



DYING WELL

COMMUNITY PANEL

PANEL PROCESS REPORT

Prepared for the North Western Melbourne Primary Health Network

December 2018

LIMITATIONS OF USE

This report has been prepared by MosaicLab on behalf of and for the exclusive use of the North Western Melbourne Primary Health Network (NWMPHN).

The sole purpose of this document is to provide a report on the methodology, research findings and process undertaken for the Dying Well Community Panel.

This report has been prepared in accordance with the scope of services set out by the NWMPHN. The NWMPHN can choose to share and distribute this report as they see fit. MosaicLab accepts no liability or responsibility whatsoever for or in respect of any use of or reliance upon this report by any third party.

MosaicLab is a Victorian based team of facilitators dedicated to bringing diverse groups of people together to solve the complex problems of today. We assist government agencies, community members, industry and the commercial sector to find ways of speaking and working together. We facilitate conversations that have meaning and can make a positive difference to decision- making and action.

What does dying well look like
and how can we help people
achieve this?



PARTNERS AND ACKNOWLEDGEMENTS



Deliberately Engaging

INTRODUCTION

In July 2018, MosaicLab was contracted by NWMPHN to facilitate a community panel to assist in defining what dying well looks like and provide recommendations on how both NWMPHN and the community can help achieve this. Over the course of four months, MosaicLab oversaw and managed the design and delivery of the two-and-a-half-day panel.

31 people were recruited as panellists, with 27 attending all days. The panel was invited to help NWMPHN answer the following questions (remit):

What does dying well look like and how can we help people achieve this?

This remit allowed for recommendations pertaining to things NWMPHN had direct control of, and also areas where NWMPHN had influence in an advocacy role.

NWMPHN provided technical expertise, background information and provided the contacts and networks for targeted recruitment.

The following report outlines the process design and implementation of the Community Panel and includes overall feedback from participants that was provided at the beginning and end of the process.



PROJECT BACKGROUND

The project is a new initiative introduced by the Federal Government Department of Health in 2018–2020. The Government is investing \$9.0 million over the next 3 years to roll out this project across Australia between 11 different PHN groups. The project aims to help improve end of life care for Australians.

80 per cent of Australians wish to die at home and only 20% of people get the opportunity to. It was clear to NWMPHN that there is a need and desire to improve how people experience end-of-life care. NWMPHN want to support people to die well and prepare for end-of-life care, especially when someone close is facing a serious or chronic illness. This will mean more people can receive the end of life care they want, when and where they want it, helping families and friends live their lives. Understanding the options and preparing for end-of-life will improve the experience and allow people to think ahead and plan their choices.

In order to effectively make change, the whole community needs to be part of this discussion which is why the community panel was organised. The panel aimed to get views from various members of the community including patients, families, friends, work colleagues, neighbours, professionals, service providers and community groups. By increasing everyone's awareness of the importance to start thinking early, people are better informed of their choices and decision-making.

The recommendations provided by the panel will help NWMPHN improve the process of dying for patients who wish to die at home. They will receive a safer, more effective and higher quality of care and services to support them dying at home.



ROLES

NWMPHN Executive Team

To provide the authority for the Dying Well Community Panel and respond to the panel's recommendations

Community Panel members

To:

- agree on the key definition of what dying well looks like
- consider the options, benefits and trade-offs for each recommendation
- provide recommendations that support people dying well to NWMPHN executives.

NWMPHN

To:

- provide the panel with the known parameters and needs within the project
- outline information that would assist participants to understand the needs, problems, challenges, data and work to date
- provide access to technical expertise, reports, information and evidence to assist the panel's deliberations
- observe the process

Deliberately Engaging

To ensure the recruitment is independent, unbiased and to provide support to panel members as needed

MosaicLab Facilitators

To support the panel's deliberations by creating a productive space that enables them to respond to their remit.



THE PROCESS: COMMUNITY PANEL

A Community Panel is a name for a group that deliberates over an issue and makes recommendations to decision makers. Deliberative engagement processes place the people affected by a decision at the centre of a decision. A randomly selected group of participants takes a 'deep dive' into the issue and works together to consider a wide range of information and perspectives, come to agreement, and respond to their remit with recommendations. These processes work on the premise that everyday people can deliver smart, long-term decisions which earn public trust if they are given enough information and time to weigh up all the perspectives, trade-offs and pros and cons related to a problem.

Expert facilitation is a vital in a deliberative process. In order to foster vibrant deliberative dialogue. MosaicLab facilitators work to create a supportive environment for panellists to discuss the issue and allow all voices to be heard, avoiding domination of the group by any one individual. The facilitators work to balance the needs of the group alongside the need for the panel to deliver recommendations in line with their remit during the time allocated.

For the Dying Well Community Panel, a selection of patients, health professionals, service providers, carers and community groups were invited. Participants were selected randomly to represent the various groups. The panellists each brought their own experiences and background into the room and discussed what was important from their perspectives.

The participants' role was to consider and critically assess the information presented to them, discuss the issue with other participants and arrive at agreement – in the case of a deliberative process, this is called a 'super majority' where at least 80% of panellists can support or 'live with' a recommendation.

THE DYING WELL COMMUNITY PANEL INVOLVED:

- A diverse group of participants
- A clear question to focus the deliberation (the remit)
- A broad and diverse range of information inputs relevant to the remit
- Time for the participants to consider and deliberate on the evidence
- Key speakers to provide additional opinions and voices as nominated by participants
- Support from experienced facilitators specialising in deliberative processes
- A 'blank page' report – participants developed their own report from scratch together in the room
- Group negotiation where the majority decision (more than 80%) was carried
- A report containing the panel's recommendations, which was presented directly to a NWMPHN executive at the completion of deliberations
- Inclusion of 'minority reports' written by some panel members that they deemed important but were not given 80% majority support by the wider panel

DELIBERATIONS



August 2018 - Welcome email

- 31 participants engaged through Deliberately Engaging



13 November 2018 - Meet and Greet

- Orientation, introductions and understanding of the task ahead.
- Opportunity to ask questions of NWMPHN and clarify the scope of the task.
- Setting agreements about how the panel would work together.
- Identifying people/groups the panel would like to hear from on day 1.
- Receive the Background Report for review.



13 November - 2 December 2018 - Online Discussion

- Panellists use online platform via *Loomio* to discuss, upload and research further information, introduce themselves and understand their task ahead.



1 December 2018 - Day 1 of Panel (27 participants)

- Discussed insights from the Background Report.
- Worked on critical thinking skills.
- Took time to explore the issue and research gaps of knowledge and understanding.
- Heard from selection of experts/speakers nominated at the Meet and Greet.
- Started defining what 'dying well' is and generated some initial ideas around the remit.



2 December 2018 - Day 2 of Panel (26 participants)

- Identified gaps in ideas and started to build on these ideas, refining and defining the rationale.
- Panel members draft initial recommendations for the issues/ideas.
- Panel reviewed and tested their ideas with the whole group, identifying their level of comfort and provided feedback on each draft recommendation (ideas rating sheets).
- Panellists begin re-writing their recommendations, incorporating the group feedback.
- As a collective group, panel members indicated whether they could 'live with' the recommendation or more (i.e. 'like it' or 'love it'). Recommendations that received 80 per cent or more support (live with it and above) included in the report. Final edits were made to the definition of 'dying well' and the preamble.
- One of the recommendations that did not received 80 per cent support was written up as a minority report by one small group.
- Presentation of final panel report to a NWMPHN executive.



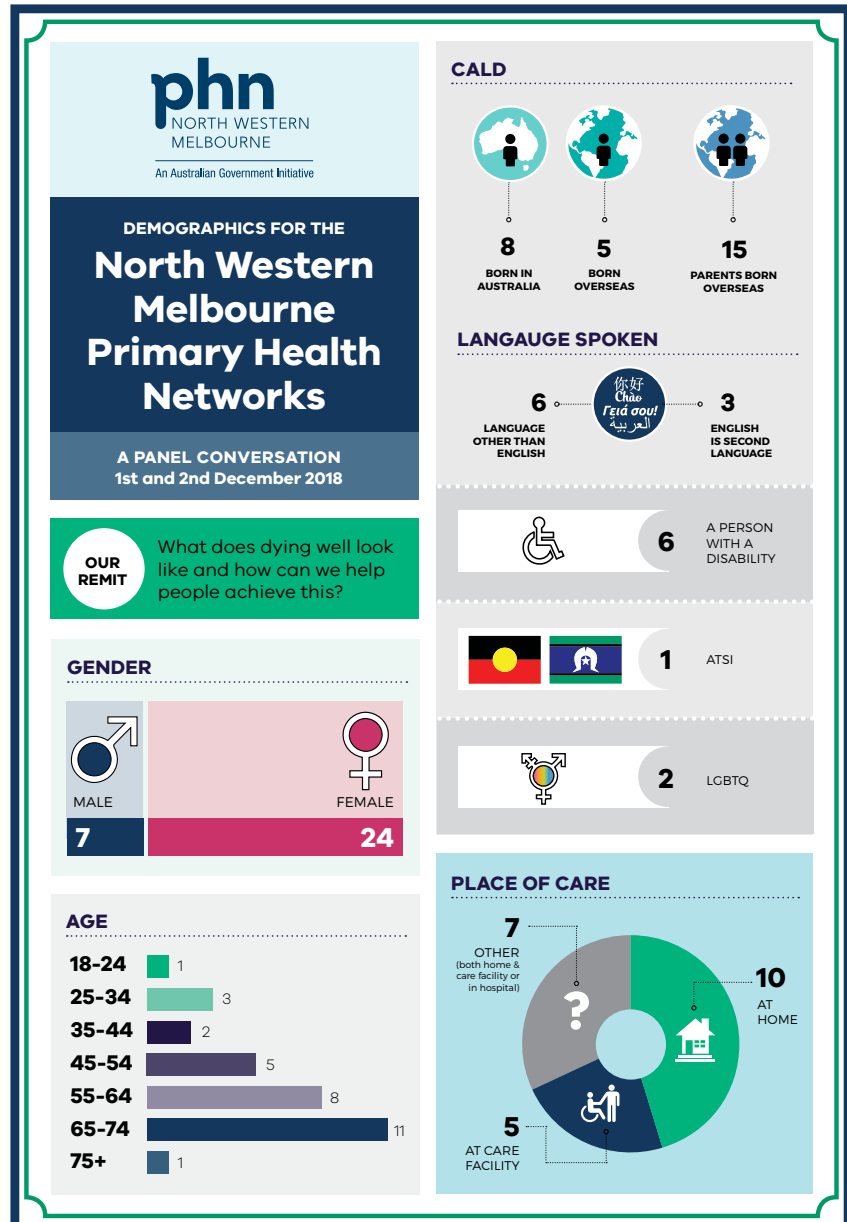
PARTICIPANTS

The Community Panel originally started with 32 members. Due to health issues, family deaths and other commitments, the final panel included 27 participants. Independent recruitment specialist, *Deliberately Engaging* worked with NWMPHN to recruit participants. Invitations were distributed by NWMPHN to organisation they had a close working relationship with, and invited those groups to extend the invitation to their networks. *Deliberately Engaging* then sent the invitation to another 140 disease, support, faith and multi-cultural groups either by email, LinkedIn or website enquiry forms.

All groups were asked to send the invites onto their networks in order to select the panel. Given the nature of the topic, it was important participants had some connection to or direct interest in palliative care.

The panel was selected with age, gender, CALD (country of birth, parents' country of birth, English as a second language), disability, ATSI and LGBTQ for both carers and consumers in mind. Consumers were invited to share the nature of their illness. Carers were asked about the nature of their care capacity, for example caring for someone living at home, or in a care facility, and their highest level of education.

MosaicLab were not involved in the selection of panel members.



PANEL INFORMATION

The panel was provided with materials that helped them explore the issue and answer their remit. This included a background paper (including an outline of the issues and opportunities) and a participant handbook to help prepare panellists for their deliberations.

During the sessions, materials were also provided that related to current legislation, international examples, academic studies and other information pertaining to end-of-life-care.

The panel heard from several speakers during the first full day of the deliberations. These speakers included:

- Cheryl Holmes – CEO (Spiritual Health Victoria)
- Alison Coelho, Co-Manager (Centre for Culture, Ethnicity & Health)
- Alexandra Clinch, Deputy Director (Royal Melbourne Hospital Palliative Care Unit)
- Dr Aria Tak Manesh, (National Home Doctor Service)

In addition to the four speakers, one submission was also presented in the room during the speaker dialogue session. This submission was from:

- Janaya Charles, Natalie Birt, Christine Ingram, Lynette Briggs and Laura Campbell (Community Programs, Victorian Aboriginal Health Service) – written submission

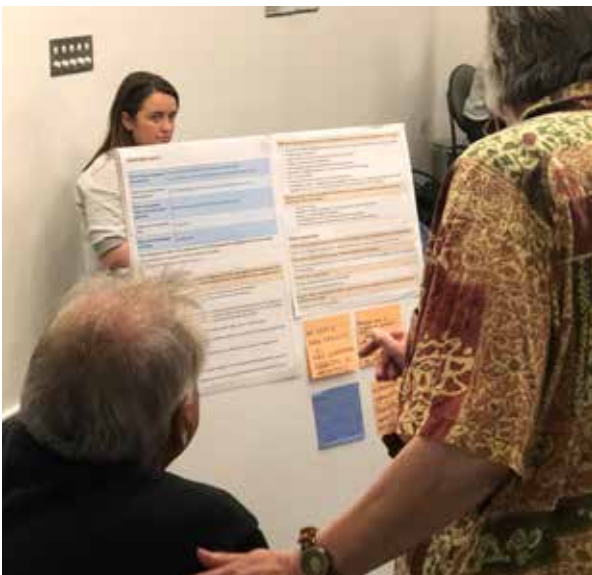


COMMUNITY PANEL REPORT

The Dying Well Community Panel's report was finalised on the 2 December 2018 and sent to NWMPHN for distribution to all participants. A hard copy was also distributed in the room at the conclusion of the session.

This report has been fully written and completed by the participants of the Panel themselves and untouched by the facilitators or NWMPHN.

The final panel's report can be attained by contacting PHN staff Cik Lee (cik.lee@nwmpnhn.or.gau) and Sarah O'Leary (sarah.oleary@nwmpnhn.org.au) or by contacting (03) 9347 1188.



PARTICIPANT FEEDBACK

Participants were invited to complete a pre and post deliberation survey in the room. The pre-deliberation survey was completed at the beginning of the meet and greet, with participants completing the post-deliberation survey at the conclusion of day 2.

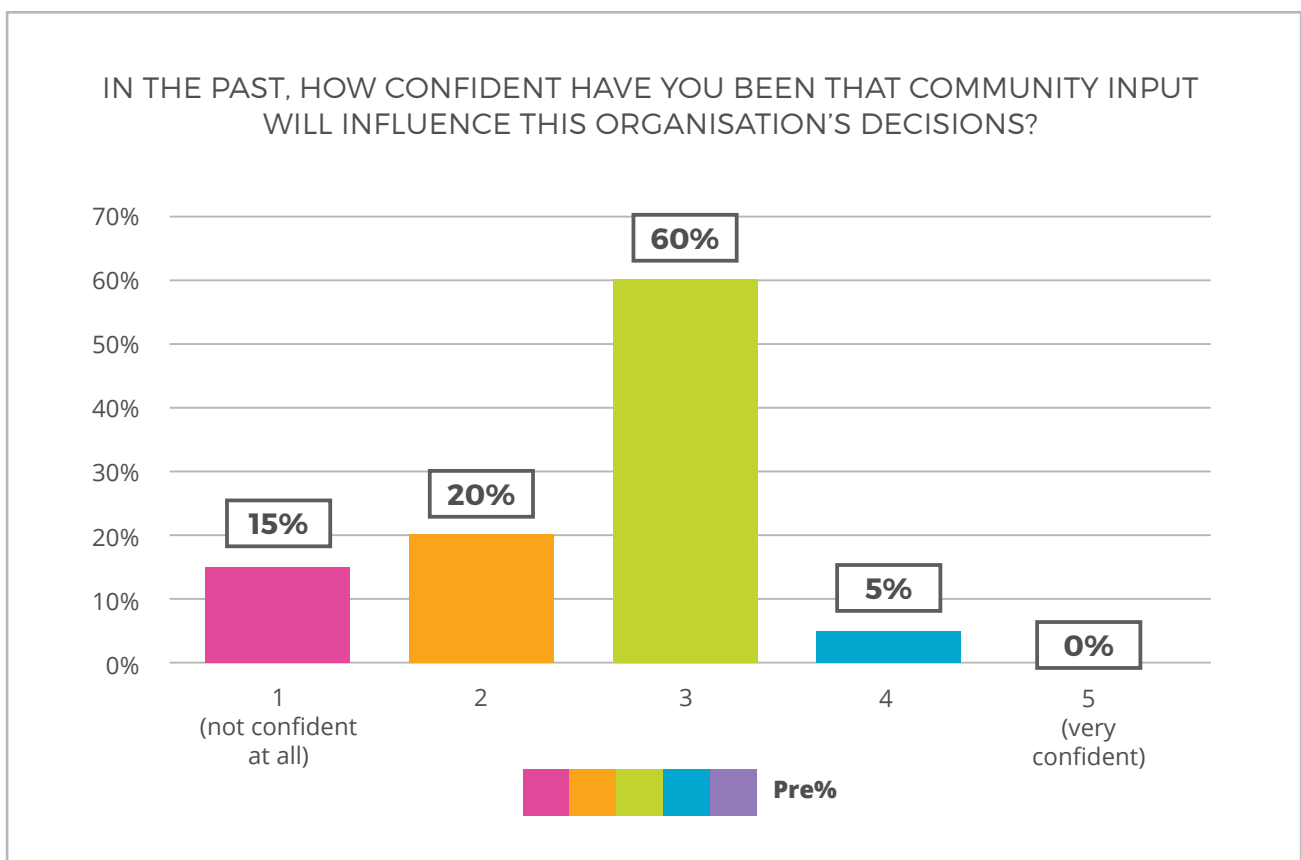
Prior to the panel, 35% of participants had little to no confidence that community input would influence NWMPHN's decisions. At the conclusion of day 2, 47% of participants were confident or very confident their recommendations would be implemented.

The biggest shift pre and post deliberation, was with the level of genuine, collaborative and worthwhile engagement from NWMPHN. Prior to the panel, only 15% of participants felt NWMPHN had engaged in a genuine, collaborative and worthwhile or very genuine, collaborative and worthwhile manner. After the deliberations, 96% of participants felt the process was genuine, collaborative and worthwhile.

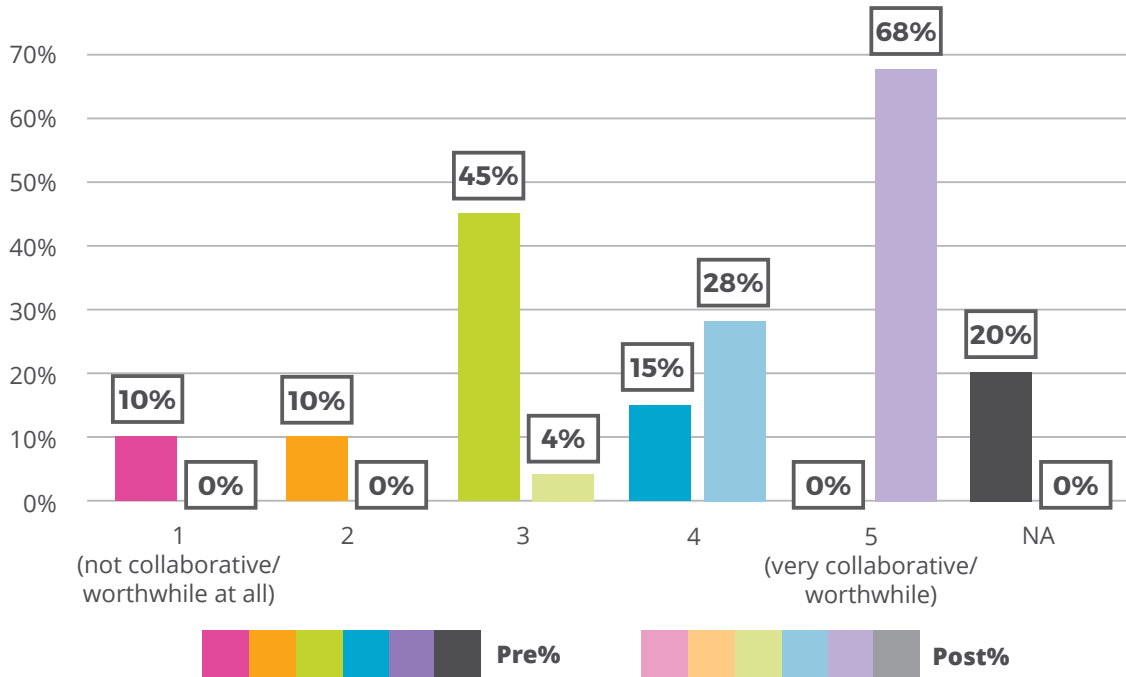
Participants also had a big shift in their willingness to participate in future government decisions that will affect them, from 35% to 87%.

The results of the pre and post polls are below.

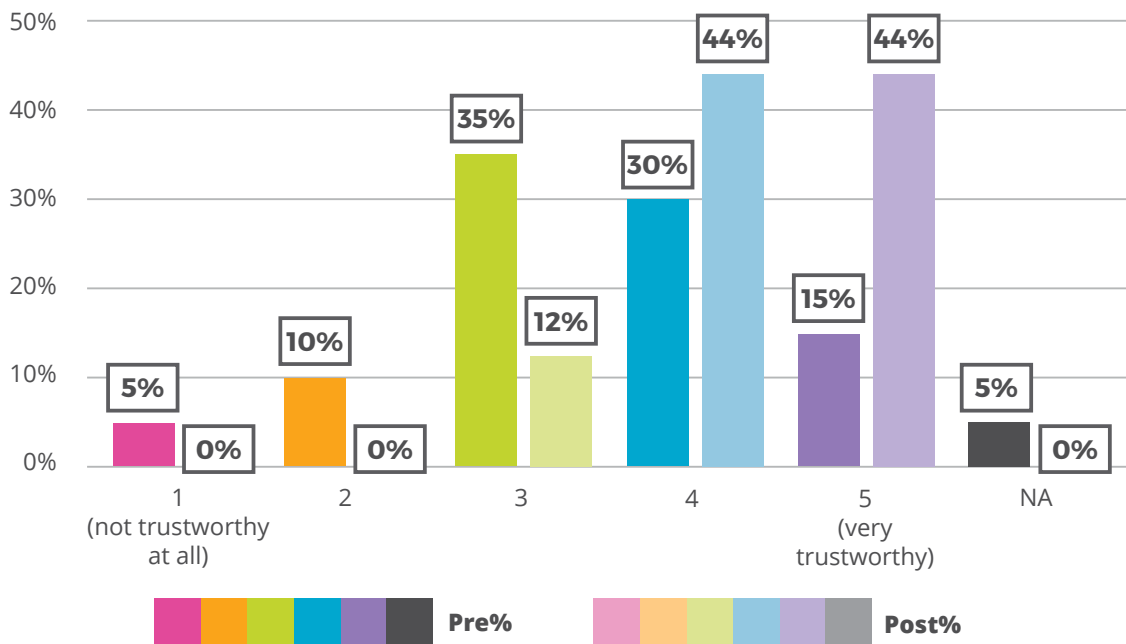
OVERALL FEEDBACK



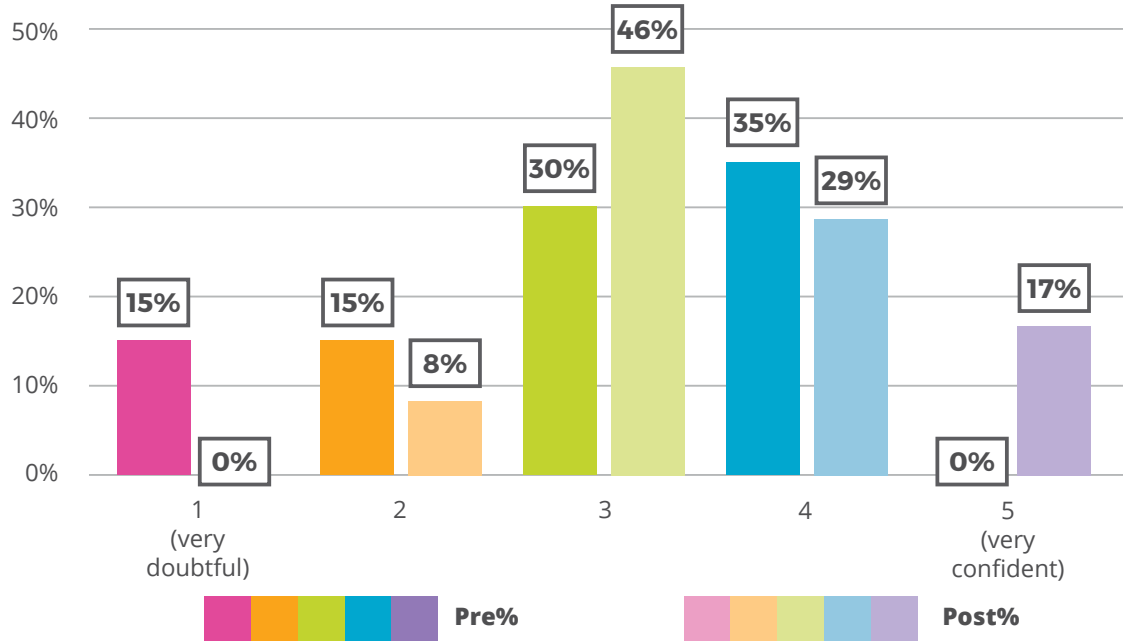
IN YOUR VIEW, HOW COLLABORATIVE, GENUINE AND WORTHWHILE HAVE THIS ORGANISATIONS' ENGAGEMENT ACTIVITIES BEEN IN THE PAST?



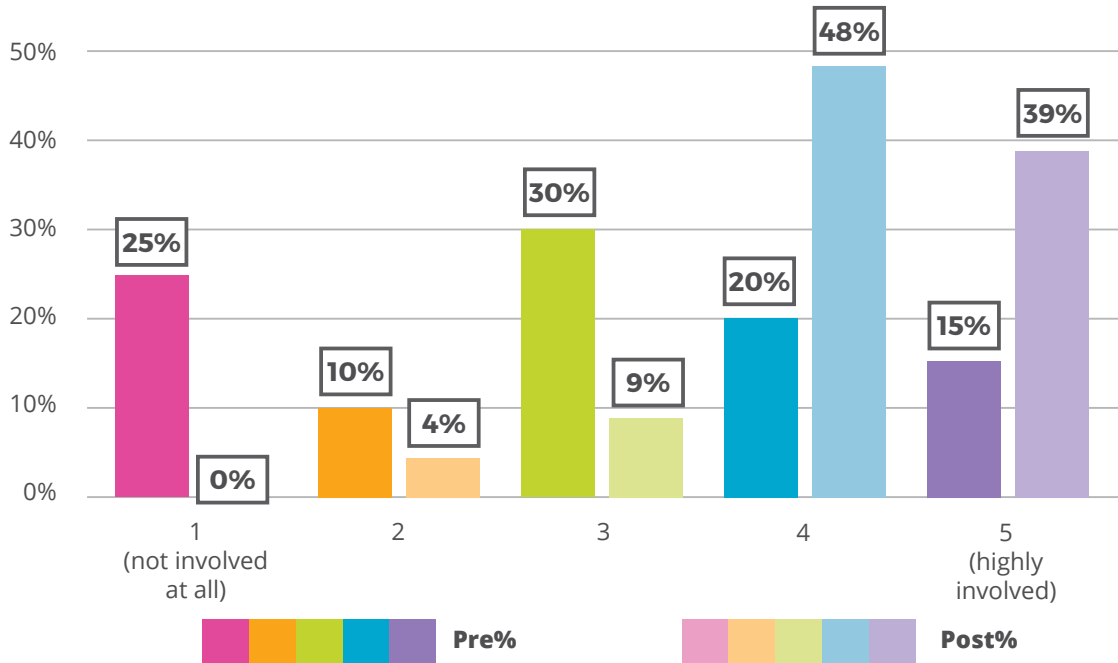
IN YOUR VIEW, HOW ACCOUNTABLE OR TRUSTWORTHY DO YOU THINK THE ORGANISATION RUNNING THIS PROCESS IS?



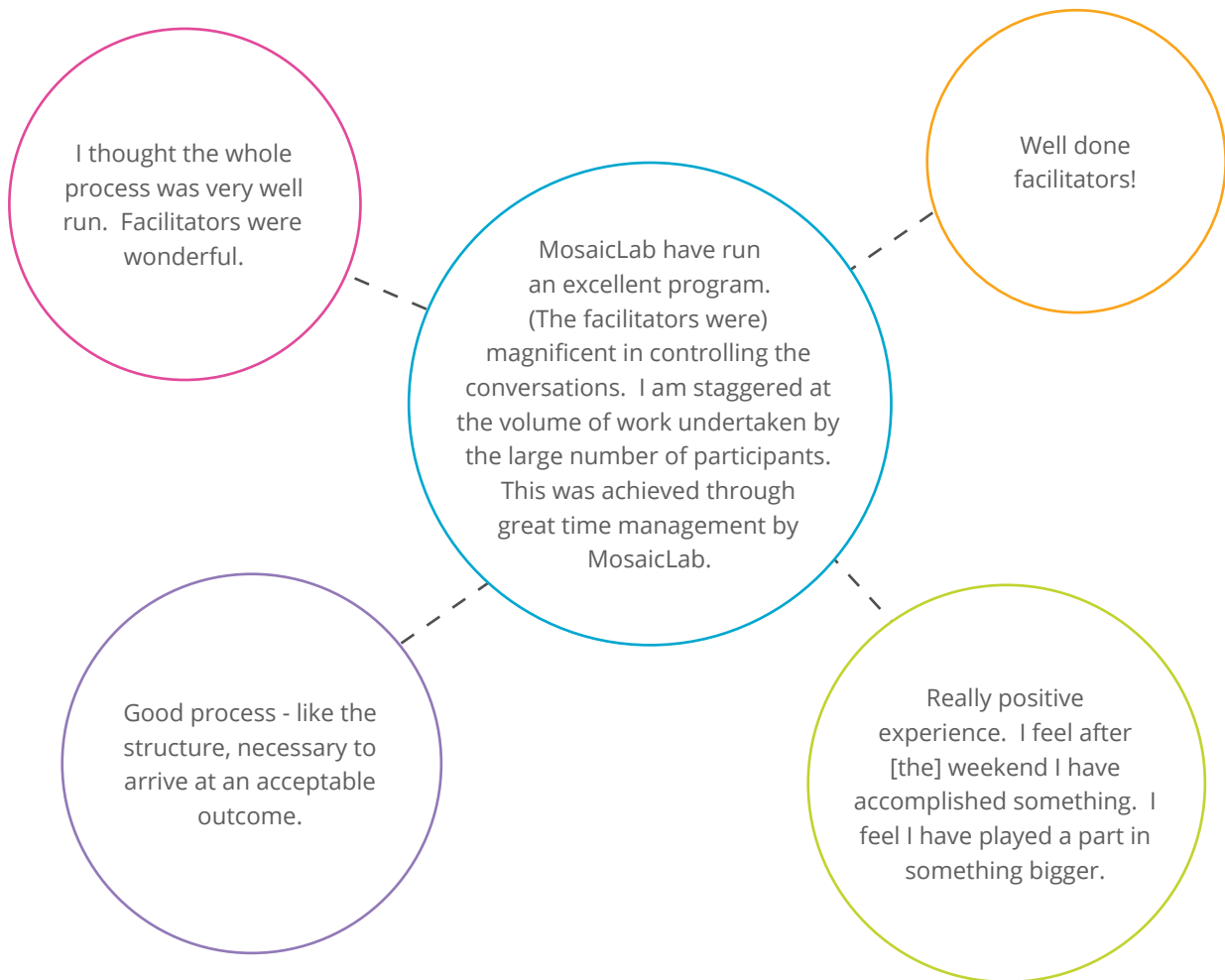
HOW CONFIDENT ARE YOU THAT YOUR RECOMMENDATIONS ON THIS CURRENT ISSUE WILL BE IMPLEMENTED?

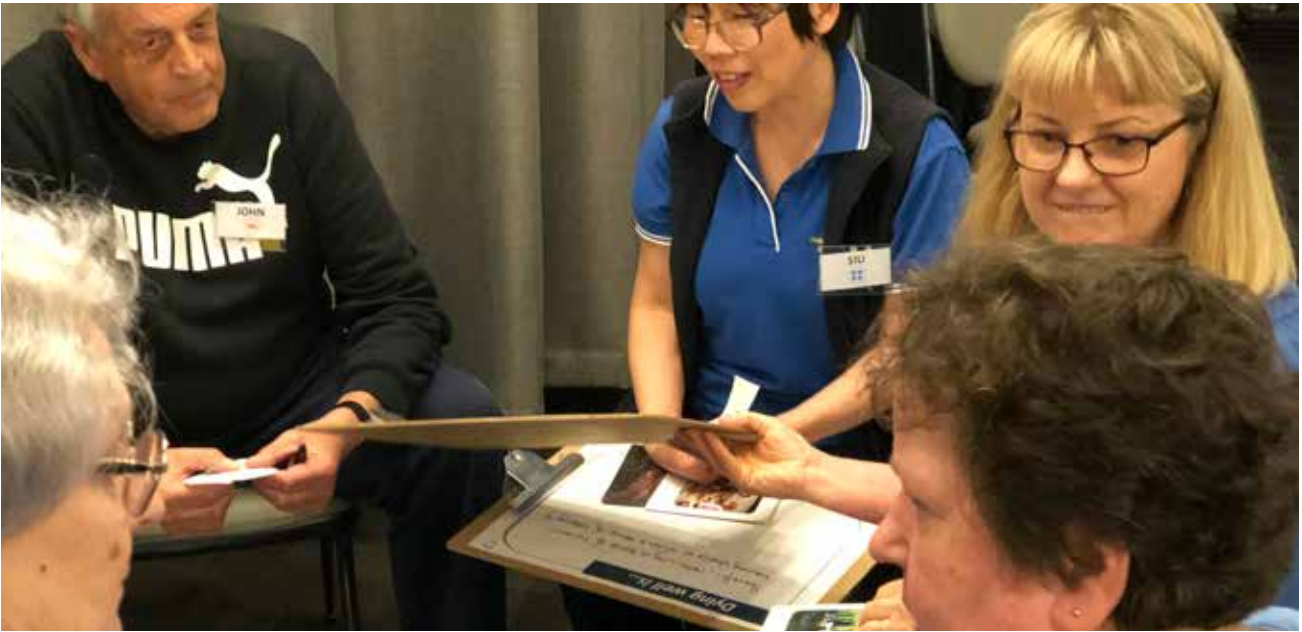


HOW INVOLVED ARE YOU CURRENTLY (PRE)/WILL YOU BE (POST) WHEN IT COMES TO GOVERNMENT DECISIONS THAT AFFECT YOU?



At the conclusion of day 2, panellists were invited to share any final comments or feedback. Participants commonly referred to the process, the facilitation team and experience. Some examples of these comments are as follows:





FACILITATORS COMMENTS

MosaicLab felt privileged to facilitate such an important conversation with passionate and committed participants. As part of this process, the facilitators noticed a number of key aspects that ensured that the process was effective. These are outlined below:

MosaicLab would like to acknowledge panellists on their willingness and openness to participate in this dialogue. The caring and respectful nature of participants allowed rich personal stories to be shared in an effort to help improve dying well. The group respectfully took the time to consider and understand each other's perspectives and were considerate of each other. The group worked flexibly together to accommodate different needs and abilities including limited mobility and sight impairments. One participant had an audio describer with them on day 2, this provided this participant with an independence to participate in their full capacity, this was especially helpful when reading recommendations for final levels of comfort.

Recruitment was conducted through NWMPHN stakeholder networks and contacts of these stakeholders. This meant the process was not fully randomised, however ensured people strongly connected to palliative care were in the room. As this was NWMPHN's first deliberative democracy process it was deemed important to capture a mix of carers, consumers and health professionals experienced in palliative care in the process.

Given the recruitment of this process, participants were their own experts with rich personal and professional experiences in palliative care and end-of-life planning. This was particularly evident in the speaker's session, where a 'pause' was included in the process. This pause allowed group members to discuss their own relevant experience and learn from each other, and proved valuable to the participants.

The speaker session also included a written submission from an indigenous organisation, Victorian Aboriginal Health Service. The addition of this submission allowed participants to consider Aboriginal perspectives when a representative was unable to attend in person. This submission was considered carefully by the participants and well used in their deliberations and recommendations.

The client, NWMPHN had never undertaken community consultation in a deliberative format. Their courage to step into the process and commit to understanding the community perspectives was key to the success of this approach. To prepare, NWMPHN sought counsel from VicHealth who has completed two citizens' juries in the past three years. This provided NWMPHN reassurance of the long-term policy setting and research benefits from the participants' recommendations. This preliminary research into the process was valuable when NWMPHN were challenged on the remit, holding their ground and trusting the process. NWMPHN were also excellent at providing alternative options for those unable to participate in the panel. NWMPHN were clear in their response to the panel at the conclusion of day 2, providing clarity of next steps and ensuring the panel knew their contributions were highly valued to the work NWMPHN does.

Whilst an online portal was set up for participants to share information and connect, this was used minimally. A majority of participants accessed the portal at least once during the process, however it appeared face-to-face conversations were more appropriate for the topic.

NEXT STEPS

18 January 2019	Panel-selected participants present the final panel report to the NWMPHN executive team to consider
January - March 2019	NWMPHN executive to assess panel's key recommendations for dying well and develop a response document.





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PLEASE NOTE: While every effort has been made to transcribe participants comments accurately a small number have not been included in this summary due to the legibility of the content. Please contact Keith Greaves at keith@mosaiclab.com.au for any suggested additions.