is best to think and ask broadly about what they would like to find at the venue. For example:

- Ensure that the building is fully accessible for wheelchair users.

- Check that toilets are close by and accessible.
- If you are using more than one room, try to ensure that they are on the same level of the building.
- If required, make sure that there is disabled parking.
- If required, use a room that is fitted with a hearing loop system.

Directing people to a meeting/ event

It is likely that research participants' preferred format for directions will vary considerably. While some will appreciate landmarks, such as 'left at the post-box', this will be of less help to others, who may prefer 'turn left at the downward slope'.

To demonstrate this variety, two people with sight loss have written directions in a way most helpful to them:

Example One: From Kew Bridge station to Pocklington's Head Office, Pier House

When you leave the station turn right, follow the path round the corner until you reach the pedestrian crossing on your left. It is a busy road junction; each crossing has 'twirl' cones to help you cross safely.

When it is safe to do so, cross the first crossing, then bear left and cross another three crossings.

Turn right and follow the path round the corner to the left until you reach a road junction (café on the opposite side of the road). Cross the junction, with the café on your left, follow the path.

You will come to a cobbled driveway; continue walking until you reach the second double doors on your left (If you pass a second cobbled driveway or Café Rouge you've gone too far!).

Our buzzer is on the right side of the door alcove.

Example Two: From someone's home to bus stop, Reading

Come out of the front door and walk straight down the drive until you come to the down kerb.

Turn right at the kerb and walk along with the road on your left.

After a hundred paces cross the road and continue walking with the road on your right. There may be overhanging bushes and parked cars on the kerb so your dog may have to take you into the road to get you safely through. This is not a busy road but traffic is often moving quickly so take care.

Continue walking until you come to the down kerb where you turn left and walk with the road on your right. The first crossing is a driveway.

Continue straight until you come to a down kerb which is sloping and has underfoot bobbles.

Cross this and turn left on the up kerb. Walk along until you come to the bus shelter, which you will recognise as the acoustics will change. You have reached your destination!

While it won't be possible to produce one set of directions that is appropriate for everyone, there are some general tips on giving practical and tactful directions:

- **Road names.** If the person with sight loss is unaccompanied, it is unlikely that road names will be as helpful indicators as landmarks.
- **Turnings.** If you ask someone to turn left at the 'third road on the right', a road turning might not be easily distinguishable from a path or a driveway.
- **Provide a contact number.** It is essential to provide a contact number in case the participant cannot find the location.
- **Offer to meet.** If feasible, offer to meet the participant at an agreed place, such as the station or the front entrance of the building. Alternatively, research teams may wish to consider providing a telephone number for a local taxi company and letting the participants know that if they would prefer to take a taxi, the cost will be reimbursed.
- **Follow the route yourself.** If possible, put directions together from personal experience rather than from a map. This way, the directions will be more specific regarding which exit from the station, which side of the road and the type of crossing.
- **Map.** Providing a map in advance may be helpful to those using magnifiers, but not to others. Some may prefer to look it up themselves on an online map if they have access to the internet, so do give a full address.
- **Be specific.** If giving directions in person, avoid pointing or using vague phrases like 'it's over there'. Use 'turn left' or 'turn right' or 'straight ahead' as it applies to the person you're advising. Specify distances.

Name badges

- Consider the appropriateness of name badges. To ensure that everyone is on an equal footing, they must not replace oral introductions.
- If they are used, print them as large as possible and with contrast between the words and the background.

Flip charts

- Consider the effectiveness of flip charts. If you are using them to keep a record of the discussion, say every entry on the flip chart out loud and give an oral summary at the end so that all participants have access to the same information.

Sending materials in advance

- All information, presentations and paperwork should be sent out – in participants' preferred formats – at least 10 days (preferably 2 weeks) in advance of the meeting.
- For guidance on how to produce materials in accessible formats, see Chapter 6.

Planning the agenda

- As the participants have sight loss and may also have mobility issues, consider the appropriateness of participatory activities such as asking them to put post-it notes on a board.
- Incorporate plenty of breaks into the agenda as focus groups and interviews require a lot of concentration.
- No agenda item should be discussed at an event if information has not been previously circulated, unless agreed with all the participants.
- Provide contact details of a member of the research team in advance in case participants have any queries ahead of the meeting.

Facilitators

- Think about the number of facilitators that should be present in order to make your event run as smoothly as possible.
- At focus groups, Pocklington requests that there are at least two facilitators. This means that if a participant arrives late to the meeting, one person will be able to greet the person and direct them to a chair while the other facilitator continues to run the event.

On the day

Offering assistance

The most effective way of identifying the level of assistance that someone with sight loss requires is to ask them. Depending on the type of interaction between researcher and participant, some of the questions that you may wish to ask are listed below. Don't be offended if someone declines your offer of assistance.

- Would you like me to guide you? Which side would you like me on?
- Would you like to me to describe the layout of the room to you?
- There are a few people here already. Shall I introduce you to them?

Sighted Guiding

Offering your elbow is an effective and dignified way to guide someone with sight loss.

Guide Dogs has produced tips on sighted guiding. A leaflet can be downloaded as a PDF or a Word document at:

Guide Dogs, How to help a blind or partially sighted person www.guidedogs.org.uk/aboutus/how-to-help-a-blind-or-partially-sighted-person#.U8hnGXaqM5Y [last accessed July 2014]. The document can also be requested in Braille, large print, audio, electronic and text formats.

The most important things to consider are listed below:

- Say who you are and offer help, communicate clearly and listen to the person's request.
- Ask where and how the person would like to be guided.
- Allow the person to take your arm, rather than you holding theirs.
- Say if you're approaching steps, kerbs or hazards. Remember to say whether the stairs go up or down.
- Say when you have finished providing assistance and are leaving the person.

- Don't be afraid to identify yourself as an inexperienced sighted guide and ask for tips on how to improve. [2]

Guide Dogs

Assistance dogs help people with disabilities with day-to-day activities. They are trained to be used by people with sight loss, hearing difficulties, epilepsy, diabetes and physical mobility problems.[3] An assistance dog is distinguishable from a pet dog by its harness and the special tag on its collar.

An assistance dog that accompanies someone with sight loss is known as a guide dog, and the owner and dog are known as a guide dog team.

If a guide dog accompanies a participant, it is good practice to consider the below:

Guide Dogs: Preparation

- **Access.** While it is a legal requirement for businesses to allow access to guide dogs, it is advised that you confirm that the building is welcoming of and fully accessible to guide dogs. Tell the venue that there might be guide dogs.
- **Space.** Check that there is enough space for the dog to rest, and a place for it to be walked.
- **Toileting.** Identify areas of grass or gardens near the venue for the dog to spend (toilet) and offer to go out with the person and their dog.
- **Water.** Owners might bring a water bowl, but research teams may wish to provide one and ensure that participants have easy access to water. Researchers may wish to ask the venue if it could provide some water for the dogs.
- **Escalators.** Only guide dogs that have received special training are able to use escalators. This may be of particular relevance if

2 This list was informed by conversations with people with sight loss and from Guide Dogs, Five helpful hints for guiding a blind or partially sighted person www.guidedogs.org.uk/aboutus/how-to-help-a-blind-or-partially-sighted-person [last accessed July 2014].

3 Assistance Dogs, www.assistedogs.org.uk/ [last accessed July 2014]; Equality and Human Rights Commission, (2013) Assistance dogs – a guide for all businesses. Equality and Human Rights Commission, London, p. 3.

participants are required to use the London Underground to come to the research team's chosen location.[4]

Guide Dogs: Behaviour

- If you see a guide dog in action, it will be concentrating on guiding its owner and should not be distracted by petting or name-calling.
- If the dog is not doing any tasks and is not in harness or on a lead, it is courteous to still ask the permission of the owner before petting the dog.
- A guide dog owner may still require sighted guiding in certain circumstances, for example when crossing a road. A guide dog owner will indicate the need for sighted guide assistance by allowing the harness-handle to lie on the dog's back, while maintaining hold of the lead. Stand on the other side of the owner to the dog, and offer your arm.
- Don't instruct a guide dog or give it any food or treats.[5]

Trip hazards

- When you set up the room and as the day progresses, watch out for and remove trip hazards, such as bags, chairs and wires.

Catering

If the event is catered, you may wish to consider the following:

- **Layout of the food.** One table of food may be better than spreading it around the room.
- **Choice of food.** Choose food that will be straightforward to serve and eat.
- **Clearly indicate what is available.** If you are providing a menu, consider providing it in large font. On the day, describe clearly what food is on offer and which area of the table it is on.

4 Guide Dogs, London Underground escalators

www.guidedogs.org.uk/supportus/campaigns/successful-campaigns/london-underground-escalators/ [last accessed July 2014].

5 This list was informed by conversations with guide dog owners; Guide Dogs, Five helpful hints on approaching a guide dog owner out working with their dog www.guidedogs.org.uk/aboutus/how-to-help-a-blind-or-partially-sighted-person#.U8hsC3aqM5Y [last accessed July 2014].

- **Mention all items.** For example, if there is a coffee break and fruit or biscuits are offered alongside drinks, make sure that this is vocalised.
- **Mention all relevant ingredients.** For example, if an apple pastry contains nuts, tell the person you are offering it to.
- **Equipment.** If possible, provide colour contrasting mugs or cups for drinks, and plates for biscuits. Mugs are easier to use than plastic cups.

Focus Groups

Like any focus group, the role of the facilitator is vital in encouraging everyone to put forward their views.

TwoCan Associates has produced guidance for facilitators that gives general advice on managing the discussion and drawing out quieter people:

TwoCan Associates (2011) Patient and public involvement in research groups – guidance for chairs. TwoCan Associates, London. It can be downloaded at www.wikihow.com/Interact-With-People-Who-Have-Disabilities [last accessed July 2014].

The following is more specific advice relating to holding focus groups with people with sight loss:

- Researchers we spoke to said that it is important to think carefully about whether focus groups are the most effective way to collect data from people with sight loss. As visual cues cannot be relied upon, some researchers found that the dialogue became more of turn-taking exercise rather than a free-flowing conversation.
- Before the discussion begins, outline how you plan to facilitate the focus group, and check that the arrangement works for everyone. Assure the participants that if they make it known they would like to speak (for example, by raising their hand) you will bring them in.
- It is good practice to have just one lead voice running the focus group. Identify this clearly before the discussion begins.
- Use people's names.

- The use of non-verbal communication is of limited use. If you wish to bring another voice into the discussion, rather than nodding or using your hands, a more effective instruction would be to say: 'Thank you Phil, I'm going to bring in Mary now'.
- Allow plenty of time for focus groups. Participants, as well as interpreters and translators, should be offered regular breaks.

Visiting someone in their home

- Prior to meeting, the researcher and the participant may decide to set a password so that the participant can be sure who they are letting into the house.
- Research participants may wish to have a family member, friend or support worker with them during the interview.
- If you move an item, let the person know, and return it to its original position.
- Be aware that someone may get around very easily in their home, but if you meet again in an area they are less familiar with, they may require more assistance.

Helpful resources

Social Care Institute for Excellence, Accessibility guidelines for events. Social Care Institute for Excellence, London. It can be downloaded from www.scie.org.uk/publications/misc/accessguidelinesevents.asp [last accessed July 2014].

Just Ask: Integrating accessibility throughout design, Interacting with people with disabilities www.uiaccess.com/accessucd/interact.html [last accessed July 2014].

University of Cambridge Disability Resource Centre, Making meetings and events accessible to disabled people. University of Cambridge, Cambridge. A PDF of this guidance can be downloaded from www.admin.cam.ac.uk/univ/disability/support/etiquette.html [last accessed July 2014].

End of document.