

DEEP - developing a national user movement of people with dementia

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What is DEEP?

DEEP stands for the Dementia Engagement and Empowerment Project. DEEP is a network of involvement/influencing groups of people with dementia. These are groups that are working together to:

- raise awareness about dementia
- provide viewpoints to policy makers and decision makers
- influence local dementia services
- challenge other people's views about what it is like to live with dementia

The network is UK wide. 50 groups are part of the network.

This paper describes the work of DEEP between 2012-2015.

Why is DEEP important?

People with dementia are increasingly sharing their views about living with dementia. By working together, people can have their views heard at a higher level. People with dementia are setting their own priorities about the issues they find important.

What does DEEP do?

There has been support to build the DEEP network from two organisations - Innovations in Dementia and Mental Health Foundation.

Support has included:

- Putting groups in touch with each other. Groups have been able to share ideas and good ways of working
- Getting groups involved in national influencing - for example, with the British Psychological Society, the House of Lords and conference presentations
- Collecting examples of different ways that groups work
- Writing monthly updates, to tell groups of each other's work

- Giving out small amounts of funding. This has helped groups to carry out work that they are interested in
- Producing guidance notes to improve the ways that other organisations work with people with dementia.

Ideas about the things that DEEP groups do to help people be involved, are in the full report.

What has been the impact of DEEP?

“Being part of a network gave our members the confidence that they have a right to have their voices heard.” from a DEEP group

- Lots of local influencing work e.g. writing books, creating dementia friendly communities, training local professionals, raising awareness, developing technology, being on local TV and radio
- Helped to develop national policy and guidance
- Created a national campaign about language and dementia - “Dementia Words Matter”
- Used technology and the media to get their views out to the public - see www.onouradar.org
- Helped conference organisers to become more dementia friendly
- People with dementia feel they have a sense of purpose. They feel valued for the work they are doing. Their skills and experiences are being used. People say they feel more confident and have more self esteem.

What happens next?

DEEP is funded for another four years until 2019. Priorities for the next phase are:

- Making sure that people with dementia are fully involved in making decisions about DEEP
- Working with funders and local services to keep groups financed and supported
- Asking other organisations and professionals to link with DEEP. Ensuring this is on the terms of people with dementia
- Involving people with more advanced dementia in DEEP. This includes people in care homes and hospitals

Working alongside networks of family carers when appropriate

You can read more about setting up a new DEEP group in the full report.