



Collecting the views of people with dementia

Key messages

- Organisations and services increasingly want to engage with people with dementia to find out their views.
- People with dementia across the UK are committed to improving services by giving their views. However, this must be organised in a supportive and respectful way.
- Organisations and services should be clear about the ways in which they will involve people with dementia in their work.

Why do organisations need the views of people with dementia?

People with dementia are users of local services. They are in a unique position to share what it is like to live with dementia. Through involving people with dementia, organisations can ensure they are providing appropriate support and services.

People with dementia also have a right to a say about dementia policy, services and support.

Which organisations need the views of people with dementia?

All organisations, services and businesses that come into contact with people with dementia may be interested to know their views, eg:

- A local NHS memory service wanting to know the best way to run its clinics.

- A local council thinking about the best kind of support service it could set up for people with dementia.
- A government department responsible for writing a dementia policy about how to live well with dementia.
- Researchers at a university thinking about carrying out research to improve the lives of people with dementia.
- A local supermarket that wants to make sure its customers with dementia can find the products they want more easily.

Ways organisations might engage with people with dementia

Visiting a group of people with dementia

There is a range of established groups of people with dementia in the UK. Some are experienced in sharing their views to influence services and policies (see www.dementivoices.org.uk). Others are part of dementia services such as day care centres or dementia support groups. Many of these groups welcome visits from other organisations as a way of sharing their views.

Advantages

- Members of the group know each other well and feel comfortable working together.
- The meeting/discussion can take place in an environment people with dementia are familiar with.
- Staff and supporters are available to help people participate in discussions and express their points of view.
- The group can confidently set the agenda for how the meeting will run.

Disadvantages

- The day-to-day business of the group may dominate the planned discussion and there may not be enough time to have a full discussion about the topic.
- The visiting organisation may not be able to prioritise the issues they would like to discuss with people with dementia.

Organising a separate discussion event

Organising a separate discussion event on a subject can provide a focused way in which people with dementia can give their views.

The event could take place in a different building or location from where the group usually meets. Or it could take place in the usual place where the group meets but at a different time. It would be advertised as a different meeting from the usual group meeting.

Advantages

- People with dementia can come together from a range of different settings.
- The discussion can be focused on a particular subject. People with dementia will know that this is a different event from their usual group meeting.
- The meeting space can help people to understand the focus of the discussion. For example, a discussion about a dementia-friendly community could take place in the local library, police station or a company headquarters.
- Meeting in a different location can be sociable and enjoyable and can be made to feel like a special occasion.

Disadvantages

- Meeting in an unfamiliar environment may make some people feel anxious.
- Lack of familiarity may make some people unsure about what the meeting is about.
- Travel arrangements may be difficult or tiring for some people.
- It may be more difficult to control external factors such as crowds, room layout and acoustics (see *Choosing a dementia-friendly meeting space*).

Running a discussion with people with dementia

Before the discussion

- Provide clear, straightforward information about the purpose of the meeting to the group beforehand. Many groups meet monthly, so you will want to make sure this is provided well in advance.

- Try to keep the information short and to the point. One or two A4 sheets is ideal. A visual, such as a diagram or picture, can be helpful (see the DEEP guide *Writing dementia-friendly information*).
- You may want to include 'frequently asked questions and answers' (FAQs) about your discussion topic.
- Think about providing a photograph of yourself so the group know who they are meeting, along with the name of your organisation and job role.
- If there is time, visit the group at an earlier meeting to introduce yourself and the discussion topic. Be clear about the purpose of your visit, some of the areas you wish to discuss, how you imagine the session unfolding, how long the discussion will last for, how people might prepare, and what will happen with the information you collect.
- Talk to the main contact of the group to understand more about the group. Share your ideas for how you will approach the session but be guided by their knowledge of the group.

On the day

- Have a clear timetable for your session, with refreshments available at set times (see *Supporting people with dementia at conferences and events*).
- Take your lead from the group. Be prepared to join in other group discussions or activities before it is time for your discussion
- Take it slowly. Don't overwhelm people with too much information at the beginning.
- Use visual aids where possible to help people connect with the discussion topic.
- Think about different ways that people can be supported to express their views. Let people know about these beforehand, eg:
 - small-group discussions: very helpful for people who are quieter or who struggle to speak in a large group
 - questions to help people begin to talk about a particular issue
 - visual aids to help people recall questions: eg noting them on a flipchart or postcard
 - creative questioning to help people get used to talking about issues, even if not related to the issue under discussion: eg Why do birds sing?

- post-it notes/flipcharts where people can write important points; seeing other people's comments can help people think about their own issues
- voting cards, which can be useful for 'yes' and 'no' questions or for expressing choices
- creative approaches to reflect views, such as making a collective picture; eg one group made a collage using pictures from magazines to express the things they needed to live well with dementia.

Make sure you have planned enough time for discussion. But don't make the session too long, as this can be tiring for people with dementia.

After the discussion

- Groups appreciate acknowledgement of their time and contribution to your work. A thankyou letter or card goes a long way.
- Tell people what will happen with the information they have given you.
- If reports are published later, be sure to let the group know. Send a copy or share a website link.

Using existing networks

There are various settings across the UK where people with dementia meet. Some of these are local influencing groups comprising people with dementia who want to have a say about the world around them (see www.dementiavoices.org.uk). Others include memory cafes, day centres, support groups and care homes.

Groups are often supported by a paid member of staff, or have an identified spokesperson for the group. Circulating your questions or documents through the spokesperson or member of staff can be another way of gathering views. This person can compile the group's viewpoints and share them with you via email or telephone.

Advantages

- The group may be more comfortable discussing a subject with a person known to them.
- The person leading the discussion is likely to know members of the group and can help them to express their viewpoints.
- The discussion can be organised as part of group activities or existing business. This may mean the discussion takes place more quickly.

Disadvantages

- Even when you provide good background information, you cannot be sure the person leading the discussion is leading in the way you would wish.
- You will not see the group dynamics or non-verbal communication, which can be important in understanding people's points of view.
- You won't be able to ask people to elaborate on certain issues that you find interesting.
- The group may feel unsure about what happens to the information they share.
- The group may not feel 'part' of something and may wonder if their views will be taken seriously.
- You will not be able to answer immediately any questions the group has.

**This guide was created
with the help of the DEEP
reference group**

DEEP guides aim to support the involvement of people with dementia. Some are aimed at DEEP groups, others at organisations wanting to work well with people with dementia. They have all been co-produced with people with dementia and will be updated regularly throughout the project. Suggestions for new guides are welcome – contact Rachael Litherland at Innovations in Dementia: email rachael@myid.org.uk or telephone 01392 420076.

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