

New Approaches to Connecting Patients, Carers and Families with Palliative Care Information

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Introduction

When a person is diagnosed with a life-limiting illness both they and their families often need support and access to information outside of 'office hours'. They need information that is informative but also easily understood, practical but not overwhelming.

For ten years CareSearch has been developing and providing online access to evidence based resources in palliative care. CareSearch provides access to collections of trustworthy information relevant across the life course, across the system and across individual roles. CareSearch has an important role in supporting everyone to take on the required skills and understanding to make informed decisions in palliative care. In 2009 we established the Patient, Carer and Families section to provide tailored support for all Australians. However, we also recognise that awareness and access to online information remains limited for many Australians and for those with access this is often of itself not enough.

To address this, a framework was developed to guide engagement with individual sectors to help us understand which information channels are preferred by each group, in what format information should be provided, and what kind of information is needed with respect to palliative care. In 2018 we held a workshop with members of the patients, carers, and families sector (community) and guided by the framework launched the Engagement Project. Here we present our findings and discuss how this has shaped subsequent activities to better connect Australians with evidence based palliative care information that is relevant to their needs and those of the people approaching death who they support.

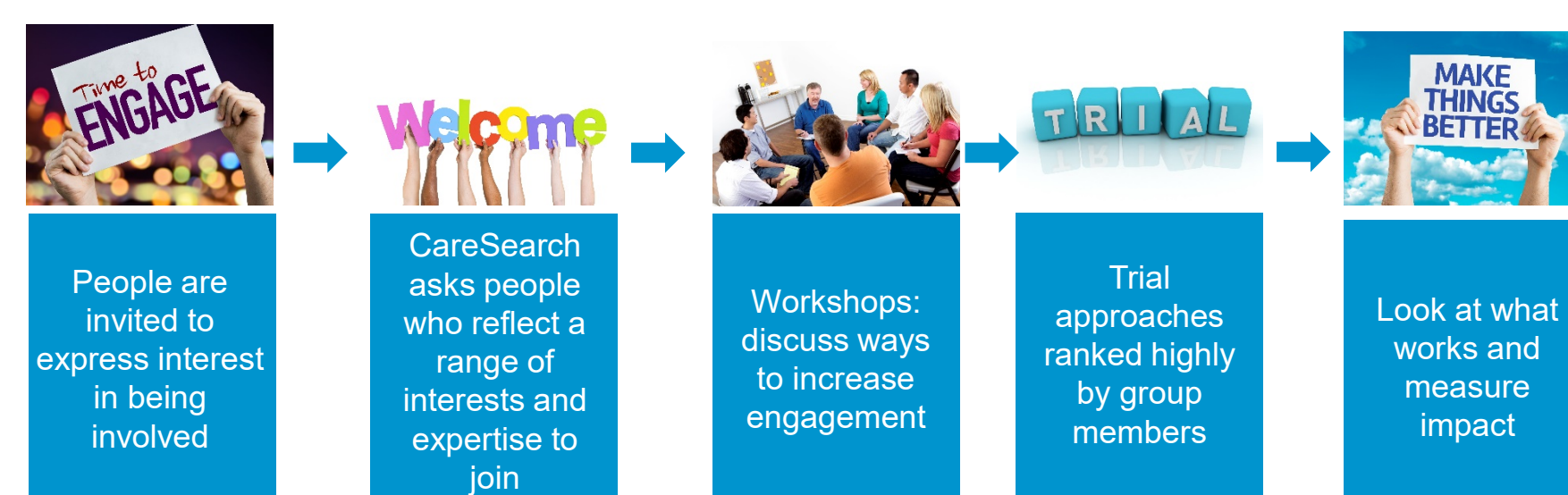


Methods

As part of the formal engagement framework a literature scan of refereed and grey literature was conducted to help us understand the context in which patients, carers and families operate. This informed approaches to motivating people to participate in the project, and to talk about the specific issues affecting awareness and use of resources.

Our analysis of the context also informed workshops with the patients, carers and families. The aim of the first workshop was to support free discussions to determine:

- how information is received by patients, carers and families,
- how it is disseminated,
- how important is the role of evidence, and
- how information should be presented.



Results & Discussion

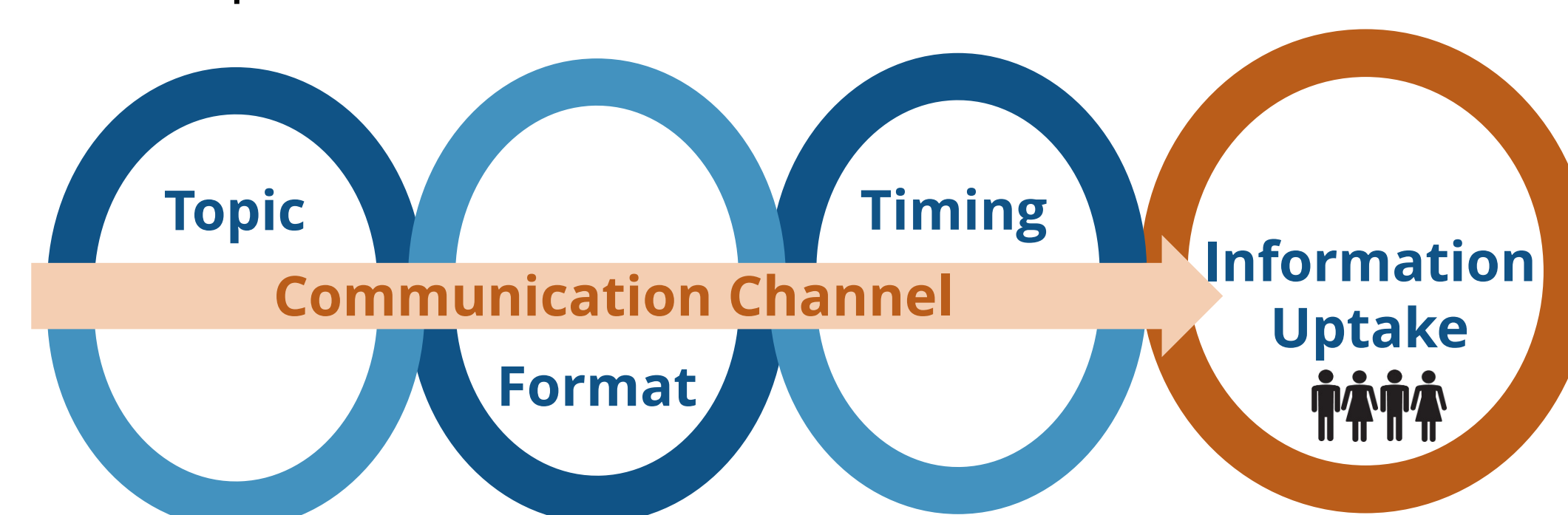
Using a formal Engagement Framework we have:

- developed a context statement for patients, carers and families,
- recruited "exemplar" participants for workshops to provide representative perspectives on value and use of evidence in their context,
- co-developed an Action Plan for the sector with the sector,
- implemented the Action Plan by engaging with multiple channels,
- assessed the impact of the Action Plan, and
- engaged with the sector to further refine ongoing approaches.

Results & Discussion (continued)

Participant perspectives on the need for information and advocacy was reflected in the comment 'There is no lead in time when you need palliative care – it is like learning to swim from the high diving board.'

Information is received by patients, carers and families through several channels including mainstream media. However, with all channels there needs to be alignment between topic, format and timing to ensure uptake.



Understanding the sector including the importance of trusted networks and shared experience is essential when developing tailored materials to meet varied needs.

Patients, carers and families face many challenges in relation to evidence in palliative care:

- Distress affects capacity to judge trustworthiness
- Education, technology skills, and health literacy vary greatly in this group and influence trustworthiness judgements
- Volume of information
- Access to research findings.

Conclusions

To improve our understanding of the use of evidence, a structured approach to engagement with representative patients, carers and families was developed and implemented. However, the challenge of sector variation and information overload remains a challenge. Trust and literacy level are key considerations.

Finding out more

Visit the Engagement Project webpage: <https://www.caresearch.com.au/EngagementProject>

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