

Patient & Public Involvement Guidelines for the Dementia Health Integration Team

Contents

Purpose of guidelines.....	1
What is ‘involvement’?	1
Why involve people affected by dementia?	2
Who should be involved?.....	3
When should involvement happen?.....	4
How do we make sure involvement is done well?	4
Feedback to all ‘involved’	4
Available PPI support	5

Purpose of guidelines

The Dementia Health Integration Team (HIT) aims to involve people affected by dementia in all aspects of its work. The views of people affected by dementia should guide decision making and involvement should take place at each stage of each project; **this is the responsibility of all Dementia HIT partner organisations.** This approach should be embedded into the practice of each organisation to ensure that the voices of people affected by dementia are heard. These guidelines are intended to support this process and have been produced with the input of people affected by dementia.

What is ‘involvement’?

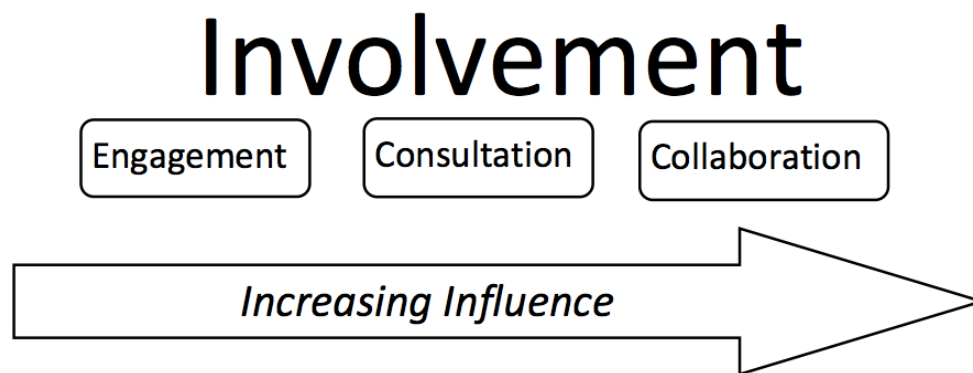
The term involvement may be used differently by different people and organisations. Within these guidelines ‘involvement’ will refer to any contribution by people affected by dementia that can influence any project, service, organisation or research study.

The phrase ‘people affected by dementia’ will refer to people living with dementia, their

carers, family and friends and other interested members of the public.

The term 'project' will refer to any service development, service evaluation or research study.

There are different levels of involvement, with different levels of influence and these are represented in the diagram below.



Increasing Influence

'Engagement' can refer to the passing of information from an organisation to the public, sometimes with only limited opportunity for the public to influence the issue in question. 'Consultation' involves actively seeking people's views at a stage where influence can be made. Involvement can also take the form of 'collaboration' where people provide more than their views and become members of a project/research team and can also become involved in decision-making. Indeed, the Dementia HIT hopes that people affected by dementia will be directly involved in implementing projects, where appropriate.

The terms 'participant' and 'participation' will not be used in these guidelines to avoid any confusion with people acting as research participants.

Why involve people affected by dementia?

- People living with dementia have the right to influence services and projects that

affect them.

- People living with dementia and their carers are able to provide unique insight into the services they use and the challenges they experience.
- Patient and public involvement improves the quality of research and can be of benefit at every stage of the research process.
- Involvement provides genuine focus on the issues and needs of people affected by dementia.
- Involvement improves transparency, making organisations accountable.
- Proper involvement adds credibility to projects.
- Patient and public involvement can inspire and motivate the workforce.
- Those who take part in involvement activities can feel empowered by doing so.

At times, some professionals may seek involvement because it is a condition of their project's funding and may only see it as a 'box-ticking' exercise. The Dementia HIT is keen to ensure that this attitude does not occur within its partner organisations and will continue to promote a positive attitude towards involvement.

Who should be involved?

- People living with dementia – living in the community or in care homes
- Carers of people living with dementia
- Families and friends of people living with dementia
- Interested members of the public

For involvement to be most effective, it needs to be inclusive. Although we can only involve those who want to take part, we should make efforts to offer involvement opportunities to underrepresented groups. We should remove or reduce barriers to involvement wherever possible and provide support to facilitate their involvement.

The Dementia HIT aims to collect a large pool of interested volunteers who are willing to take part in involvement activities. This will ensure a wide range of views on a project and that individuals are not asked to take part too often.

Although professionals working with people with dementia can offer useful perspectives, their input should not be seen as a substitute for the views of people affected by dementia. Equally, the input of people affected by dementia cannot be replaced by that of interested members of the public; the unique insight of those living

with dementia is invaluable. [SEP]

When should involvement happen?

Involvement should happen at every stage of our projects. However, involvement should only be carried out when there are clear objectives for the work and efforts should be made to find out and use what is already known about people's views and experiences of a particular issue, so as not to have unnecessary repetition.

Involvement should: [SEP]

- **Begin as early as possible in any project:** This gives more opportunity for influence e.g. when setting research priorities and identifying service improvement issues and priorities.
- **Be incorporated into all project plans:** This allows involvement to be an integral part of the project rather than an 'add on'. Careful thought should be given to how 'involvement' can guide a project through each stage.
- **Be used systematically by organisations** so that corporate decision-making is linked to the views and needs of the community.

How do we make sure involvement is done well?

All members of the HIT have a responsibility to ensure their work is informed by the views of people affected by dementia.

Effective involvement requires commitment and leadership from senior members of each organisation and a systematic approach to involvement that links corporate decision-making to the community. Organisations also need to support staff by providing the necessary resources and enabling them to develop the skills required.

- All involvement work requires clear objectives, a plan of tasks to be completed and an understanding of expected outcomes.
- All projects should keep a record of involvement activities.
- Organisations need to demonstrate change as a result of involvement work.
- All involvement activities should be evaluated to measure how effective the activity [SEP] has been and the impact it has had. [SEP]

Feedback to all 'involved'

People who takes part in an involvement activity must be provided with feedback:

- All individuals ‘involved’ must be thanked for their time and contribution
- All must be told what will happen with the information they have provided

Once a project ends:

- All must be given information about the impact of their involvement and the results, regardless of outcome, e.g. if a bid was unsuccessful.
- If a publication is produced (e.g. a report or scientific paper) people ‘involved’ need to be informed and provided with a copy or a link to the document as well as a summary written specifically for people living with dementia.
- If project timescales are long, update reports can be circulated. These will need to be written or edited specifically for people living with dementia.

Feedback is crucial. People receiving proper feedback are more likely to choose to take part in future involvement opportunities. Involvement should leave people feeling empowered and valued. However, this is less likely to happen without proper feedback.

Available PPI support

A [‘Dementia HIT PPI Resource List’](#) is available on the Dementia HIT web site. The resources include guides and reports that will be useful for the planning, development and evaluation of PPI activities with people affected by dementia.

HIT members who require more than PPI advice and would like PPI support (e.g. the setting up of a focus group) should contact the Dementia HIT coordinator by emailing dementia@bristolhealthpartners.org.uk

The coordinator will work with the applicant to create the most effective involvement opportunity for their needs. A fee is likely to be charged for support, to be agreed in advance. A minimum of six weeks’ notice is required for PPI support requests.