

Chapter 3: Recruiting and engaging research participants

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Introduction

This chapter offers guidance on the recruitment of people with sight loss as research participants. It draws from the experience of previous research teams that have carried out Pocklington projects. It also raises points to consider when obtaining informed consent and, if applicable to the project, issuing rewards to participants.

Pocklington has compiled a list of sources through which researchers might find research participants called 'Where to find research participants'. This document is available on request for research teams commissioned by Pocklington.

How to find research participants

Researchers have reported that this was a time-consuming element of their project that required patience and persistence. The following guidance is drawn from their experience:

- It must be considered at the start of the project.
- Consider the limitations that each potential source presents. For example, if participants are found only through internet-based avenues, those less familiar with assistive software might be excluded. If participants are found only through sight loss organisations, your pool might include few people who have been recently diagnosed.
- The sources you approach may have procedures as to how they verify and approve calls for participants, which may cause some delay to recruitment.
- Some organisational sources circulate publications every week, whereas some only a few times a year. Researchers should plan ahead to meet the varying deadlines for submissions.

- Write an engaging and simple blurb about your research project and the nature of participant involvement. It can then be sent out to organisations to circulate it to their members or individuals to send it to their personal contacts.
For tips on how to write a lay abstract, see: Asthma UK, Writing a lay abstract <http://www.asthma.org.uk/research-writing-a-lay-abstract> [last accessed July 2014].
- If a participant approaches you, ask how they first heard about it to help you build a picture of which recruitment methods work.
- Think about the ways in which the people you are looking for communicate with each other and the networks they might use.
- Avenues through which participants are sourced are likely to be suitable places through which to disseminate findings.

Informed consent process

To ensure that potential research participants can be fully informed about the project and record their consent in a way that is accessible to them, previous research teams have tailored the process accordingly. Researchers reported that this lengthened the time taken, as it might involve reading the information out loud and answering questions of clarification, but was essential.

It is good practice to set out and be realistic about what you think the research project can achieve. A project looking at the recommended design of homes for blind and partially sighted people is unlikely to result in immediate improvements to an individual's house. However, you can tell participants who the recommendations will be shared with and promoted by.

The chosen method of informed consent, and all other aspects of the process, will be subject to ethics approval from – where relevant – the researchers' university or organisation's ethics committee, an NHS ethics committee or the Social Care Institute for Excellence (SCIE) Social Care Research Ethics Committee. If researchers are recruiting through the NHS or local authority social care routes, their research governance and ethical approvals will be required.

Information on the SCIE Social Care Research Ethics Committee can be found at the following:

<http://www.scie.org.uk/research/ethics-committee/> [last accessed July 2014].

Researchers might consider providing information about the project in the following ways:

- Large print forms in individual's preferred font and type size.
- Electronic documents that people can read through in their own time. See Chapter 6 for guidance on producing an accessible document.
- Offer to read the form out loud to participants.
- Provide an audio version of the information sheet, for example on a disk or memory stick.

It is best not to assume that someone knows how to sign their name or that they can see the place on the document where they are expected to sign. The following techniques might enable participants to sign independently:

- **Use a signature guide.** A signature guide is the size of a credit card, made of plastic or card and has a rectangular cut-out in the middle. Once the guide is lined up with the writing line, the participant can sign their name independently in the writing space. A black signature guide provides good contrast with light-coloured paper.
- **Make a crease in the paper.** Sharply creasing the paper along the writing space, or layering a few post-it notes along the line, will make it easier to locate and feel.
- **Oral consent.** Read the form aloud and record consent orally. This might be especially relevant if conducting a phone interview and not meeting the participant in person.

Expenses

It is generally expected that research teams will cover travel and subsistence expenses for participants. These costs will usually be included in the project budget and dealt with directly by the research team. Arrangements will be confirmed during the planning stages of the project.

Rewards

During the design of the methodology for the project, research teams might decide that participants are to receive a reward. If so, consider the following:

- Make it clear from the outset which form of reward is being offered and when it will be paid. This gives people who are in receipt of benefits time to seek advice about whether it affects their entitlement.
- Pocklington would like to be assured that this reward can be presented as a token of appreciation for the participant's time, rather than as an incentive to participate.

The reward itself might be in the form of cash or a voucher. It is recommended that you consider the following when choosing the preferred means of reward:

Voucher

- To ensure that all participants will be able to use the vouchers, think about the shop's accessibility (i.e. from remote areas) and affordability. Vouchers that can be used in a range of well-known shops might be more appropriate.
- When giving the voucher to participants, tell recipients where it can be spent and how much it is for.

Cash

- Seek clarification from the relevant body (such as the Department for Work and Pensions, the Disability Rights Handbook or the Citizens Advice Bureau) as to whether participants are expected to declare the cash reward and if it might have any effect on their benefits. When reporting back to participants, reference the source of this information so that they can be assured of its validity and find further information if necessary.
- If the chosen research methodology does not require you and your participant to meet, consider the appropriateness of sending cash by post.

The National Institute for Health Research has produced a guide on payment for involvement. It discusses the principles of payment and provides information on its possible effects on benefits entitlement:

National Institute for Health Research (2010), Payment for involvement: a guide for making payments to members of the public actively involved in NHS, public health and social care research. National Institute for Health Research, Eastleigh. A PDF version can be found at the following link: www.invo.org.uk/wp-content/uploads/2012/11/INVOLVEPayment-Guiderev2012.pdf [last accessed July 2014]

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