

# Participatory research involving people with dementia: guidance for researchers



## Key points

- Involve participants at all stages of the research process including the method design, the study and reporting.
- All research should be conducted in the spirit of collaboration with the aim of making products and services more dementia friendly.
- Follow a plan but remain flexible enough to explore new ideas and perspectives.

## Overview

**Involving people with dementia in research gives a unique insight into their lives and perspectives. To make the most of your research it's helpful to know which techniques work well and which ones are not so helpful.**

This guidance has been created following a series of consumer research projects across the UK with groups from DEEP, the UK network of Dementia Voices. It lays out some pitfalls to avoid and good practice to follow to maximise the likelihood of gathering meaningful and consistent data. It's not meant to be an exhaustive list of dos and don'ts, but more a guide to help the researcher understand the perspective and experiences of the people with dementia involved in the project.

## Setting up the research

### Participant engagement

We recommend you involve people who have dementia through national associations such as the Alzheimer's Society or Innovations in Dementia, locally through Dementia Engagement Empowerment (DEEP) groups, or through the National Health Service (NHS). Often these groups are interconnected and they have good on-the-ground support networks.

It's important to get people involved right at the start. Active engagement as early as possible with the participants involved in the research is preferable. Early contact helps to establish a good

rapport: it facilitates greater group involvement by generating discussion and ideas. It also allows members of the group to meet the researchers in a familiar setting. Even if the research method is quite rigid, the research will always benefit from the knowledge and insight of the local dementia group co-ordinators and participants.

## **Participants' needs**

Find out whether the people participating have any particular needs relating to their dementia. Ask them if they can tell you how their dementia affects them to help you gain awareness of specific considerations for the research. These can range from accessibility issues to the timing of the research and will be different depending on the scope and type of research undertaken.



## **Venue**

Once the research activities have been agreed, it's important to think about where these will take place. This might include a visit to a place or space of interest, followed by meeting in a room to review what has been experienced. It's important to make a visit to the research venues beforehand to scope the environment. This gives an opportunity to become better acquainted with the venues and their contacts, and will help you visualise how the research day might unfold. You'll be able to see first-hand the spaces available, flag any potential issues, request additional resources and so on. If possible, invite the local group co-ordinator to come along, and request their input.

## **Partners**

Where there's involvement from another partner - which will typically be a representative from the place, product or service being researched - it's important to gain their engagement and commitment to the research. Communication and co-ordination are the key elements in achieving this. It's essential that the research is conducted in the spirit of collaboration. Where the research investigates a particular venue, activity or product, make it clear that the research is not intended to act as an inspection, but rather to identify what does and does not work well for people with dementia. It's also important to focus on both the positives and negatives and suggest measures that might be taken to make improvements based on the findings.

## **Practicalities**

Consideration must also be given to paperwork and materials. If possible, try to arrange for paperwork to be shared and completed before the research takes place (consent and expenses forms, information sheets, topic guides and so on). The more that can be done before, the more time can be spent on the activity on the day, and this will put less pressure on those reading and signing the documentation. Consent should however always be discussed again on the day itself, to ensure that people remain happy to participate. It's advisable also to bring spare copies of all forms and documents.

# Risk assessment and ethics

Researchers have an obligation to ensure the safety and well-being of the participants involved in their research. You also have an ethical obligation to make sure the research is fully understood by participants to ensure there is informed consent, that any data collected is kept securely and complies with the General Data Protection Regulation (GDPR) and that people's names are anonymised in any reports. Both a risk and an ethics assessment should be undertaken for the research and further advice sought if necessary.

## Different types of research

There are many different methods of research for consumer testing. RiDC has used the following in our research involving people with dementia:

- Focus groups
- In-situ activities
- Product usability testing
- Interviews
- Design workshops
- Mystery shopping

Each method has advantages and disadvantages. Whilst these are not explored here, we offer some suggestions that can help facilitate data collection:

- Use as many different means of data collection as possible – make it interesting! This might mean using post-it notes, taking photographs, video and audio recording and note-taking, for example. This adds depth and quality to the final report.
- Thought should be given to the research planning. For example, will there be different sessions such as break-out groups, whole group discussions or testing activities? If so, how will these be managed? How many researchers will you need and how many rooms?
- People like to be welcomed, offered a refreshment and made to feel as comfortable and relaxed as possible.
- Where appropriate use name labels. Not only will this help you to identify research participants, it will also help them to identify you. Remember they may only have met you once, if at all.
- Maintain as authentic a situation as possible. This is particularly important with in-situ activities where you might be observing participants from a distance. You need to strike a balance between maintaining a presence and minimising your influence on their behaviour and decision-making.
- Active listening – have a topic guide for reference but don't be afraid to break away from this. With in-situ activities it is often necessary to be opportunistic, allowing things that are said in the moment to be explored.
- Encourage turn-taking. This is particularly important when running focus groups, or product-testing activities, as it ensures that everyone is given an opportunity to contribute and can help with the general flow.

# On the day . . .



## About us

The Research Institute for Disabled Consumers - leading experts in user-centred research involving disabled and older consumers.

We are an independent, national charity with a board of twelve trustees, all of whom have personal experience of disability.

Founded by Which?, we have over 50 years' experience of specialist research and publishing high-quality information.

We do three things:

- Help businesses and charities improve products and services for disabled and older consumers
- Provide consumer information and user reviews to help disabled and older people choose the right products and services to lead an independent life
- Take the voice of disabled and older consumers to decision makers

All of our work is carried out with our research forum of 800+ disabled and older consumers, who take part in our research.

How the day unfolds will depend on a number of different factors: the planned activity, the venue, the research methods employed and so on. Consider the following recommendations:

- Have a familiar person present (a group co-ordinator, for example) to assist with meet-and-greet, and with the general facilitation of the day's events.
- Come prepared with stationery, cameras, voice recorders, additional copies of any paperwork, documentation and any other relevant gear.
- Arrive in advance of participants to set up and prepare.
- Have defined roles for researchers but be flexible, to respond to unforeseen circumstances.

## Following up

**After completing the research always follow up with the local group and any partner, both to thank them for their involvement and to provide a draft of the report for their feedback. There might be issues that have been missed, or which warrant greater or lesser attention.**

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