"I'm sorry I haven't a clue": Public perceptions of anticipatory (advance) care planning (ACP) - scoping review, public consultations, and websites

Anne Canny,[1] Bruce Mason,[1] Rebecca Patterson[2] , Kirsty Boyd[1]

[1] University of Edinburgh, Primary Palliative Care Research Group. [2] Scottish Partnership for Palliative Care, Director GLGDGG.

Abbreviated abstract: ACP benefits are clear but uptake remains low nationally and internationally. Data from a scoping review, public consultations, and a review of online ACP resources found limited public knowledge of ACP and inadequate information to promote public awareness and engagement. Poor understanding led to fear, mistrust, superstition and avoidance. People are looking for resources in diverse formats with clear and succinct text, easy navigation, and images and videos to widen access.

Related publications:
1. Selman L, Lapwood S, Jones N, Pocock L, Anderson R, *et al*. What enables or hinders people in the community to make or update advance care plans in the context of Covid-19, and how can those working in health and social care best support this process, CEBM Research, Oxford. 2020:1-62, page 23.
2. McIlfatrick S, Slater P, Bamidele O, Muldrew D, Beck E, *et al*. 'It's almost superstition: If I don't think about it , it won't happen'. Public knowledge and attitudes towards advance care planning: A sequential mixed methods study. Palliat Med. 2021;1-10, page 7.

anne.canny@ed.ac.uk-1

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4-ACP: integrated care planning and electronic care coordination intervention in primary care for people living at home or in a care home

❖**Effective ACP is underpinned by meaningful public engagement and accessible information**
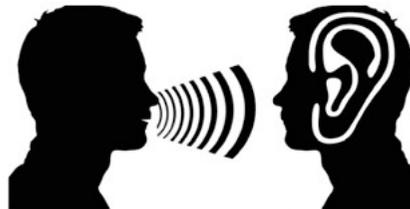
3-Phase Approach

Scoping review

stories
information reality facts evidence
indisputable FACTS alleged
fictions clearly lies fictions
fibs existance deceptions
obvious
GOGRAPH
gg59990575 www.gograph.com

17 articles
> 19,600 participants

Public Consultations

https://www.clipartmax.com/middle/m2H7Z5K9Z5K9i8i8

8 focus groups (n=33)

Online resources

https://iconscout.com/icon/internet-searching-1875026
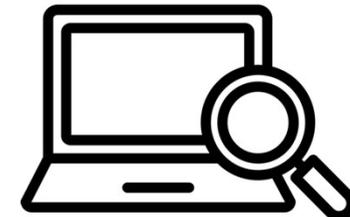
UK & Ireland =26
International = 63

4 ACP

Marie Curie
Care and support
through terminal illness

THE UNIVERSITY of EDINBURGH | usher institute

Scottish Partnership for Palliative Care

anne.canny@ed.ac.uk-2

Methods

Scoping Review

- Joanna Briggs methodology for scoping reviews.

- Search terms included ACP, public perceptions through related MeSH terms and Boolean operators.

- Embase, PubMed, PsycArticles, Cochrane library, CEBM Oxford.

- Hand searches of public opinion databases and grey literature

- 1045 studies identified from databases. Results uploaded to Covidence.

- Two researchers agreed final selections.

- 17 studies met inclusion criteria. Europe (n=7), North America (n=6), Australasia (n=2) and Asia (n=2)

Public Consultations

- Key collaborators facilitated public discussions groups following citizen consent.

- A total of 8 groups involving 33 people.

- Older people, relatives of care homes, learning disability support workers, minority ethnic community members, leaders and advocates.

- Citizens expressed views of ACP over zoom.

- With permission, conversations were audio recorded, transcribed and synthesised via thematic analysis in accordance with the literature.

Online resources

- Publicly available ACP websites identified through search terms consistent with a scoping review methodology.

- Search carried out in google 'incognito' to avoid 3rd party internet cookies.

- International search applied to 193 United Nations member states on an individual basis.

- A total of 89 websites identified; (UK/Ireland n=26, International n=63).

- Scottish websites reviewed by members of the public and study team PPI members.

- UK/Ireland/International websites reviewed by PPI and research team members.

Results

Public consultations

'I haven't heard of the term ACP, but I would think it relates to end of life care'. (6C21)

'Some families are not able to talk about ACP. My children will not engage in ACP conversations'. (1C1)

'I associate ACP with giving up present life to go into residential care'. (7C23)

'Why can't we have a national programme on ACP, legislated by the government and delivered by NHS'. (4C17)

'But if you don't know that it's there and you don't know where to look, then you don't know what support can become part of the care plan'. (7P24)

Scoping Review

https://blog.adtrue.com/2017/03/13/programmatic-advertising-challenges/knowledge/

https://www.thecoachingtoolscompany.com/5-types-of-fears-dr-karl-albrecht/

https://www.shutterstock.com/image-photo/have-knowhow-knowledge-hand-turns-dice-1355716169

http://chrisbrauns.com/2014/09/head-sand-approach-bad-idea/

Websites review

'There is a lot of dense reading. It seems to be aimed at an above average level of education'. (Q3R2)

'I was given an overall view of anticipatory care planning, but nothing specific e.g. how to actually make an anticipatory care plan or links to further information'. (Q1R8)

'I didn't find it helpful despite several visits to it. It didn't make it clear what ACP was and in what sort of circumstance it would be relevant'. (Q2R1)

'some of the content could have been delivered in different formats and the content itself could be simplified'. (Q4R6)

'The 'ACP Matters' video was helpful showing different circumstances where ACP is helpful - real people'. (Q2R8)

The font size was very good on this website and made reading much easier than other websites. (Q2R2)

Summary: Public information is not engaging people with ACP. Accessible resources in diverse formats and public campaigns need to address poor information and motivational barriers.

anne.canny@ed.ac.uk-4