

Developing patient research agendas: meaningful involvement of people with dementia

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Project method

There is little opportunity for people with dementia to have involvement in setting research and practice agendas. We convened facilitated workshops involving researchers, people with dementia and their carers, and third-sector practitioners. Where possible, people with dementia and carers met in different rooms so that the perspective of each group could be captured separately and to permit open and frank peer discussion. Facilitators received advance training in communicating effectively with people with dementia. Venue, layout, timekeeping, and approach were designed centred on the needs of people with dementia.

Project results/evaluation

People with dementia and their carers were able to identify important topics requiring research from the perspective of those using the services and gained insight into each other's views. The approach developed in the course of this work we have used subsequently to train further groups, including student groups, in how to work collaboratively with people with dementia.

Project area classification

Hospital care		Emergency care	
GP care		Dementia	X
Social care	X	Learning disability	
Voluntary sector		Other mental health	
Financial services		Palliative care	
Police		Advance planning, LPAs	
Legal		Commissioning	
Community health care	X	Training	
Nursing and care home		For professionals?	X
Acute care		For public and service users?	X
Chronic care			