

CLAHRC BITE

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A bite-sized summary of CLAHRC research: Not all patients want to die at home



**“CLAHRC review reveals complexity in
preferences for place of death”**



What?

A new paper by CLAHRC EoE researchers examines preferences for place of death and has major implications for UK End of Life Care policy.

Why?

The paper questions the policy assumption that most patients want to die at home. The systematic review of UK studies showed that it was unknown what proportion of patients preferred home, due to the number of missing preferences.

What next?

The findings are helping to dissuade policymakers from using place of death as a measure of success in End of Life Care provision.

Background

Current end-of-life care policy is premised on the idea that most patients want to die at home, with a consequent key aim of enabling more patients to die at home. Success is measured by the proportion of patients dying in the community.

The paper, a systematic review of UK studies reporting preferences for place of death, found that it cannot be stated that most patients wish to die at home. The researchers investigated preferences for place of death by health diagnosis. The proportions of these preferences were then recalculated to include 'missing data'; the views of those whose preferences were not asked, expressed or reported or absent in studies. Missing data were common. Across all health conditions when missing data were excluded the majority preference was for home: when missing data were included, it was not known what proportion of patients with cancer, non-cancer or multiple conditions preferred home.

Findings

Published in November 2015 in the journal PLOS ONE (1), the paper's conclusion that it is unknown what proportion of UK patients prefer to die at home or elsewhere has significant implications for both policy and practice. It has been discussed by senior policy officials, including Professor Bee Wee, NHS England's National Clinical Director for End of Life Care. This CLAHRC research and research of other academics is being used to dissuade policymakers from using place of death as an ambition target for end of life care provision and have prompted further consideration of alternative metrics for measuring patient choice in end-of-life care.

The findings from the review have been disseminated widely, with invited talks at national conferences and healthcare practitioner events, extensive social media interest and inclusion in print media. The review has been cited in over 20 academic papers and included in NIHR and NHS publications. The paper implications for measuring end-of-life care has initiated research to identify better measures for end-of-life care.

Reference

1. Hoare, S., Morris, Z. S., Kelly, M. P., Kuhn, I., & Barclay, S. (2015). Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death. PLoS One, 10 (11), e0142723. doi:10.1371/journal.pone.0142723

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.

For more information:

Website: <http://www.dahrc-eoe.nihr.ac.uk/2015/11/uncertainty-about-where-patients-want-to-die-not-everyone-chooses-home/>

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