



CLAHRCBITE

Brokering Innovation Through Evidence

June 2019

How should end-of-life Advance Care Planning discussions be implemented according to patients and informal carers?



The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Greater Manchester is a partnership between providers and commissioners from the NHS, industry, the third sector and the University of Manchester.

We aim to improve the health of people in Greater Manchester and beyond through carrying out research and putting it into practice.

What was the aim of the project?

As part of our consultation event to establish research priority setting for end of life care in Greater Manchester, stakeholders identified that further research on Advance Care Planning (ACP) was a key priority. We investigated this by synthesising the existing research literature pertaining to patients' and carers' perspectives on ACP discussions to address four broad objectives arising from the priority setting event:

- Describe how ACP discussions are held with patients and carers;
- Explore who patients and carers feel should be initiating ACP discussions;
- Identify when patients and carers feel is the most appropriate time to have ACP discussions;
- Identify the perceived value placed by patients and carers on ACP discussions.

What did we do?

We systematically reviewed the existing research literature pertaining to patients' and carers' perspectives on ACP discussions. There is an abundance of literature reviews on ACP, therefore we conducted a 'review of reviews' to synthesise the information on patient and carer perspectives within these existing reviews. We included 55 literature reviews that helped us address the objectives arising from our priority-setting event.

Why was it important?

ACP is an internationally-recognised term to describe discussions between people, their families and informal carers, and health care professionals about a person's future preferences for care. ACP can have positive effects on the quality of end-of-life and in the UK it is endorsed by a range of organisations including the Department of Health, NICE, and the General Medical Council. There is a body of guidance for professionals about the general principles of ACP, but there is a lack of clarity about how patients and carers feel ACP discussions should be implemented. This is important because there is a need to ensure that policy, practice, and research are aligned with patients' and carers' preferences about how ACP should be implemented.

What's next?

There is a balance to be found between standardisation and flexibility of ACP implementation. Standardisation could help ensure greater equity in who is offered ACP and help practitioners feel more confident. However, it would also need to respect the diverse preferences of patients and carers for the implementation of ACP.

Health care professionals need the time, and the psychological and emotional skills, to explore individual patient and family preferences so that they can tailor ACP implementation to their specific content.

Key findings

- ACP discussions are happening most often with patients who are older, white, female, well educated, and have cancer.
- ACP discussions are supported via a range of tools, and through print, video and computerised formats. All of these are generally acceptable to patients and carers.
- Family carers have a strong influence on whether ACP discussions happen, and often mediate between patients and health care professionals.
- Patients and carers prefer health care professionals to initiate ACP discussions. This should be a professional who knows the patient and family well.
- There are mixed views about the best time to begin ACP discussions. For people with dementia, patients and carers generally would prefer to begin earlier. For people with other conditions, the picture is much more variable.
- Patients and carers generally view ACP discussions as positive and worthwhile, but they can also raise complex and conflicting emotions, and highlight differences in opinion.
- Sociocultural beliefs have an important influence upon the perceived value of ACP.
- Patient autonomy may not always be the most important perceived benefit of ACP, as some patients may be more motivated to reduce stress on their family members.

What is NIHR CLAHRC GM?

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Find out more

www.clahrc-gm.nihr.ac.uk/projects/advance-care-planning

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