

# CLAHRC BITE

CLAHRC CP BITE 4

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A bite-sized summary of CLAHRC research




## Who?

People with Chronic Obstructive Pulmonary Disease (COPD) or Heart Failure.

## Findings...

- Heart failure and COPD are both progressive, incurable and unpredictable illnesses with uncertain prognoses.
- Preferences for conversations at the end of life (known as End of Life Care or EOLC conversations), vary greatly from person to person; some people would prefer not to talk about dying at all.
- Timing discussions is difficult, and often EOLC issues are not addressed as it is left too late.



**The NHS End of Life Care Strategy recommends open discussion with patients as end of life approaches, but such conversations rarely take place.**

Studies regarding end of life care (EOLC) conversations have largely been based on the experience of cancer patients at the end of life. In this study, systematic reviews of the literature were carried out in order to gather evidence on the end of life experience of patients with heart failure and chronic obstructive pulmonary disease (COPD). The findings of this study showed:

The barriers to EOLC conversations:

- The complexity of prognosis, the unpredictability and uncertainty of the disease
- There is a low recognition of COPD and heart failure as life threatening diseases
- There is limited consultation time for conversations
- There is little current training for clinicians on undertaking EOLC conversations.

The facilitators to EOLC conversations:

- An established relationship between clinician and patient
- Experience and training of health professionals

The desired content of EOLC conversations:

- There needs to be an explanation of the uncertainty of the illness trajectory
- Honesty and sensitivity between patient and doctor.

## References

Momen N, Hadfield P, Kuhn I, Smith E, Barclay S, Discussing an uncertain future: end of life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis, Thorax online, 16 July 2012. doi:10.1136/thoraxjnl-2012-201835

Barclay S, Momen N, Case-Upton S, Kuhn I, Smith E, End of life care conversations with heart failure patients: a systematic literature review and narrative synthesis, Br J Gen Pract. 2011 Jan; 61(582): e49-62.

## An explanation of CLAHRC CP and its role

The Cambridgeshire and Peterborough Collaboration for Leadership in Applied Health Research and Care (CLAHRC CP) is a partnership between the University of Cambridge, NHS organisations in Cambridgeshire and Peterborough, and Cambridgeshire County Council.

Funded by the National Institute for Health Research, our mission is to undertake high quality applied research to improve health and social care across the East of England.

This is a bite-sized summary of a piece of CLAHRC CP research. It is part of a series designed to make our research findings available to clinicians, commissioners and policy-makers.

CLAHRC CP End of life care research led by Dr Stephen Barclay, is now part of the Dementia, Frailty and End of life care theme of the CLAHRC East of England.

<http://www.clahrc-eoe.nihr.ac.uk/research/research-themes/dementia-frailty-and-end-of-life-care/>

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