

# Effects of including patient and public comments in development of a systematic review: Eating and Drinking Well IN dementia (EDWINA)

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## Background

- Over 0.8 million people are living with dementia in the UK. Their needs become increasingly complex as the illness progresses.
- Eating and drinking difficulties are a major source of ill health and stress across the stages of dementia in multiple settings.
- People with dementia are more likely to drink insufficient fluid, to be malnourished, and the risk of malnutrition increases as dementia progresses.
- The evidence on what interventions support people with dementia in continuing to eat and drink well needs to be updated, and the full set of interventions assessed.



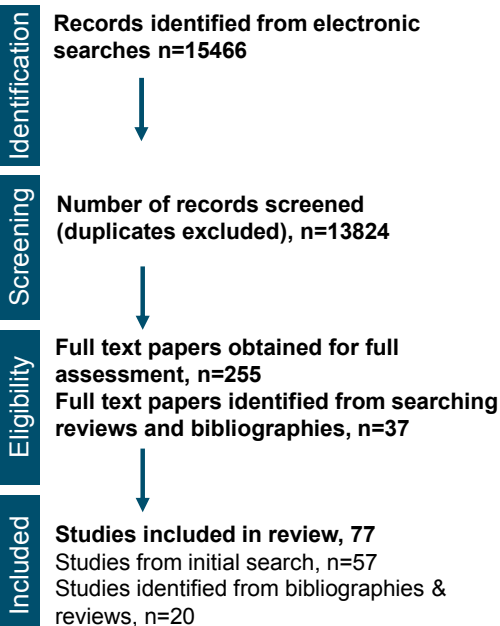
## Aims

- The review aimed to assess the effectiveness of interventions to improve, maintain or facilitate oral food and drink intake, nutrition and hydration status, in dementia patients (in any setting, with varying levels of care, and with different types and degrees of dementia).
- We examined the effects of including patient, public & stakeholder comments on the review protocol on the review questions.

## Methods

- The draft protocol (along with a lay summary) was shared with members of two patient and public involvement groups (the Public & Patient Involvement in Research, PPIRes, from Norfolk and Suffolk and the Public Involvement in Research Group, PIRG, from Hertfordshire), and our stakeholders at AGE UK Norfolk and NorseCare.
- The members were asked to comment on the protocol and suggest questions they would like the review to address.
- Compiled questions were added to inform our search strategies.
- The final systematic review protocol, including the questions developed in conjunction with patient, public and stakeholders, is registered with, and available from, PROSPERO at <http://www.crd.york.ac.uk/PROSPERO/DisplayPDF.php?ID=CRD42014007611>.
- The completed systematic review should be published later this year.

## Results



- Comments and suggested questions were received from seven members of the two PPI groups plus two organisations. Suggestions relevant to the review aim were grouped and formulated by the review team into specific research questions.
- Specific questions to be addressed by the review, generated through this process, include issues around the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake, nutritional status:
  1. Which interventions are useful at specific stages of dementia or for people in specific settings and for people with specific types of dementia?
  2. What interventions around food support meaningful activity (activity around food or drink that is personally fulfilling, that people enjoy, look forward to or find important)?
  3. Are there any interventions that; worsen food or fluid intake, worsen enjoyment or quality of life, or worsen meaningful activity or social inclusion?
  4. Do individualised interventions appear more effective than those that are not individualised, in helping people with dementia to maintain or improve food and/or drink intake, nutrition or hydration status?
  5. Do interventions to assess and/or treat swallowing problems have any effect on food or drink intake, nutrition or hydration status?
  6. Do interventions to improve oral hygiene have any effect on food or drink intake, nutrition or hydration status?
  7. For people with dementia does type of carer providing the intervention or emotional closeness of the carer affect the outcomes?
  8. Are there any interventions that are particularly effective in helping people with dementia to maintain or improve food and/or drink intake, nutrition or hydration status during periods of acute illness?
- The data extraction tool was designed to collect data needed to answer our specific questions.

## Conclusions

Including members of the public in setting specific questions to address within a systematic review on eating and drinking in dementia has produced a useful set of questions that are important to address, as these are the questions being asked by those with dementia, or caring for people with dementia. We hope that addressing these questions specifically will improve the utility of the review, and also aid in dissemination to people who want and need to support those with dementia in eating and drinking well.

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