

# *To plan or not to plan just yet?*

## Early support and care planning for people with poor prognosis cancers in primary care

Anne Canny<sup>1</sup>, Alan Christie<sup>2</sup>, Lucy Wall<sup>2</sup>, Louise Graham<sup>2</sup>, Kerry Horstman<sup>4</sup>, Richard Skipworth<sup>3</sup>, Joanna Bowden<sup>4</sup>, Chris Weir<sup>1</sup>, Kirsty Boyd<sup>1</sup>.

*Institute(s):* <sup>1</sup>University of Edinburgh, Primary Palliative Care Research Group. <sup>2</sup>NHS Lothian, Edinburgh Cancer Centre.

<sup>3</sup>NHS Lothian, Royal Infirmary of Edinburgh, Surgical Unit. <sup>4</sup>NHS Fife, Palliative Care, Dunfermline.

**Abbreviated abstract:** Primary care teams coordinate support for patients and families integrated with oncology and palliative care. A mixed-method feasibility trial evaluated an early contact with primary care for anticipatory care planning (ACP) for people with pancreatic or upper gastrointestinal cancers starting palliative oncology treatments. 37% of participants (n=46) died or withdrew due to deteriorating health by 24 weeks. Patient-carer-GP interviews at 6-8 and 20 weeks highlighted the challenges of '*thinking and planning ahead*' while navigating a cancer diagnosis and treatment. People tried to maintain a 'normal' life. Palliative care and planning for dying were often not acceptable yet.

**Related publications:** Tapsfield J, Hall C, Lunan C, et al. BMJ Supportive & Palliative Care Published Online First: 13 April 2016, doi:10.1136/bmjspcare-2015-001014



THE UNIVERSITY  
of EDINBURGH



[Anne.canny@ed.ac.uk](mailto:Anne.canny@ed.ac.uk)

This poster is part of the  
SPPC poster  
exhibition  
2020  
The logo for the Scottish Partnership for Palliative Care, featuring a stylized blue 'C' with the text 'Scottish Partnership for Palliative Care' inside it.

# Background & methods

Scottish Government initiatives promote Key Information Summaries (KIS), including Anticipatory Care Planning (ACP), recorded in GP practices for patients with life-limiting illnesses.

## Challenges

- Difficulties with identification and timing – when to start planning?
- Involves sensitive and complex conversations with patient/carers.
- Low patient-public and professional engagement.

<https://ihub.scot/improvement-programmes/living-well-in-communities/anticipatory-care-planning/>

<https://www.ec4h.org.uk/covid-19-effective-communication-for-professionals/>

## Aims/objectives

- Empower patients to seek early support and care planning in primary care.
- Explore facilitators and barriers to earlier ACP for people with poor prognosis cancer
- Outcomes: timing of ACP, quality of life, service use, patient-carer-GP experiences.

## Strategy

- Evaluate feasibility and acceptability of an early contact letter for patients to take to their GP from the oncologist; information on ACP for patients, families and GPs .



THE UNIVERSITY  
of EDINBURGH



[Anne.canny@ed.ac.uk](mailto:Anne.canny@ed.ac.uk)

### REDMAP FRAMEWORK

- R**EADY - CAN WE TALK ABOUT YOUR CARE?
- E**XPECT - WHAT DO YOU KNOW/WANT TO ASK?
- D**IAGNOSIS - WE KNOW/DON'T KNOW
- M**ATTERS - WHAT MATTERS TO YOU?
- A**CTION - THIS CAN HELP / THIS WILL NOT HELP
- P**LAN - LET'S PLAN GOOD CARE FOR YOU + YOUR FAMILY

REDMAP CREDIT: EC4H - UNIVERSITY OF EDINBURGH | NHS SCOTLAND

# Findings: patients & families

*We're just no feeling at that stage yet actually. I'll sort of cross that bridge when I come to it. We've got too much to live for.*

43P, early support, interview 1

*It's just a sledgehammer blow, and then they come out with all this stuff and you're going, hang on a minute, what, what, what.*

14P- carer, standard care , interview 1

*To discuss it ahead and you know where you stand.. Do you want to be at home or in a care centre....you know what I mean?*

18P, early support, interview 1

*Our GP took the bull by the horns right from the start. She asked me about end of life.*

23P, standard care, interview 2.



THE UNIVERSITY  
of EDINBURGH

**usher**  
institute

[Anne.canny@ed.ac.uk](mailto:Anne.canny@ed.ac.uk)

This poster is part of the  
SPPC poster  
exhibition  
2020



## Findings: GPs

*I think some people are keen to have the discussion, other people, they're obviously not ready or wanting to have that conversation.*

38P- GP, early support, interview 1.

*I think that she just wants to live day to day and enjoy it, and I think em when she realises that she's starting to be limited then I feel at that point I will probably reach out.*

14P - GP, standard care, interview 1.

*The KIS itself is not a problem. It's when you start to talk about palliative care. A lot of patients haven't really thought about resuscitation...their place of death. They haven't had that conversation with their next of kin, and it's very emotive.*

26P - GP, early support, interview 1

Care planning engagement depended on patient, family and GP perspectives.

Funded by

**MACMILLAN**  
CANCER SUPPORT

[Anne.canny@ed.ac.uk](mailto:Anne.canny@ed.ac.uk)

This poster is part of the  
SPPC poster  
exhibition  
2020

Scottish  
Partnership  
for Palliative Care