

Realist review of palliative and end of life care programmes in primary care and community settings

Protocol at: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018097218

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In the UK, there are many new policies and services which aim to make care at the end of life more widely available in the community as well as to support patients to die at home, if this is their wish. The priorities of patients for end of life care are, however, about much more than location. In addition, 'community' is far from a simple concept. Community care does not become patient-centred and of high quality only because of the places in which it is provided.

We are doing a literature review on palliative and end of life care in UK primary care and the community, which uses a relatively new approach – 'realist methodology'. Most literature reviews in medical and health research aim to answer the question 'does this work?' (e.g. a drug, an intervention). The realist approach seeks more nuance. It looks at 'mechanisms' of change and the effects of different contexts. It aims to find out what works for whom, when, how and in what circumstances.

We are looking at academic research studies as well as reports and documents coming from policy makers (e.g. Department of Health), charities (e.g. Macmillan Cancer Support and Marie Curie), coalitions committed to improving end of life care (e.g. Leadership Alliance for the Care of Dying People). We will cover the last 20 years: 10 years before the National End of Life Care Strategy (2008), which was a turning point for end of life care in the UK, and 10 years after it (2008 - now).

Our focus will be on:

- Programmes which aim to improve palliative end of life care in the community, the mechanisms through which they work, and the contexts in which they work more or less effectively.
- The outcomes which, according to research studies and other documents, matter to patients and carers and the extent to which the above programmes help achieve them.

A Patient and Public Involvement Group and a health professionals-focused Advisory Group are supporting our work.

We aim to publish findings from our review in academic journals, but also feed them back to policy makers, charities and the broader public.

If you are interested in our work, please contact Mila at mp686@medschl.cam.ac.uk. Your thoughts and suggestions are most welcome!