Reflections on PPI from the ‘Action on Living Well: Asking You’(ALWAYs) advisory network of people with dementia and carers as part of the IDEAL study.

The ALWAYs group

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Abstract:

Patient and Public Involvement is an explicit expectation for research projects. This article describes the work of the ALWAYs group - an involvement group of people with dementia and carers attached to the IDEAL research study. The article describes the work of the group from the project outset, the methods and practical support that have helped them to stay involved, people’s perspectives on their experiences of being involved and the impact it has had, for themselves and others. People identified that the creation of a group identity, accessible meetings, regularly working together and the formation of positive relationships with the research team, all helped to make their involvement a good experience. The article has been written following a reflective piece of work with the ALWAYs group to review and remember the work of the past four years. It concludes with recommendations for other researchers. An accompanying film brings to life the work and activities of the group.