



Tips for organisations wanting to consult people with dementia about written documents

Key messages

- Many organisations produce documents that may affect the lives of people with dementia.
- Organisations can improve their documents if people with dementia share their views.
- Many people with dementia can take part in consultations on written documents but they may need support to do so.
- People with dementia have the right to have input into strategies, policies and procedures that affect them.

Why consult people with dementia

'Nothing about us without us!' This saying reflects the fact that people have a right to a say in decisions that affect their lives.

People with dementia and their carers often have unique insight into an issue and valuable knowledge and experience.

Consulting with people with dementia will add credibility to your work, especially, but not only, if the document is about dementia.

Working with groups or individuals?

Some people with dementia are able and willing to work in a group, while others prefer to work one-to-one or alone, perhaps with the support of a carer.

Working with individuals one-to-one allows them to go through the document in their own time and in the comfort of their own home. Many people with dementia will be supported to work through the document by a family carer or friend.

Groups of people with dementia can offer a different perspective. A group situation can encourage creativity and the exploration of different issues and perspectives. Being part of a supportive group may also boost people's confidence and their ability to contribute.

In general, people with pronounced communication difficulties and those who need a lot of support to give their views may find group working more difficult – or need more help to take part.

Preparation

When inviting people to comment on a consultation, be clear about what you are asking them to do. It is often helpful to provide a written outline beforehand. Headings could include:

- The subject of the consultation
- Who you are and the organisation you represent
- Why you are seeking the views of people with dementia
- How the consultation will happen; what the options are for contributing views (eg through group work or working one-to-one)
- Timescales and schedule.
- What will happen after the consultation
- If there are thank you payments, what the arrangements will be.

See *Writing dementia-friendly information for ideas of how to write a good outline.*

Don't assume anything about the abilities of the people with dementia you are consulting. Some people may have problems reading; some may have difficulty reading. Allow for plenty of time to read through the documents with the group or individual, clarifying and expanding on points where needed.

Find out if anyone has any communication problems and think about how they might be supported. Groups often have a facilitator who will be able to guide you about the support needs of group members.

Some people like to have the documentation and questions beforehand. Others may find this puts too much pressure on them. Find out what is wanted.

Most important – avoid bureaucracy and too much paperwork.

Presentation of the text

Most people with dementia will have difficulties reading long, complicated documents. So write a summary or only ask for views on specific sections of the document.

Think about how the document is presented: large clear type with lots of white space is easier to read and allows people to write comments on the document as they go through if they wish.

Some people find images easier to understand. Consider whether some information could be presented graphically, for example as a flowchart. However, avoid images that can be misunderstood or that are childish or patronising.

Ask people how they would like the consultation documents to be delivered – for example, by post or email. Remember that many people do not use or have access to the internet. And those who do may have trouble opening email attachments and may not be happy printing out more than one page.

Be clear about how you want to gather feedback

Agree how people's responses to the consultation will be used. Many people will be happy to give their views but might want to remain anonymous or for their views to be attributed to the group as a whole.

In a group situation, a facilitator can take notes. These notes should be written up and given back to the group to confirm they are accurate and to give them a chance to make additions.

If you are working with individuals, some may be happy to respond to your questions, either on their own or with the support of a carer.

Consider setting up a telephone or personal interview to gather individual views if the person with dementia prefers this.

Always make sure that your questions are clear and relevant.

After the consultation

People should always be thanked for their input.

People should be informed about how their contributions have been used and what the results or consequences of the consultation are. This could be in writing to individuals or through a presentation to a group.

Any payments or expenses should be paid promptly.

See also...

For more information about consulting people with dementia see *Collecting the views of people with dementia*.

This guidance was
created with the help
of the Staple Hill
Thinking Together 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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