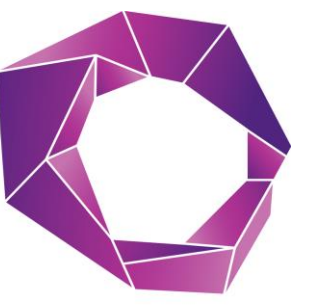


# Enabling End of Life conversations between people affected by cancer and their clinicians

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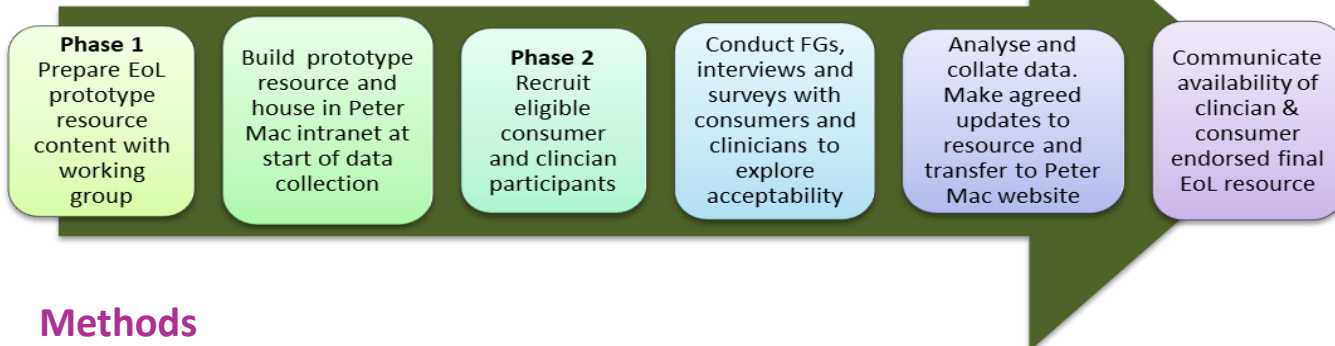
The study outcome is a novel co-designed consumer and clinician endorsed resource to support meaningful end of life conversations.

## Introduction

Death and dying are often difficult topics to broach for patients, family and cancer clinicians. While many people want to talk about end of life with their treating team<sup>1,2</sup> as few as one third of people who want this conversation with their clinicians have this<sup>3,4</sup> and opportunities for these discussions are often missed<sup>5</sup>. Having end of life conversations are associated with less aggressive medical care close to death, earlier palliative care referrals and better support for grieving families.<sup>6,7</sup>

This study set out to co-design a digital resource to support patients and carers to initiate end-of-life conversations with their cancer team.

The schema outlines the project activities:



## Methods

Consumers, researchers and clinicians drafted the resource together. Informed by the Theoretical Framework of Acceptability<sup>8</sup> data was gathered from patients, carers and clinicians through audio-recorded focus groups and interviews. Participants provided feedback on the content, functionality, and "values fit" of the new resource.

**Results** Seventeen consumers and ten clinicians endorsed the resource content and value. A sample of responses is provided below:

Acceptability domain	Participant quote
<b>Affective Attitude:</b> How an individual feels about the intervention	<i>'supportive, gentle'</i> <i>'It's not daunting, and says I can do this'</i>
<b>Burden:</b> Perceived effort to participate in intervention	<i>'there are no setbacks using this, people won't look if they are not ready to'</i>
<b>Ethicality:</b> The extent to which the intervention is a fit with the individual's values	<i>'It's empowering for patient's, there's no jargon, key messages are strong...the resource invites you in'</i>
<b>Intervention Coherence:</b> Extent the participant understands the intervention and how it works	<i>'Simple, straight forward, calm'</i> <i>'love the questions and stems'</i>
<b>Perceived effectiveness:</b> Extent the intervention is perceived as likely to achieve its purpose	<i>'Patients can use with families, may help them be at ease to talk to family because it's a Peter Mac resource'</i>

Participants said the resource has the potential to enable end of life conversations with between the patient and their cancer team; within the patients' family; and be used as a teaching tool with staff new to end of life care. Psycho-oncology and palliative care staff described being 'thrilled' to have a dedicated resource to provide to consumers to support end of life conversations.

*"I don't fear dying, it's the impact on people around me."*

Lindy, with advanced breast cancer

*"Some patients knew they were not curable, but they had not discussed end of life. We empowered them to talk to their team and reassured them that it's okay to not have treatment."*

Lisa, cancer nurse researcher

## Preparing for End of Life

This resource aims to assist individuals and their families discuss end of life matters. We provide information to help you consider your priorities, ask questions, and have meaningful conversations with your cancer team, preparing you for the journey ahead.

You may wish to read through the resource now, or just know that it is here if you want to read it at another time.



### Thinking about End of Life

This resource will help you and your family think about what is important to you and the questions...Read more



### My concerns

Knowing that life is close to its end can be difficult to accept or cope with. Its normal to feel...Read more



### My hopes

Thinking about what we want at the end of life is important for all of us to consider. Talking...Read more



### End of life care

Some people with cancer will have preferences about where they would like to die. Talk with your...Read more



### My family

Telling family and friends that end of life is near, and seeing them upset by the news is...Read more



### Planning ahead

We prepare for many important stages in our lives; adulthood, getting married, children being...Read more



### What happens at the end

Patients and carers have told us how important it is that healthcare staff prepare them for what...Read more



Access **Preparing for end of life** via this QR code

**Conversation starters and Question prompts** included in all topics were reported to be a "useful and empowering" component of the resource.

Ask as many questions as you would like answered. This will help you make decisions with your cancer team about the care and treatment that is right for you

Ways to begin a conversation with your cancer team

You could say	Your questions might be
I would like to talk about what's important to me in the time that I have left	What can I expect if I choose to have this treatment? What difference will it make?
I want to tell you about some of things that I would like to do in the time I have left	I don't feel I want any more treatment. What does this mean for my care?
I need to talk about the treatments I am having and how they are making me feel	What can I expect if I decide to stop treatment and focus on quality of life?
I want you to know what my preference is when there is a choice between quantity and quality of life	I want to talk about what happens now that my treatment has stopped. Are you able to help me with that conversation?
I want to talk about living with my advanced cancer.	What are some things I can do to help keep me feeling as well as possible?
I want to be involved in making decisions about the treatment I am having.	How can palliative care help? Can you help refer me to a palliative care team?
I want to talk about and share decisions about my care from now with my partner/children	

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Landing page including all web pages topics.