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CONFERENCE ABSTRACT

An innovative, consumer-centered approach of community engagement: the Dying Well Community Panel

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Introduction: Most Australians prefer to die well and as they wish, but not everyone can have their end-of-life wishes fulfilled. There is a knowledge gap in understanding our communities' needs in end-of-life care.

To address the gap, we engaged a Community Panel to participate in a deliberative dialogue process to hear their views about end-of-life care.

Short description of practice change implemented: As a Primary Health Network, we recognise that communities have the right to influence decisions that impact their health.

To improve our communities' end-of-life experience, it is important to identify and understand our communities' needs, their values, beliefs and choices.

Aim and theory of change: The aims and the roles of the Community Panel were to:

- Consider the remit: 'What does dying well look like and how can we help people achieve this?'; and

- Create a set of meaningful recommendations that can help people to achieve dying well, to be considered for future investment.

Targeted population: Twenty-seven consumers and carers participated in the process. They were identified and recruited from the community/public members living in Melbourne's north and western regions. They ranged in age, were from diverse backgrounds, and had varied end-of-life experiences.

Timeline: Throughout the engagement process (August 2018 – December 2018), the Community Panel were supported by experienced facilitators through a range of activities. They came together for two-and-half days in November and December 2018 to work, discuss and provide recommendations on the remit.

Highlights: Using a Deliberative Democracy Process, it empowered the Panel to participate meaningfully in the following activities:

- a welcome email

- a 'Meet and Greet' session

- sharing of information via an online platform

- face to face engagement over two-full weekend days to respond to the remit and develop recommendations; and

- follow-up meeting to present their recommendation and report to the health decision makers.

Despite it being an emotive topic, we successfully demonstrated that open and safe discussions can be achieved using this innovative deliberative process, which gives a greater insight into what it is important to patients and the community. This enables more effective targeting of resource to improve outcomes.

Comments on sustainability: Community involvement through this process will inform more effective and sustainable planning, design and implementation of end-of-life support and services.

Comments on transferability: This will also ensure that our service planning is relevant/applicable and transferrable to meet our future population’s needs. The deliberative process can be applied to other priority areas and programs.

Conclusions: This engagement activity has enhanced our understanding of our local communities’ needs in end-of-life care. The Panel developed a report that provided 14 consensus-driven recommendations on how to support people to die well, and a definition for what dying well entails.

Discussions: The Panel’s recommendations are now being used to guide commissioning intentions and activities for our local communities.

Lessons learned: The process has led to a change of attitudes towards public participation from the community members, and a greater understanding across our organisation of the value of collaborative public participation.