



Setting up an influencing group

Key messages

- **The DEEP network is made up of many different types of group.**
- **Certain features are common to many of the groups.**
- **Addressing practical considerations will help a group to run smoothly – other DEEP guides might be useful.**
- **Linking with other groups in the DEEP network will help.**

Involvement groups that are part of the DEEP network come in all shapes and sizes.

They are set up for different reasons and are shaped by group members and local issues and variances.

It is not possible (or desirable) to define what a group that is part of the DEEP network should look like or how it should operate.

Common features for groups in the DEEP network

There are certain features that work well for many of the groups in the DEEP network.

These ideas could be used as the basis for building a new involvement group.

- Making sure that people with dementia are involved at every level as equals, preferably leading and making decisions.
- Agreeing terms of reference or a constitution as well as agreed ways of working, including ground rules. People want to be clear about the purpose of the group and their role in it.

- Having interesting things to work on. Many groups begin by focusing on health and social care issues, but often branch out into other areas that group members find important e.g. accessible transport, dementia friendly communities and product development.
- Being clear about how other people and organisations will engage with the group. Asking for accessibly written documents, straightforward engagement processes and feedback after people have been involved.
- Providing strong support in the form of paid group co-ordinators and/or volunteer support. Their role should be to take care of the practicalities of involvement (e.g. diary co-ordination, booking venues and transport) as well as maintaining positive group dynamics.
- Using approaches that enable all group members to contribute to the work and discussions of the group. This will often be built into ground rules and may include turn taking, using props such as a red card to indicate when a person wants to speak, or a person with dementia acting as chair. Many groups break from business discussions during meetings to share news, or take part in a different kind of activity such as poetry reading. This can give people who find it difficult to contribute to the business part of the meeting a chance to join in.
- Using different ways for people who are not comfortable speaking out in larger groups to contribute their views, e.g. small group discussions, sticky notes to write down ideas, individual support from a volunteer.
- Reviewing processes to ensure that all members of the group are being appropriately supported and still feel that the group is relevant to them.
- Developing relationships with key local commissioners and decision-makers – in terms of achieving change it really helps to have direct access to local professionals who can help to take forward the goals of the group.

Some practical things that groups do to support people with dementia to be involved

- Give a lot of attention to the practicalities e.g. transport (booking taxis etc), choosing venues, time of day, refreshments, support, reminders. This can be expensive and needs time and patience. It also requires the building and sustaining of a close relationship with each individual.
- Use a range of methods to help people with dementia to understand the issue or the engagement activity. This might include visual prompts to

reinforce the discussion (e.g. discussing menus in a dining room or kitchen), using photos and pictures, using flipcharts and posters to record ideas and summarising discussions at regular intervals so that people can re-connect to the ideas.

- Check and double check people's viewpoint. It may be that your own expectations or feelings colour what you think you are hearing people say or communicate.
- Give enough time to any specific involvement activity. Give people the space to communicate their ideas, and ensure people who need it receive support so they can contribute.
- Be aware that involvement can be challenging – inviting people to think about tricky issues may raise emotions and cause people to be cross or anxious. This doesn't mean that you should avoid these tricky issues, but pre-empt them as much as possible and ensure you have thought through how you might respond.
- Make any involvement experience as accessible as possible, but without being patronizing. Ensure any written materials are accessible, that straightforward language is used without any acronyms, that events and meetings are structured well, with restricted agendas and good approaches to allow a range of people with dementia to participate fully.
- Acknowledge that involving people with dementia can feel challenging. It needs time, creativity, flexibility, strong listening skills, and often a real drive to keep it a priority within stretched organisational settings. Staff and volunteers can create their own support by linking with those who are working to support people with dementia to be more involved.
- Ensure that people with dementia are consenting to be involved and engaged; involvement isn't something that should be done to people. Follow an appropriate consent procedure that is accessible for people with dementia. Avoid assuming that people lack capacity to be involved which often results automatically in excluding people with more advanced dementia.
- Remember, it is not just about work. Build in some fun and social time – often the best ideas come out in these moments.

Examples of groups that are part of the DEEP network

EDUCATE (Stockport)

Early Dementia Users Co-operative Aiming to Educate

EDUCATE is a group supported by the NHS. It has 18 members who take an active role in delivering training to professionals across Stockport (and sometimes nationwide) alongside dementia training staff. Members share their individual stories of living with dementia and also highlight their expectations of how professionals should engage with and support people with dementia. Find out more about EDUCATE at www.educatestockport.org.uk

The Forget Me Nots, Swindon

The Forget Me Nots are members of a day care service in Swindon. The service provides care and support to up to 40 people with dementia each week. The ethos of the service is about engagement, participation and maintaining people's sense of role, contribution and purpose in life. The Forget Me Nots have been involved in a range of influencing work including redeveloping the Social Care Institute for Excellence (SCIE) Dementia Gateway (www.scie.org.uk/dementia), making films about dementia (www.innovationsindementia.org.uk/films/) and providing a user perspective to a European grant-making process.

SURF group (Liverpool)

The Service Users Reference Forum (SURF) is a large involvement group made up of people with dementia and carers, sitting alongside a range of commissioners, dementia leads, and members of the Liverpool Dementia Action Alliance. The group is co-chaired by two people with dementia. They work on a range of issues including creating a dementia friendly Liverpool, raising awareness with school children, and working on innovative product development.

This guide was created by
working with all the DEEP
groups

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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