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Charles Darwin University

## Engage, understand, listen and act

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# Engage, understand, listen and act: evaluation of Community Panels to privilege First Nations voices in pandemic planning and response in Australia

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## ABSTRACT

**Introduction** First Nations Peoples of Australia have not been included in the development nor prioritised in pre-2009 pandemic plans despite being a priority population in Australian health policy. Marginalised groups experience amplified barriers and systemic disadvantage in emergencies, however, their voices have not been heard in past pandemic responses. Through effective engagement with disadvantaged and oppressed groups, health authorities can gain a deeper understanding of how to design and implement pandemic control strategies. There have been limited studies with First Nations Peoples that has focused on pandemic planning and response strategies. Deliberative inclusive approaches such as citizens juries have been a way to uncover public perceptions. **Methods** Qualitative thematic research methods were used to conduct the study. We convened five First Nations Community Panels in three locations in Australia between 2019 and 2020. We used an Indigenist research approach, community-based Participatory Action Research framework and ‘yarning’ to understand whether Community Panels were an acceptable and appropriate way of engaging First Nations Peoples. Forty First Nations participants were purposively recruited through local and cultural networks. Panels heard evidence supporting various pandemic response strategies, and cross-questioned public health experts.

**Results** All 40 participants from the 5 panels verbally indicated strong support of the Community Panels approach as an effective way of engaging First Nations Peoples in making decisions about pandemic planning and response strategies. The main theme of ‘respect’ centred on the overarching principle that First Nations Peoples are important in the context of continuation of culture and ongoing political resistance.

**Conclusion** First Nations Community Panels are a way of enabling active participation of First Nations peoples, increasing knowledge and understanding, and a way for government and policymakers to respectfully listen to First Nations opinions and values.

## INTRODUCTION

Despite resistance and hard-won political advancements of First Nations Peoples of Australia, racism and discriminatory practices

## WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ First Nations Peoples were excluded from Australian pre-2009 pandemic plans and yet experienced disproportionately far worse health outcomes in terms of unmet health needs, hospitalisations, intensive care unit admissions and death.
- ⇒ Health emergency plans in Australia often frame First Nations Peoples within a deficit lens, fail to reflect social realities, nor understand the root cause of the described disparity or health outcome, which is ongoing colonisation, racism and unmet health needs.
- ⇒ First Nations health is often measured against the health of non-First Nations Australians, which inadvertently pushes the public health benchmark into a Western context and worldview.
- ⇒ This worldview does not necessarily meet the goals or needs of First Nations Peoples in pandemic health plans.
- ⇒ There is limited evidence of effective engagement with First Nations Peoples in pandemic governance.
- ⇒ One-off or rushed ‘consultations’ with First Nations Peoples have the potential to cause harm, and often fail to incorporate and value the historical, cultural and social contexts of First Nations Peoples in the development and implementation of health plans, programmes and policy.
- ⇒ While current national COVID-19 pandemic plans have been developed specifically for First Nations Peoples and highlight the need for health services to engage First Nations communities in the development of local plans, these plans do not outline how this could be done.

## WHAT THIS STUDY ADDS

- ⇒ A way for government authorities and policymakers to meaningfully engage First Nations Peoples in decision-making around pandemic response.

remain a detrimental determinant of First Nations health.<sup>1–3</sup> The ongoing impacts of colonisation, discriminatory acts and genocidal policies bolster a history of oppression sustained by entrenched systemic and

### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ This study shows that listening and taking time, building approaches and understanding with First Nations Peoples in a culturally appropriate and acceptable governance structure can make a difference.
- ⇒ Respecting First Nations ways through two-way learning and communication with non-First Nations Peoples can help develop deeper understanding of the realities of the past, present and future that can also be incorporated into important public health policy.

institutional racism.<sup>4</sup> Systemic racism and discrimination, structural inequities, dispossession and loss of culture, language and lore are root causes of health inequities and lower health outcomes for First Nations Peoples.<sup>5 6</sup> Like other oppressed groups worldwide, Australia has a long history of non-First Nations Peoples making decisions for, and without First Nations Peoples. As such, First Nations Peoples have been excluded from full participation in the development of policies on public health emergencies.

The spectrum of Australian public health emergency response pigeonholes First Nations Peoples into a frame of deficit and disparity. Often, it does not acknowledge the strengths of First Nations Peoples and imposes and promotes a negative narrative interpreted and imposed from a settler privilege perspective. The dominant colonial lens hides the strength of culture, connection to land or community and the health gains of First Nations Peoples.<sup>7 8</sup> Social and cultural determinants of health can facilitate better health outcomes for First Nations Peoples in a public health emergency and focusing on deficits creates exclusion and perpetuates distrust of mainstream health systems, and continues transgenerational trauma, racism and dispossession.

#### Past pandemics and lessons learnt

In 2006, First Nations communities raised concerns about the ineffectiveness of disease control strategies to prevent an outbreak of pandemic influenza, and recommended public health authorities support strategies that made sense for families and communities.<sup>9</sup> Learnings from this work highlighted that whole-of-population response strategies for marginalised, disadvantaged and oppressed populations are unlikely to work, and has potential to cause harm,<sup>10 11</sup> and perpetuate colonisation.<sup>10 12</sup> Public health measures and strategies do not often consider historical experiences that continue to impact on the social and cultural well-being of First Nations peoples. When a dominant population tailors a whole-of-population public health response, their benchmarks may present barriers for minority population groups, who consequently may not be adequately reached, which can further maintain health inequities.<sup>13</sup>

Public health policy and strategies must centre families and value culture, and be informed by First Nations Peoples within a respectful governance model that

reflects First Nations ways of being and doing and “*if you get the process right, the outcomes look after themselves*”.<sup>9 11</sup>

First Nations Peoples were omitted from Australia’s pre-2009 pandemic plan. Consequently, disease control strategies were not tailored to First Nations ways, did not reflect social connectedness of families and communities, or value culture. The 2009 H1N1 pandemic exposed serious gaps in governance and containment strategies, which were implemented without meaningful engagement with First Nations Peoples and therefore caused distrust and scepticism. This highlighted a need for specific plans for First Nations peoples.

Contemporary Australian national<sup>14 15</sup> and state<sup>16</sup> pandemic plans outline the need for equity; focus on priority populations; require health services to consult with First Nations communities in the development of local action plans and acknowledge the importance of two-way communication. However, all plans lack a blueprint for how this could be achieved. There is no single definition of engagement from a First Nations perspective or what such a definition looks like within an Australian context. Although little is published about the effectiveness of engagement strategies, there are drivers of success that are known to work for developing effective relationships with First Nations communities including; understanding historical, cultural and social diversity of First Nations communities; clear information about purpose and intentions of engagement for building trust and respectful relationships and effective governance and feasible timeframes for engagement and deliberation.<sup>17 18</sup>

#### Deliberative inclusive approaches

Citizens are central to effective public health emergency response and are best placed to manage their own risks through practical actions to protect themselves, their families and communities.<sup>19</sup> However, effective public health emergency response can only be achieved through genuine and respectful inclusion and active participation of citizens.<sup>19</sup> Typically, government and biomedically dominated emergency response models recognise citizens as ‘interest’ groups, rather than participants that can make informed decisions and contribute to pandemic planning and responses.<sup>20</sup> Effective citizen engagement during a pandemic is reliant on recognising the legitimacy of and placing value on other knowledge systems and practices across regions and cultural groups.<sup>21</sup>

Citizens’ juries have been used as deliberative inclusive approaches for engaging citizens to make public health policy decisions.<sup>22 23</sup> They are organised like a legal jury, where members of the public come together to thoroughly examine a difficult problem, cross-question experts, discuss the issue, present a verdict and produce recommendations reports intended to influence policy change.<sup>22</sup> The reports are not legally binding, however, juries are an opportunity for public engagement and expression of informed opinions and preferences.<sup>22 23</sup>

There have been a number of studies conducted over recent decades using the citizens' juries model, however, the adaptations for First Nations communities have not been evaluated.<sup>22</sup> Citizens' juries have been conducted with First Nations Peoples in Australia, but have mainly focused on primary healthcare services,<sup>24</sup> and allied health and health promotion.<sup>25</sup> Juries concerned with infectious disease control strategies have not focused on First Nations peoples.<sup>26</sup> There is limited evidence on deliberative approaches in First Nations communities and pandemic response. The terminology of citizens' juries was changed to First Nations Community Panels, to be more strengths-based and reflective of reality.

We aimed to understand from First Nations participants if First Nations Community Panels are an acceptable and appropriate way of engaging First Nations Peoples in making decisions around infectious disease emergencies.

## METHODS

### Study type

We employed a First Nations-led Indigenist research and community-based Participatory Action Research (PAR) approach, a decolonising methodology that challenges the Western knowledge paradigm.<sup>27 28</sup> We adapted the citizens' juries model to incorporate First Nations values, principles and practices into the engagement model.<sup>6 8</sup>

Indigenist research methodology centres First Nations Peoples in the research process, values Indigenous ways of knowing, being and doing and focuses on historical, social experiences and struggles of First Nations Peoples in a culturally safe way.<sup>27</sup> PAR methods are recognised as a culturally appropriate and collaborative way of facilitating community perspectives through an action cycle: planning, acting, observing and reflecting. PAR attempts to bridge gaps existing between top-down approaches to developing policy, and bottom-up community engagement based on community knowledges and values.

'Yarning' is a cultural form of conversation that follows cultural protocols to share stories and knowledge and is a unique way for First Nations Peoples to connect to each other.<sup>29</sup> Yarning (shared talking and listening) has been used as a decolonising data collection tool to centre Indigenous worldviews and experiences.<sup>28</sup> We used multiple yarning techniques throughout the Panel process: research yarning, social yarning, collaborative yarning and therapeutic yarning.<sup>29</sup> We moved between all four yarning types throughout the Panel meetings. 'Research yarning' framed the discussion process to gather information through participants experiences and stories,<sup>29 30</sup> and was weaved throughout all sessions to understand if the Community Panel process was a good way for community to have a say in pandemic planning, and to share their experiences of the Panel process.<sup>29</sup> 'Social yarning' was used to hear people's experiences of pandemics during the prepanel yarning sessions. 'Collaborative yarning' occurred often throughout the Panel meeting, where participants explored and shared ideas

together, which often led to individuals adjusting their view or preferences. Participants had opportunities to share personal stories and experiences that were sometimes traumatic or emotional, and 'therapeutic'.

### Study settings

Face-to-face First Nations Community Panels were held in two geographically distinct communities in New South Wales and Queensland in 2019, using a hypothetical scenario of how best to distribute pandemic influenza vaccinations. These Community Panels were held on 2 days, 1 week apart in a location convenient for the community as identified by a local First Nations health worker.

In 2020, we implemented a First Nations Community Panel virtually via Zoom in three communities (New South Wales, Queensland, Western Australia) to explore ways to keep First Nations Peoples safe from COVID-19. The virtual Community Panels explored three topics, held over 2 days a week, for 3 weeks.

Two First Nations researchers facilitated the Panels. A non-First Nations public health clinician was present in the sessions for questions or clarification on the issue.

### Community Panel recruitment

First Nations Peoples were best placed to identify and invite potential participants.<sup>31 32</sup> To ensure broad and inclusive community involvement, the research team engaged with First Nations stakeholders at each site and sought their input and advice to ensure relevance for the community. We engaged and worked with local First Nations health workers to purposively recruit participants through cultural networks, to distribute informative flyers about the Panels and to consider age, gender, family position and household size of potential participants. Community leaders also identified people to join the Community Panel.

Participants were compensated for their time. Eleven experts recruited according to professional roles and knowledge of the field relevant to the topic provided evidence-based information to Panels as prerecorded presentations.

### Community involvement and engagement

The project team engaged the local Aboriginal Community Controlled Health Services and First Nations community representatives to discuss the issue and gain understanding if the topic was of relevance or a priority. The team engaged with community members and leaders before, during and after the study. Yarning is recognised as a culturally appropriate methodology,<sup>29</sup> and was used as a way to understand community priorities, preferences and experiences. Together, with the researchers, the participants produced a recommendations report, with suggestions for dissemination.

### Community Panel facilitation

Community Panels were facilitated by at least two First Nations researchers, in collaboration with a local First

Nations health worker. A Community Panel programme plan was developed to support the facilitators to deliver the Community Panels, outlining the panel process, structure and timing for each meeting.

### Community Panel process

A five-step process used traditional approaches of collective decision-making and yarning as key elements to understand local contextual issues (box 1), involving a prepanel process, 1 day of evidence (prerecorded expert presentations), a second day of deliberation, a follow-up yarning session and production of a final recommendations report. The Panels had the opportunity to phone or videoconference an expert if more information was required to form a decision on the questions they were being asked to respond to.

### Data collection and analysis

All participants received a Participant Information Statement and provided informed written consent prior to the Panels. Panel meetings were digitally recorded and/or video-recorded (via Zoom), and notes taken. Recordings were transcribed by an external transcription service for analysis by the research team. Qualitative thematic research methods were used. At least two First Nations researchers and one non-First Nations researcher conducted data analysis. Main themes and subthemes emerged from participants experiences, perspectives, opinions and preferences of appropriate engagement approaches to pandemic planning and responses. Action themes were identified as important references to suggest ways for government and health authorities to move beyond rhetoric to the reality of actioning and privileging First Nations Peoples voices in pandemic planning and responses.

Participants identified and weighted key issues according to importance, preferences and priorities. Yarning circles were used to gauge experiences and perceptions of the Panel process; what they liked, did not like and to assess if participants felt they had an opportunity to contribute to real decision-making.

Participants engaged in small group work before, during and after expert presentations to record their positions on each issue. Online surveys were used throughout the virtual Panel sessions to record participants' positions.

Participants had opportunities to include local community feedback in the final report. Follow-up yarning sessions took place after the final deliberation day to seek clarification and final input on the Panels' positions. A final recommendations report was produced, summarising panellists' perspectives and decisions on each key issue.

## RESULTS

### Participant characteristics

We conducted five First Nations Community Panels across Australia between September and November 2019, and

## Box 1 First Nations Community Panel process

### Step 1: community engagement

Engagement with the local Aboriginal Community Controlled Health Organisation in each area and with community representatives to discuss the topic and gauge knowledge and understanding. Engagement with community members took place before, during and after the study.

### Step 2: prepanel yarning session

Panel members were invited to attend a yarning circle scheduled the night before the first panel session. Prepanel yarning provided an opportunity for participants to meet one another and the research team, and informally discuss the topic and share their experiences. Panel composition ranged from 7 to 11 participants per Panel.

### Step 3: evidence and deliberation days

Day 1: evidence day

1. Panel sessions commenced with an acknowledgement of country, welcome and introductions, an icebreaker activity, followed by an orientation session outlining the process, the topics and questions and confirmation of participant consent.
2. Panel members received a booklet with information about the research team and expert presenters, the panel process and questions for panel members to consider and respond to.
3. Participants listened to evidence from expert presenters via pre-recorded presentations. Experts were First Nations and non-First Nations contributors in positions including but not limited to a public health professor, epidemiologist, clinical nurse consultant and paediatric infectious disease specialist. A different topic was presented each week.
4. Panel members engaged with the experts following their presentations with questions and opportunities to challenge or seek clarification about the presented evidence. For face-to-face panels, the experts were available by teleconference call and the virtual panels engaged using virtual technology.
5. Small group activities were incorporated throughout the sessions to elicit discussion and work through panel member questions.
6. Time was allocated between the evidence and deliberation sessions for panel members to 'yarn' with their families and communities about the topic, to enable family and community voices in the decision-making.

Day 2: deliberation day

1. Panels reconvened to discuss the community feedback, come to a consensus, and draft a recommendations report with the research team.
2. For the pandemic influenza vaccine scenario panels, members were presented with evidence, and 2 weeks later the research team visited the panels to deliberate which allowed time for family and community feedback.
3. For the COVID-19 virtual panels participants met twice a week for 3–4 weeks.
4. Participants received a 'Yarning with mob: your voice, your decisions, your way' take home pack, which is a way to encourage participants to 'yarn' about the issue and discuss the panel questions with their families and communities. The take home pack included a set of questions for participants to initiate conversations, and expert presentations.

### Step 4: follow-up yarning session

Check-in session/s were held to understand if the panels changed their position following the evidence and deliberation days.

### Step 5: production of a final recommendations report

Panel co-facilitators, in collaboration with the panel members produced a recommendations report to submit to health policy decision-makers for consideration.

September and December 2020, with a total of 40 participants (2019, n=18; 2020, n=22). The Panels included participants from a range of age groups and most participants were women (31/40). Panel composition ranged between 7 and 11 participants per Panel.

All 40 participants from the five Panels verbally indicated strong support of the First Nations Community Panels approach as an effective way of engaging First Nations Peoples in making decisions about pandemic planning and responses.

Key themes that emerged were centred on the principle that First Nations Peoples are important in the context of continuation of culture, connection to country and ongoing political resistance. The stories, shared experiences and collective wisdom of the First Nations Community Panels can be understood under the overarching theme of respect, and through two main themes: 'First Nations ways are important' and 'Trust'. Respect is a foundation for good relationships and expresses human rights in honouring the unique value of each person and diversity between people.<sup>33</sup>

Six subthemes of *'First Nations ways are important'* emerged:

1. *'Self-determination'* enables First Nations Peoples to have control over aspects of their health. Participants emphasised the need for real commitment and a shift in power-sharing. First Nations lives, families, communities, voices and decisions are important, and must be empowered to exercise autonomy over their health. This can be achieved if government health departments *'support and resource [First Nations] communities towards 'self-determination', 'self-sufficiency' and 'self-management' in preparation for pandemics or other disasters impacting on communities'*.
2. There was a sense of *'ongoing resistance'* to challenge current public health policy that reflect social realities of First Nations lives; *'make noise and be proud and loud'; "We are still stuck in policies around assimilation...policies are not reflective enough of the [First Nations] context or experience... There needs to be some exclusivity...in recognition of our First Nation's status as the First Nations People..."*
3. First Nations Peoples continue to thrive because cultural knowing, kinship systems and good *'governance'* and pandemic plans and responses must focus on First Nations best practices that reflects local cultural protocols, family, protects elders, is community-controlled and community-based and strategies that make *'... practical sense to prevent and have a lot more preventative programmes, which is what the community came up within the first instance in their concept of primary health'*, as First Nations Peoples have *"always wanted to do things for ourselves...and have that opportunity for...communities to have control and be able to not only recognise what issues are important, prioritise which ones they want to tackle first..."*
4. Systemic racism exists within the health system. Participants openly shared their experiences of discrimination and the ongoing impacts of discriminatory government legislation and practices on their health

and well-being. *'Equity and First Nations rights'* as a sub-theme recognises that First Nations communities must be prioritised and adequately funded, resourced and supported to enable the opportunity and the right to access fair, equitable and culturally appropriate healthcare.

5. The strength of First Nations Peoples lay in the *'Connectedness; families, communities, culture, holistic'* and that approaches to pandemic planning and responses and policies must value First Nations culture and ongoing connection to each other and be *'driven about working in two-worlds and two-ways'*.
6. First Nations Peoples must *'be involved in those decision-making processes'*. Participants highlighted that First Nations Peoples are often mentioned in local, state and national pandemic plans and responses and are recognised as being central to service delivery, however, this does not often translate into practice. There is a real *'strength of inclusiveness'* when First Nations Peoples are prioritised and given opportunities to participate in the development of pandemic plans and policies that is informed by the context and experiences of First Nations communities.

We're often the forgotten ones...and it's times like this, it really shows how under-resourced and how forgotten we are. Out of sight, out of mind when it comes to any kind of strategies, and...here we are. We're doing this after the fact. That's not what our health definition is. We want to stop our mob from getting sick.

An action theme emerged from the six subthemes above, offering a way to engage in understanding of histories, struggles and strengths through *'communication as a two-way learning'*, where the dominant culture gives up space and time and really listens so that First Nations Peoples can freely share knowledges and perspectives.

Four sub-themes of *'Trust'* emerged:

1. Understanding that First Nations Peoples have an ongoing connection to the *'past, present and future; as a continuum of time'*. The movement over this continuum is fluid and evolving, and must be acknowledged, valued, respected. This means learning and listening to the *'past'*, changing today (present) to create a better tomorrow (future).
2. *'First Nations ways work'* because of *'cultural knowledge and community connections', 'ways of sharing knowledge and storytelling'* and it is through good governance structures where First Nations Peoples actively participate in real and meaningful decision-making, and exercise true leadership, empowerment and autonomy.
3. *'Fear and trust balance'* is always going to be challenging because historical influences and negative relationships with government authorities. This has led to fear of the unknown with pandemics, which can lead to fear and distrust in the government because of the perceived deception or withholding information; *'Health authorities telling individuals what to do, but not telling them why'*. Trust is essential for decreasing fear

and enabling two-way and open and transparent communication and *'have information that is clear, consistent and reliable and not scaremongering or instilling fear in people'*.

4. *'We therefore need understanding, together'*, where First Nations values and principles are given real priority, and First Nations Peoples determine the way.

An action theme emerged from the four subthemes above, with the understanding and trust that First Nations ways work, therefore *'privileging First Nations voices to drive system change'* is important and must participate fully in shared decision-making through culturally appropriate governance structures.

### Engaging First Nations Peoples

Participants found the Community Panel process engaging. For many, this was the first example of *'authentic engagement'*. Participants expressed that Panels should be a *'general rule'* for engaging with First Nations Peoples and a *'very important process for [First Nations] people to be aware of'*. The work highlighted the importance of government authorities working better with First Nations Peoples through shared-listening, shared-understanding and shared-respect:

Government should be respectful of [First Nations] ways of being, and adjust the way of how we live, and respect diversity of communities, by listening to the community on cultural and community processes and protocols.

All panels identified that systemic racism exists within the Australian health system and broader government. The questions presented and subsequent Panel discussions, brought up trigger points for participants who openly shared their experiences of racism from past and current government legislation and practices. The discussions, strategies and decisions highlighted power-imbalances between First Nations Peoples and government decision-makers.

We are still stuck in policies around assimilation....policies are [not]...reflective enough of the [First Nations] context or experience. There needs to be some exclusivity for [First Nations] People in recognition of our first nation's status as the First Nation's People of this world.

Participants stressed the importance of health policies being inclusive of and valuing First Nations People's worldviews and knowledges, that are informed by cultural protocols and values, and the context and experiences of First Nations communities; *"we are not...an interest group...we are traditional owners from all over this nation"*.

Participants felt the Panel gave them a voice, *"whether or not [policymakers] take on what we say, at least we know that we've put our points across"*, and felt they were proactive in engaging in discussions and decisions and to *"do what's best for [our] people and...community"*. One participant said, *"no one ever comes back and asks us how could we do it better, how could we help you to look after your mob better...I've never had anybody come back and ask 'what's your input?'"*

There was a sense of scepticism about government authorities listening and questions about *'whether or not policy makers want to listen to the words of First Nation[s] People'*, however, there was more trust because the Community Panel approach was led and facilitated by First Nations people, *'it is...important about who the messenger is'*. Some participants were wary of the process at first and wondered if the research was a way of *'setting us up for something...to be the scapegoats if something goes wrong, but [felt it was] more creating the opportunity...to have input and a say...and getting community views...[and] for [community] to learn about the process'*.

However, there was genuine trust and hope for uptake of recommendations because there are First Nations Peoples at the table in leadership positions representing participants *'up the top...chucking tantrums to make them listen'*, and if policymakers did not take on their recommendations, Panel members were confident they were proactive in getting their points across and doing what is best for their people; *"We're making decisions on contributing towards policy development based on evidence, practical evidence in the community. Not evidence on paper where decisions inside a board meeting, within four walls"*. There seemed to be more trust in this engagement process because there was a genuine space and time given to participants being proactive in putting their voices and points across *"to do what's best for our people and our community"*.

The bigger picture is that we finally have a voice to do something, to be at the forefront, but at the beginning of this, not the end, add-ons, and we are making decisions and making recommendations that will help our people.

[I] actually believe that this process will go towards that... because I've sat on many things like this, and it goes nowhere, but I have got a sense that this will go somewhere, and that it will help our people in what happens if a pandemic in this area. And we have the leaders...to move it forward.

Despite some hesitancy, participants trusted the process, and there was hope that First Nations Peoples would be heard, and their decisions were *'not just going to sit there, [and] fall on deaf ears and [their voices] go nowhere'*. One participant suggested this way of working is genuine engagement and *"good to see proper consultation, giving us time to think about things and re-evaluate it in our own heads, and with our families and communities, because this kind of engagement doesn't happen"*.

Feedback on the Panel process indicated that they: enabled grassroots perspectives; empowered community to understand how they can make changes and that when there is real investment of time into good engagement that the *'outcomes look after themselves'*. There was a real sense of pride to be able to share knowledge and understanding with family and community; *"we are trying to do what's best for our people and our community"*. Panel members felt it was an *"enjoyable experience...we share so many sorrowful things but happy things too. This is a very important process that"*

*we want our Peoples to be aware of...it's this community involvement [that] is precious".*

### Panel design, structure and format

The design of the Panels enabled participants to work together in a “*safe environment and...able to speak freely... [because] we connect...understand...and [are] able to have a say but...to make sure that community [also] has a say*”. Incorporating a cyclical engagement process appeared to be a key element of why participants felt safe in this space. Developing and maintaining respectful and trusting relationships was essential and allowed for open discussions between participants and researchers. Participants emphasised the central importance of First Nations Peoples delivering the sessions in a format that seeks and enables active engagement. Participants reflected on the process and identified that an interactive approach through yarning and small group activities allowed participants to review, reflect and seek points of view from their peers. Additionally, participants enjoyed the communication and cooperation evident in the Panels.

*...the process is...good with the repetition of the questions, making us come back and look at it again and reflect... there are different things that we learn and there are different people we talk to, so we come back with sometimes a different point of view....*

Although some participants stated that face-to-face sessions were better than virtual, the latter was acceptable given travel restrictions and provided a medium with potential to reach more people.

Participants said they felt safe voicing their opinions and ideas in small group activities and did not feel pressured or intimidated to go with group consensus; *‘small groups is far less intimidating...as opposed to sitting at a large table, it wouldn't be as interactive...’* and *“you didn't feel pressured...to go with general consensus, there was still a safety in numbers that you could share your opinion”*.

Participants identified the content of expert presentations was in language that could be understood, increased knowledge and awareness on the issue, and provided context to make informed decisions, although *‘it did not make their decisions any easier’*. The presence of an expert in the meetings was appreciated to clarify questions, speak to concerns and contribute to discussions. Hearing information from the experts enabled participants to develop deeper understanding prior to decision-making. One Panel felt a strong obligation and responsibility to feed back the information to their community.

### Suggestions for improvement

Participants provided suggestions on ways the Panel process could be improved:

- ▶ The ‘yarning with the mob’ take home resource could be communicated better in plain language to be more relatable for and enable deeper interaction with communities, however, some questions with examples (such as Black Lives Matter) helped initiate conversations with families.

- ▶ There was 1 week in between the ‘evidence day’ to the ‘deliberation day’ for the face-to-face panels’, in which participants felt was insufficient time to engage their families and communities.
- ▶ More face-to-face interaction with experts as opposed to phone calls, and for more visual and interactive expert face-to-face and online presentations.
- ▶ Online panels consisted of ‘evidence day’ and ‘deliberation day’ in the same week. Participants suggested that online panels could be scheduled to allow a week for participants to engage in community conversation about the issue.

All Community Panels stated the importance of having a diverse group of individuals representing communities

*Given the fact we have a diverse group of people, from different walks of life, different levels of health education, histories and lived experience, everyone comes with a different perspective, and have been able to share their perspectives respectfully, and it then helps give us as individuals more insight and challenge our own ideas, and to look deeper to other ideas than what we would have to start with.*

Although the research team made efforts to identify and recruit a diverse range of people, there was a gender imbalance which participants felt strongly should be addressed.

### DISCUSSION

While we continue to experience the COVID-19 pandemic, it is imperative to understand the opinions and preferences of First Nations Peoples in the ongoing implementation of Australian public health advice and guidelines. Decision-making during a pandemic must be evidenced-based, however, unless asked, policymakers can only assume the opinions and values of First Nations Peoples and are therefore likely to continue to develop and implement public health policies that do not align with or support First Nations health or cultural values. Our study shows that First Nations Community Panels allow for deeper understanding of real and contextual issues with First Nations Peoples, based on shared decision-making, shared understanding and mutual responsibility. This form of engagement highlighted strengths of a process that enabled participant understanding and deliberation, cross-questioning of experts and supported community yarning.

Participants valued opportunities to change opinions at multiple points. One-off ‘consultations’ often seek to get answers and responses from First Nations communities at one point in time, however, we found the Community Panels process enabled people the chance to grow their understanding, knowledge and confidence and not get ‘stuck’ on their first thoughts or opinions. This way of engaging with First Nations Peoples may have been an unfamiliar space for participants as a different way of working, with genuine interest of researchers to understand preferences and values. This research reinforces



how valuable and important it is to get the process of engagement right with First Nations Peoples, and how values of respect, ways of working, culture, deep listening and determination to change things for the better, now and in the future.

Applying an Indigenist framework and PAR approach informed by First Nations researchers enabled raw and open discussion as well as control of all aspects of the research process. Parts of the PAR process proved to be important for participants; in developing trust; providing immediate feedback; making changes to the process following feedback and the research becoming health action with contextual issues and strategies potentially embedded into national guidance. This research demonstrates that listening and taking the time to build understanding of the social realities in a governance structure that enhances active participation in conversations, that values culture and privileges First Nations Peoples' voices, does promote trust and two-way learning. Further research is needed to understand the perspectives of public health organisations, funding bodies, government health authorities and if this model could be used at a broader, national scale.

This research takes a strengths-based engagement approach with First Nations Peoples by rejecting focus on deficit approaches, that is usually developed and implemented by non-First Nations researchers. Indigenising the citizens' juries model enables First Nations worldviews and priorities to be explored and interpreted from a First Nations lens. This research seeks to promote protective holistic health and well-being factors over a continuum of time (past, present, future), acknowledging the innate connection to culture, land and people. The Panel design, and implementation strategies, aligns with cultural protocols with specific focus on ensuring it is community controlled and seeks proactive ways of collaboratively working with First Nations Peoples and communities.

Although three First Nations communities in Australia participated in the research, we found commonalities across the Panels related to shared histories of racism, ongoing impact of colonisation and desire to care for community. Therefore, generalisation of the findings in this context is not necessary, rather transferability of the findings is more pertinent. The methods used in this study means this model of engagement with First Nations communities can be transferred to other settings and adapted to context, and local needs and priorities. Additionally, a lack of prior engagement on pandemic strategies meant there was no strong knowledge base to form our methodologies, which became a strength of the study through this journey of learning together.

This model of engaging First Nations Peoples was developed, and determined by First Nations Peoples, in consultation with non-First Nations peoples, whereby First Nations Peoples centre themselves within the narrative. This model aligns with the principles of expert elicitation through informed judgement and support of

structured decision-making in the development of public health policy,<sup>34 35</sup> through effective engagement with citizens' and health authorities. This model can be used and modified by other First Nations Peoples where there is mutually respectful and trusting relationships with communities.<sup>20</sup> Engaging First Nations Peoples using the Community Panel approach could provide better outcomes, when culturally appropriate processes are in place, and could be implemented as a standard approach to pandemic planning and responses. Our research has shown it can be embedded into government public health emergency response.

## CONCLUSIONS

First Nations Peoples of Australia are recognised as a priority population, but despite targeted pandemic responses, continue to experience ongoing health inequities which stem from Western centred pandemic policies and responses. First Nations Peoples' experiences, values and perspectives need to be embedded into disease control strategies and responses, which can be achieved on a foundation of good governance. This research suggests that First Nations Community Panels appear to be a process that works for effectively engaging communities in decision-making about infectious disease emergencies and offers a way for government health authorities to work collaboratively with First Nations Peoples, in two-way learning, understanding and communication in the design of public health policy.

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