

CLAHRC BITE

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A bite-sized summary of a piece of CLAHRC research



**Informing the dementia research
agenda**



What?

CLAHRC East of England worked with external organisations with an interest in dementia, and with research funders, to inform the national and international dementia research agenda.

Who?

We worked with people with dementia, their carers, clinicians and other health and social care professionals with the aim of identifying, prioritising and disseminating unanswered research questions relating to dementia.

Why?

Incorporating the views of people with dementia and their carers and other stakeholders is important to ensure that issues of importance to them are researched.

This CLAHRC project was a major piece of work to inform the national/international dementia research agenda and was done as part of a collaboration with the Dementia Priority Setting Partnership (a collaboration with the Alzheimer's Society and other dementia stakeholders representing patients, carers, clinicians, health and social care professionals). The process was independently facilitated and chaired by the James Lind Alliance (a not-for-profit organisation now part of the National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordinating Centre (NETSCC)).

The work involved people with dementia, their carers, clinicians and other health and social care professionals and was aimed at identifying, prioritising and disseminating unanswered research questions relating to dementia. This was done by collecting questions relating to dementia prevention, treatment, diagnosis and care from all stakeholders. The extensive amount of data gathered was formatted into research questions that were then checked against published evidence, resulting in 146 unanswered questions. After an interim prioritisation stage involving voting by stakeholder representatives and a final face to face prioritisation workshop, a top 10 priorities for dementia research were identified. These identified priorities have influenced several major funding calls relating to dementia and a number of projects directly relating to the questions identified have been funded.

The World Health Organisation is currently conducting its own research prioritisation process in dementia. The Dementia PSP priorities were submitted to that process and some have been included in the top 50 priorities recently circulated for voting.

References

Read the outcomes from the James Lind Alliance priority setting partnership at http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=222

What is NIHR CLAHRC East of England?

The National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England is a five year programme of applied health and social care research which focuses on the needs of people with complex problems, often vulnerable, when multiple agencies are involved in their care: young people, frail older people, those with dementia, learning disabilities, acquired brain injuries or mental ill health.

The CLAHRC East of England collaboration encompasses some thirty-six organisations, with research hubs in the Universities of Cambridge, Hertfordshire and East Anglia working closely with individuals and organisations involved in the whole care pathway.

Service users and carers are at the heart of what we do, in parallel with an ambitious public health research programme. Co-production and collaboration at all stages of the research process are fundamental to making a positive impact through applied health research.

Read more about this study on our website

<http://www.clahrc-eeo.nihr.ac.uk/2015/05/dementia-priority-setting-partnership-with-the-james-lind-alliance/>

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