

The frontiers of research democracy: involving people with dementia in a systematic review

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Background and purpose:

Modern social welfare places user involvement at the heart of democratic decision-making, ensuring that people who use services participate in policymaking and in research. People with dementia are rarely included in these processes. Practitioners and researchers often assume that a diagnosis of dementia means that people cannot contribute to policymaking or to research. This project challenges this by involving people with dementia in a systematic review. The study had two aims – to undertake a pilot systematic review of the views of people with dementia, and to explore ways of ensuring the participation of people with dementia in reviews of this kind.

Methods:

Seven people with dementia joined a research group which met three times to consider:

- a. what studies to include in the systematic review;
- b. what quality criteria to apply to the research; and
- c. whether the initial themes made sense to them.

A pilot systematic review was undertaken to provide the material for the research group. Pragmatic search methods were used to identify 214 studies from 18 countries published since 2000.

Results:

This pilot study showed that it is possible to involve people living with dementia as partners in the review process. By paying careful attention both to how the material is presented and to group processes, the group allowed people to participate and express their views, while preserving their emotional health and well-being. People with dementia offered clear views about what should be included, what counts as quality and whether the key themes made sense to them.

Conclusion and implications:

As Europe ages, the number of people with dementia will inevitably increase. Our democratic processes must include our ageing citizens by ensuring their views influence research and policy.

Keywords: People with dementia, Research, User involvement, Systematic review