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## **“It puts a human face on the researched”**

### **A qualitative evaluation of an Indigenous health research governance model**

#### **Abstract**

- Objective:** This study aimed to describe the Inala Aboriginal and Torres Strait Islander Community Jury for Health Research, and evaluate its usefulness as a model of Indigenous research governance within an urban Indigenous primary health care service from the perspectives of Jury members and researchers.
- Methods:** Informed by a phenomenological approach and using narrative inquiry, a focus group was conducted with Jury members and key informant interviews were undertaken with researchers who had presented to the Community Jury in its first year of operation.
- Results:** The Jury was a site of identity work for researchers and Jury members, providing an opportunity to observe and affirm community cultural protocols. Although researchers and Jury members had differing levels of research literacy, the Jury processes enabled respectful communication and relationships to form which positively influenced research practice, community aspirations and clinical care.
- Discussion:** The Jury processes facilitated transformative research practice among researchers, and resulted in transference of power from researchers to the Jury members to the mutual benefit of both.
- Conclusion:** Ethical Indigenous health research practice requires an engagement with Indigenous peoples and knowledges at the research governance level, not simply as subjects or objects of research.
- Key words:** ethics, community engagement, research governance, Aboriginal and Torres Strait Islander peoples

## Background

While interest in Indigenous health research has grown in recent decades, its inglorious history<sup>1</sup> has often left Indigenous Australians feeling exploited.<sup>2-8</sup> At worst, research acted as an overt tool of colonial control espousing and enacting racial pseudoscientific theory and, at best, Aboriginal and Torres Strait Islander peoples, communities, aspirations and realities were ignored.<sup>9,10</sup> Little attention was given to the need for Indigenous people to own, drive and benefit from health research. This agenda emerged more recently through the introduction of national guidelines for ethical research in Aboriginal and Torres Strait Islander health, which promote Indigenous community ownership, consent, control and engagement through principles of respect, reciprocity, responsibility, equality, survival and protection as well as spirit and integrity.<sup>11</sup> These guidelines provide encouragement for greater and more respectful inclusion of Indigenous people in research, although they can result in the procedural observance of rules or tokenistic gesturing to appease human research ethics committees.<sup>12-15</sup>

The push towards meaningful engagement of Indigenous people and communities in research has spawned an emerging literature describing more precisely how this can be achieved.<sup>16-20</sup> Despite this, defining 'community' remains problematic. The diverse and dispersed nature of urban Indigenous communities may make consultation with 'community' challenging. Accessing a broad range of community members through appropriate Aboriginal organisation(s) is therefore recommended, as is giving Indigenous people the opportunity to contribute to guide and monitor the research.<sup>21</sup> Non-Indigenous researchers identify the need for greater guidance around navigating community politics<sup>6</sup> while concerns have been raised about conceptualising 'community' in these endeavours and the assumed capacities of communities to participate.

The Southern Queensland Centre of Excellence in Aboriginal and Torres Strait Islander Primary Health Care (Centre of Excellence) has grappled with many of the tensions articulated in the literature. Established as an Indigenous primary health care service in Inala (an outer western suburb of Brisbane), the service provides primary health care, specialist clinics, allied health and community engagement initiatives,<sup>22</sup> but also has an expanding research program and profile.<sup>23-27</sup> Despite being an 'Indigenous' health service the Centre of Excellence is government run, thus intensifying the imperative for a local Indigenous community governance model for health research within the community. The Centre of Excellence established the Inala Community Jury for Aboriginal and Torres Strait Islander Health Research in 2011 to ensure that the research undertaken by the service was in the community's interests and that the assessment of 'community interest and benefit' would be determined by the local Indigenous community.

Conceptualisation and development of the Community Jury was shaped by a process called 'Citizens' Juries' and/or 'deliberative democracies'.<sup>28,29</sup> While common in the US and UK, Citizens' Juries have had limited applications within health research contexts in Australia. Citizens' Juries enable 'lay' involvement in decision making processes that directly affect them and usually involve a randomly selected broad cross-section of the community considering evidence from 'experts', much like a traditional jury. Social justice is a central goal of citizens' juries, in that non-specialist knowledge is valued, particularly from citizens previously excluded from participating in traditional decision-making processes.<sup>29</sup> It was this goal that was most alluring to the Centre of Excellence, given the historical and contemporary context of Indigenous engagement in and governance of health research. Given that citizenship is a relatively new concept for Indigenous Australians, the Centre for Excellence elected to use the term 'Community Jury' in lieu of 'Citizens' Jury'. This nomenclature was also endorsed by the Jury members at the inaugural Jury meeting.

#### *The Inala Community Jury Model*

The Community Jury comprises of 14 Aboriginal and Torres Strait Islander community members; representatives of the four local Indigenous community controlled organisations and 10 members who were purposefully selected following a call for expressions of interest to ensure a mix of ages, gender and both Aboriginal and Torres Strait Islander members. Independently facilitated, Jury members are paid for their time and review all research being undertaken by or with the Centre of Excellence prior to its proposed commencement and/or development. No research can be undertaken at or through the Centre of Excellence without being approved by the Jury, and although the Jury process is supplementary to existing ethics requirements, the local Human Research Ethics Committee will not approve a project that has not been approved by the Jury.

Jury meetings are convened quarterly for between four and seven hours. Researchers are required to present directly to the Jury at these meetings with a one-page brief supported by an oral presentation and approximately one hour for discussion. The researchers explain, in lay terms, why the research is being done, the methods being used, and how the research will benefit the community. Jury members question the researchers about any aspect of the research to be confident that the research will benefit the community and that the burden of participation (if any) is warranted. Researchers return to the Jury on completion of their research and report back their main findings with updates provided to each meeting in the interim. Researchers may also engage with the Jury for help resolving specific aspects of the research, for example, recruitment strategies. If the Jury is supportive of a proposed research project, a letter of support signed by the Chair of the Jury is provided to the researchers. If a research proposal is not supported, the research

cannot progress, however researchers may return to the Jury with a revised proposal for review.

## **Methods**

This study aimed to evaluate the usefulness of the Community Jury as a model of community governance and engagement from the perspectives of Jury members and researchers. This study did not aim to evaluate the Jury according to predetermined markers of success. Rather, the study is informed by a phenomenological approach in which “human perception, not external influences or objects in the material world...is at the core of the analysis”.<sup>30 p.181</sup> Thus the study elucidates the value of the Jury model from the narrative accounts of those participating in the process.

### *Design*

The study used narrative inquiry to explore the impact of engagement between researchers and community members as they described their experiences of Jury participation. Narrative inquiry works with “people’s consciously told stories, recognising that these build on deeper stories of which people are often unaware”.<sup>31 p.209</sup> Researchers were asked to recount their experiences of engagement with the Jury, and the strengths and challenges of the model of engagement in terms of how it influenced their practice. The Community Jury focus group explored Jury members’ motivations for joining the Jury, experiences of the process, alongside challenges, strengths and recommendations for the model. While there were broad domains of inquiry, the research instruments remained largely unstructured to enable participants to tell stories that were meaningful for them.<sup>32</sup> Support to undertake this study was provided by the Community Jury, and ethical clearance was obtained from the Metro South Human Research Ethics Committee.

### *Participants and data collection*

Of the 12 researchers who had presented to the Jury in its first year of operation, nine were invited to participate in this study to represent a broad cross-section of researchers participating in the Jury processes. The types of research undertaken during this time included quantitative and qualitative, clinic and community-based research in areas as diverse as antenatal care, inhalant use, nutrition, dietetic services, social prescribing by GPs, and childhood developmental and behavioural problems.<sup>25-27, 33</sup> During the time of this study, the jury endorsed all the research that was presented, but not necessarily at the first presentation or without revision or amendment. No researchers refused to participate. Six of the researchers were also clinicians (either based at the Centre of Excellence or elsewhere) while the remaining three were full-time researchers. Two of these researchers are co-authors (CB and DA), and one is Indigenous and a Jury facilitator (CB). Interviews were conducted by authors CB and WF.

All Jury members were invited to participate in the focus group, which author WF conducted after a Community Jury meeting. All members in attendance at the meeting (n=12) elected to participate. All participants provided written consent prior to data collection. The focus group and the interviews were audio-recorded with participant consent and transcribed and de-identified prior to analysis.

We acknowledge our multiple subject positions as both insiders and outsiders (as researchers, Indigenous community member, employees of the Centre of Excellence, Jury participants and jury facilitator). While there are benefits to our insider status in terms of “generating contextually embedded knowledge that emerges from experience”<sup>34 p.60</sup> we consciously sought to minimise bias in data collection and analysis. WF conducted the Jury focus group because she did not have a role in coordination or facilitation of the Jury. Further, researchers were interviewed by either WF or CB, depending on which interviewer had had the least prior contact with the researcher. Two researchers from within the Centre of Excellence research team were not invited to participate in this research to minimise the over-representation of the internal research staff. ~~During the analysis process, the findings were presented back to both Jury members and researchers for member checking; of which all concurred with the results.~~

### *Analysis*

Authors CB and WF collaborated to organise the data according to the broad domains of inquiry in relation to the strengths, challenges and recommendations for improving the Jury model. All transcripts were coded together using NVivo version 9.<sup>35</sup> In analysing the data according to these themes, the research team identified that there was little demarcation between ‘strengths’ and ‘challenges’. The challenges of the model provided opportunities for learning and reflection which were then recounted by research participants as strengths. Thus, further analysis was undertaken within the research team to explore the key narratives that emerged in terms of the usefulness of the Jury model as stated explicitly and implicitly within participants’ accounts.

Despite our attempts to minimise bias in data collection, we acknowledge that our relationship to the research participants and the Community Jury may be seen as problematic. However, the relatedness of the researchers to the participants and the research governance model enabled the capturing of nuances in the narratives of both researchers and community members. -During the analysis process, the findings were presented back to both Jury members and researchers for member checking; of which all concurred with the results.

## Results

~~We found two distinct narratives which essentially~~ Researchers and Community Jury members' narratives told two different, but interrelated 'stories' of the usefulness of the Community Jury as a model of Indigenous community governance of health research. The benefits that Jury members and researchers derived were not limited to the Centre of Excellence's goal of an Indigenous community controlled health research agenda but nonetheless were complimentary to that task. Both parties articulated experiences of strength, benefit and usefulness that related to personal, collective, professional, cultural and/or clinical practice. Incorporated in this analysis are the first author's reflections as a researcher, facilitator and local Indigenous community member, and are presented here to highlight the intersecting nature of these tasks.

### *Engagement as a site for identity work [personal and community]*

For both Jury members and researchers, the Community Jury operated as a site for important identity work in terms of both personal and broader community identity. The Jury provided the opportunity to have one's identity affirmed, either as an Indigenous person and/or as a researcher working in Aboriginal and Torres Strait Islander health research. For one Jury member, participating in the Jury was an opportunity for greater Indigenous community contact, thus enabling a confirmation of his cultural identity and improvements in his overall wellness. In terms of his motivations for participation, this identity work appeared to have primacy over the health research agenda.

*I joined because for years...I wasn't involved in the Aboriginal movement... And I said to my wife, "I feel like I need that black contact" because there was something missing in my life. And that [the Jury] kind of filled me up, and I feel much happier for it now.*

Jury member - Aboriginal Male Elder

Other Jury members described how the Jury provided a mechanism for them to be 'active' within their community and perform their community duties. Meanwhile for researchers, the Jury processes provided security in their own identity as researchers working in an Indigenous health context. This was particularly important as eight of the nine participating researchers were non-Indigenous, and conscious they could potentially subjugate Indigenous voices and aspirations through research.

*So being new, coming in, as a non-Aboriginal person and then thinking..."Oh God, they're probably thinking who's this non-Aboriginal person coming to do research again?" So that was in my mind. And after the meeting and them being so lovely and*

*accepting of me ...and feeling like they were approving my research...I remember thinking at the time of the Community Jury, "this is actually quite good". Like, of course, "Who am I to think I can just go in?"*

Researcher – Female Allied Health Professional

Engaging in discussions with Jury members, receiving guidance and eliciting support from a broad cross-section of the local Aboriginal and Torres Strait Islander community represented on the Jury increased researchers confidence in working in this space, and in the relevance and importance of their research. For the Indigenous researcher, the Jury provided a platform for her professional identity to be discernible within her own community.

*I've always felt living in this community as a researcher; the essence of who I am professionally is really at the background because it doesn't make sense to most people that I engage with socially. What I like about the Jury is it allows me to yarn with my own mob about the stuff that I love doing... I can 'out' myself as a researcher...*

Researcher and Indigenous community member

Jury members' narratives also revealed the important community identity work that was undertaken through Jury meetings. Jury members spoke about Jury participation as an opportunity to 'represent' community interests, but also acknowledged the obligation they felt to 'respond' to community interests as a result of Jury participation.

*I talk to family about it and I talk to work colleagues, working in Indigenous organisations...It depends on the topic. So where I work if I'm dealing with young Indigenous women who have recently fallen pregnant, I'll say, "Oh, I've heard there might be a program going on at the medical centre. Go and ask about this or that"*

Jury Member - Middle Aged Aboriginal Female

Jury members readily identified the importance of representing the community strength to visiting researchers. These efforts were witnessed in researcher accounts and reconfigured their pre-existing imaginings of the community. A number of researchers recounted stories of being approached by Jury members to clarify the findings from particular research projects so that they could spread the word within the community. For example, an antenatal study revealed local women were taking iron supplements early in pregnancy but not folate.<sup>27</sup> A group of senior women sought clarification on what advice they should be giving young mothers with regards to increasing folate intake pre-conception and in early pregnancy. Being approached in this manner proved powerful for researchers, particularly among those who were clinicians within the service, as their primary encounters with



Indigenous people are with individuals who are sick and at their most vulnerable, thus distorting the imaginative possibilities of Aboriginality and of the local community.

*And you can sometimes get a sense in the clinic that the community is a bit disengaged and don't really want to do anything with their health. I've tried very hard to quell my own nihilism in those types of consultations but it was a really positive injection of optimism and activism that this Jury gave me. And I felt really energised and I think it really has helped back in the clinic"*

Researcher - Male General Practitioner

The opportunity to engage with local community members as a collective and cohesive group who is invested in health advancement, enabled researchers to rethink their own imaginings of the 'community identity' and think critically about how these were enacted in research and clinical practice. Most researchers spoke of their surprise at appearing before a Jury of community members who each appeared strong physically and culturally, individually and collectively. The community identity work undertaken by the Jury was transformative for researchers, with the local Indigenous community reconfigured from passive, ill, subjects of research to active, engaged and healthy citizens.

*Learning to talk and learning through talk*

The power of yarning was a key theme to emerge in the narratives of researchers and the Jury members. Experiencing respectful talk was important to Jury members and was witnessed when researchers acknowledged Country, showed signs of nervousness, and spoke to Jury members in a way that they could understand. Not being spoken 'down to' was the basis of respectful engagement and empowering encounters.

*We're not told, we're not spoken down to like it's not a regimental thing or it's a "we're above you, you black fellas in Inala, we know what's best for you". It's not like that, it's empowering us to empower ourselves.*

Jury Member - Young Aboriginal Male

Jury members spoke of having to get researchers to speak 'their' language and stated that they were quite comfortable in asking researchers to adjust their terminology. These manifestations of respect enabled a safe space for Jury members to freely ask questions of the researchers. Researchers were aware of differing levels in general health and health research literacy, particularly as the research team usually needed to edit the one-page briefs prior to submission to the Jury to ensure their accessibility for a 'lay' audience. Upon reflection, some researchers questioned whether the lack of health research literacy of Jury members was a barrier to

meaningful engagement, however it seemed that this ‘barrier’ was also an enabler to more meaningful understandings of the community attitudes, values and knowledge [of a particular health issue](#).

*I would know that now going in, that I would need to informalise my terminology whereas I almost came expecting them to know what an [allied health professional] was....And actually speaking to them in the Jury meeting and asking questions about “Well, hang on you want to do this research, but what do you do?” ...And I was like, “Oh hang on, I hadn’t even thought of that”...They don’t need to accept the research but they have to accept what a [health professional] is in this community... I found I wasn’t talking about the research, it was talking about who I was and I think even where I was from before working there, so it was a lot more than just the research...So always in the beginning of my consultations now I ask them [patients] “What do you understand about me being here for you as an [allied health professional]?”.*

Researcher - Female Allied Health Professional

The questions asked of researchers by the Jury members was revealing for researchers in ways that they hadn’t anticipated, but led to enhanced practice. Researchers could not hide behind shared understanding of research language and practice, and instead had to develop translational skills in health research terminology. Researchers also had to learn how to communicate their relatedness to the proposed research. Jury members examined less the researcher’s methodology, and more the researcher’s identity, passion and relationship to the work they were doing. The health research literacy gap thus became part of the task for better research [communication and](#) practice rather than a deficiency of the Indigenous community.

A particularly interesting aspect of talk acknowledged by Jury members and researchers was the use of story by Jury members. Jury members frequently responded to researchers and each other through the recounting of stories. There were sad stories, amusing stories, and stories that had been recounted more than once. At times, the stories shared related specifically to a jury member’s experience of the health research issue, while other times, the stories shared revealed the broader historical, social, cultural and political context of Indigenous health. Jury members highly valued this method of transmitting knowledge. For some Jury members, witnessing stories were privileged opportunities, particularly those between Elders and young people, serving cultural identity work as described earlier.

*I personally love coming [to the Jury meetings] and I know that our focus is the research and our new projects, but I love sitting here and I love hearing about the*

*stories. Everybody gives their own little personal story about what they're talking about. I personally love hearing how it was for Uncle and for Auntie when they were growing up...you have more respect and it makes you feel so grateful for what we have today.*

Jury Member - Young Aboriginal Female

Here, the mechanics of health research ran secondary to learning, expressing and affirming community cultural protocols. The process of talking and learning through story was an unfamiliar experience for some of the researchers, particularly those who expected 'traditional' ethics review procedures. Some researchers expressed concern that Jury members might have gone off on a tangent and that discussions weren't focused on the research questions. Interestingly, four of the researchers interviewed articulated how Jury member interactions influenced their research agenda, not through specifically articulated directives but rather as a result of thinking deeply about the Jury members' stories. In this context, Indigenous stories operated powerfully to convey a deeper understanding of Indigenous experiences which influenced health research practice, despite the apparent lack of mastery of health research language by Jury members.

*So the main thing I think in everything that I've been involved with here has been about moving knowledge – things that I knew but knew in my head, to thinking about what that would actually feel...around what does it mean to be an Aboriginal or Torres Strait Islander person in Australia. What is life like for people? What is it like for some of the Elders who grew up say on a mission? What would that actually mean? What would that actually be like?*

Researcher - Female Researcher

*An enabler of empowerment and accountability*

The Jury process enabled researchers and Jury members to explore and affirm local community protocols and proved empowering for both, albeit challenging at times. For example, some researchers were uncertain about local protocols, appropriate language use, and/or were unfamiliar with learning through story, however the research team within the Centre of Excellence were important intermediaries in preparing researchers for Jury meetings. Community members valued the Jury process as an opportunity to express and affirm cultural protocols in terms of observing rules regarding acknowledging country, telling one's own identity story, attending to women's/men's and sorry business, managing shame or shameful issues, attending to Elders, and inclusion of young people's voices. These rules and protocols were negotiated and discussed.

*All of us here are staunch on our culture and our customs...I want to support my community and know that my Elders that sit with me here, that I want to do them a service and to show that us young people are here to support them as well and to learn the process.*

Jury Member - Young Aboriginal Male

Researchers had the opportunity to learn about community protocol but from a different perspective. One researcher whose proposal was not initially supported by the Jury reflected on her own experiences and how she learnt about community cultural processes through that engagement. The researcher was initially challenged in her understandings of the community but through this process learnt how to navigate these relationships.

*I came back to the Jury at the next meeting with a revised proposal. I actually acknowledged the fact that I had been really challenged by [the discussions at the previous Jury meeting]... but that I'd really learnt from it. I'd gone away and thought about the issues that they had raised. I felt very timid at that meeting...I didn't know how that, that would have gone down. But [local researcher] said that went down really really really well, that she could see from people's reactions that they were "Oh,[she] listened, she heard!". And something I did notice after that is that one of the Jury members started calling me 'Dr Deb'-Barb\*' at that meeting. What was interesting is that – the previous meeting where I was in the hole, that same Jury member was calling [local researcher] Doctor and there was "'Dr [(name)]" and there was 'DebbiBarbiee\*2' [(me)]. And that was an interesting experience as well, I mean I knew it. But it was an absolute, have it there in my face that, in this setting, [local researcher] was the one with respect already. And I'm still way – got a long way to go to really gain that respect.*

Researcher - Female Researcher [\*pseudonym]

Here the researcher learnt about the process of gaining respect within the community through respectful engagement rather than through professional titles. Yet the articulation of those titles was evidence of respect. Interestingly, few researchers articulated or problematised their low cultural/community literacy prior to encountering the Jury, but their narratives revealed how the interface of engagement via the Jury prompted a deeper and unanticipated understanding of local community cultural arrangements. For the Indigenous researcher, the challenge of navigating between community and research protocols was revealed.

*There have been times where the Jury has scrutinised the researchers... I felt as the Indigenous person in this service, supporting this process, that I probably should've been a bit more upfront...in terms of ensuring the cultural safety of all participants*

*that come to the Jury...I know one of the Jury members is very affected by sniffing within her family and youth suicide...I got a sense that she felt uncomfortable during that time [presentation on project about inhalant use] and I thought...I wish I could've handled that better."*

Researcher and Indigenous community member

Jury members and researchers spoke of the longer term effects of the Jury process for them personally and collectively. The outcome of empowerment was expressed through accounts of a more collaborative health service research agenda but extended beyond these to include new and strong representations of community, better health outcomes, and cohesive community governance processes.

*I think our confidence goes up a notch when we are respected on what final outcomes we come to and I think that's very important otherwise you go away disillusioned. We're kicking goals and these goals are going to be long-term. We're leaving a legacy for young people to follow. That's how I feel as an Elder.*

Jury Member - Aboriginal Male Elder

Jury members felt empowered as a result of respectful engagement with researchers and the health service and the respect given to the Jury's decisions. The respect that researchers had for the Jury was evidenced in each of their accounts. The act of meeting face-to-face with community stakeholders to explain the research was new and daunting for most researchers. However this model of engagement was ultimately empowering, providing researchers with a stronger sense of accountability than had previously been present.

*I think that it means that everything that I plan to do in the future, I'll always keep in the back of my mind that I'm going to have to present it and be accountable to the Jury. And there's nothing like presenting research in person, face-to-face with members of the community to focus your mind on, is this really in the community's best interest? You can perhaps kid yourself that it's in the community's best interest when really it's in your best interest or some other interest. But there's nothing like actually having to go and present and make you think well, what am I going to say? Is this really – what response am I going to get? Because you don't want to go to that Jury and have an uncomfortable experience. That would be terrible.*

Researcher - Male General Practitioner

For the Indigenous researcher, the Jury process was empowering because, despite the potential challenges personally, it enabled a new type of research engagement to emerge; one which does not exploit but respects Indigenous peoples, knowledges and perspectives.

*One of our Elders in the Jury constantly talks about – the need to be respectful and honour the dignity of humans beings. And he’s experienced a lifetime where that hasn’t been given to him. And I like that the Jury does that. We respect our community...I’m proud that we put on a good day for them...and people walk away feeling that they’ve been looked after. And I love that we give people that feeling in this research process and we should be doing that.*

Researcher and Indigenous community member

## **Discussion**

The importance of meaningful engagement of Indigenous peoples and communities in health research is recognised as a key component of ethical research.<sup>11, 13</sup> There is a growing body of literature describing effective engagement strategies.<sup>3, 6, 8, 17, 21, 36-40</sup> However, we note that for some researchers and research institutions, the ethical, moral and cultural imperative to engage Indigenous communities in research practice and governance can be overlooked or undervalued. Moreover, some researchers may be ill-prepared to engage effectively with Indigenous people and communities and the time taken to do so can be perceived as a barrier to engagement. We acknowledge that this model of engagement has required a significant investment from the service in terms of jury coordination and facilitation as well as allowing sufficient time in the research process for review and approval by the jury.7 Additionally, there are financial outlays with venue hire, catering and Jury member remuneration; -as well as the coordination of the Jury, however the return on these investments has been substantial. Rather than act as impediment to research, the Jury model described here facilitated better research by enhancing individual researcher skills and knowledge, community accountability and more respectful and appropriate engagement with Indigenous knowledges and perspectives within the local community cultural context. The benefits derived by researchers extended beyond research practice to enhanced clinical practice.

Similarly for Jury members, the Jury was a site of agency and activism that extended beyond reviewing health research within the service. Important community work operated within and outside of the Jury processes with Jury members enacting, affirming, articulating and maintaining individual and collective cultural agendas. Through this process, new and positive narrative truths could be asserted about the Indigenous community, and Indigenous “ways of knowing, being and doing”<sup>41</sup> were made visible to health researchers. We observed that Jury members were not resistant to health research within their community but rather, wanted to ensure that health research would lead to improved health outcomes for their community.

Jury members took pride in their Jury participation and saw tremendous value in health research, while remaining cautious of its exploitative possibilities. Rather than examine specific research methods, Jury members tended to question the researchers in terms of their personal background, professional work, and commitment to Indigenous health and the local Indigenous community. The Jury assessed the spirit and integrity, not of the research, but of the researchers, much to the researchers' surprise. The examination of the researcher's integrity was factored into Jury decision determinations which appeared to be influenced s-were determined by a complex interplay of factors including the perceived benefits of the research for the local community, Jury members' personal attitudes and experiences of the health issue being researched as well as the researcher's presentation style and personality, and the strength of the researcher's relationship with the community prior to presenting to the Jury. ~~Jury members' personal attitudes and experiences of the health issue being researched and the perceived benefits of the research for the local community.~~ This form of inquiry prompted greater researcher reflexivity and was evidenced in most researcher accounts resulting in a greater sense of self-efficacy in engaging with Indigenous people in clinical, community, and research environments. We simply did not find a procedural observance to ethical guidelines or rules among the researchers interviewed; rather we found a highly valued richer understanding of the Indigenous community cultural context where the researchers were operating.

The social justice goal of Citizens' Juries<sup>29</sup> was evidenced in the accounts of Jury members and researchers. Both reflected on the shift in power of these relationships made possible through the model (e.g. face-to-face meeting in a community rather than clinical setting, community members outnumbering researchers, researcher/clinician seeking permission rather than instructing). Central to the transformative possibilities of the Jury model was the transformation of hierarchical relationships between researchers and Indigenous people. Not simply 'subjects' of research, the Jury model repositioned Indigenous people as 'contributors' and to some extent 'drivers' of Indigenous health research. The Community Jury thus operates as more than a convenient rhetorical device to rebrand existing research processes. The Jury processes inspired transformative research practice because it transformed relationships of power between Indigenous people, researchers and research institutions, privileging Indigenous voices, experiences and perspectives in informing urban Indigenous primary health care research. The demarcation between 'lay' people and 'experts' was blurred with Jury members and researchers bringing both expertise and knowledge gaps. Interestingly, concerns about the health literacy of community members were soon overshadowed by opportunities that health researchers gained to improve their community cultural literacy.

Narrative inquiry as a form of evaluation of the Inala Community Jury proved useful as it enabled a raft of unanticipated benefits of the model to emerge. Through this approach we were able to capture the deeper stories or “private contexts of practice”<sup>42 p.227</sup> expressed by Jury members and researchers which we would not have gained through a more traditional process/outcome evaluation. We acknowledge our central role as co-narrators in this study, as representatives of the health service, as researchers, as a facilitator and as a local Indigenous community member. These positions enabled us to more fully describe the Jury model, and make sense of the accounts of researchers and Indigenous community members.

### **Conclusion**

The Centre of Excellence is still new on its journey of transformative practice in Indigenous health research and we are cautious not to overstate the significance of the Community Jury as ‘the model’ that remedies the politics of community engagement and governance of Indigenous health research. This study highlights the benefits that can be derived from meaningful engagement of Indigenous peoples and communities in the governance of health research. We recognise that trusting and respectful relationships with Indigenous communities is central to meaningful Indigenous engagement in health research and acknowledge that much of the Jury’s work benefits from the relationship the service has established within the local community over the past 20 years. No doubt the interface between other research institutions and communities will differ from ours. Regardless of the different contexts in which Indigenous people and researchers operate, there remains a cultural, political and ethical imperative to reposition Indigenous peoples from passive subjects of research to autonomous actors in health research governance.

### **Acknowledgments**

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### **References**

1. Walker P. Colonising research: Academia's structural violence towards Indigenous peoples. *Social Alternatives*. 2003;22(3):37-40.
2. Humphery K. Dirty questions: Indigenous health and ‘Western research’. *Aust N Z J Public Health*. 2001;25(3):197-202.
3. Koolmatrie T. Finding my ground in public health research: lessons from my Grandmother's kitchen. *BMC Pub Health*. 2011;11(Suppl 5):1-4.



4. Rowley KG, Thorpe AH. Research, information and consent for the Australian Health Survey: a separate standard for Indigenous people? *Med J Aust*. 2011;195(3):158-9.
5. Smith L. *Decolonizing methodologies: research and indigenous peoples*. London: Zed Books; 1999.
6. Isaacs AN, Pepper H, Pyett P, Gruis HA, Waples-Crowe P, Oakley-Browne MA. "What You Do is Important But How You Do it is More Important". *Qual Res J*. 2011;11(1):51 - 61.
7. Mentha RA, Vries Jd, Simon PR, Fewquandie BN, Brady J, Ingram S. Bringing our voices into the research world: lessons from the Kanyini Vascular Collaboration. *Med J Aust* 2012;197(1):55-6.
8. Kelly J, Saggars S, Taylor K, Pearce G, Massey P, Bull J, et al. "Makes you proud to be black eh?": Reflections on meaningful Indigenous research participation. *Int J Equity Health*. 2012;11.
9. Brough M. Healthy imaginations: A social history of epidemiology of Aboriginal and Torres Strait Islander health. *Med Anthropol*. 2000;20:65-89.
10. Lake P. A decade of Aboriginal health research. *Aborig Health Proj Bull*. 1992;17:12-6.
11. National Health and Medical Research Council. *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research*. Canberra: Commonwealth of Australia; 2003.
12. Ivanitz M. *Culture, Ethics & Participatory Methodology in Cross-Cultural Research*. Aboriginal Politics and Public Sector Management Research Paper No 7. Brisbane: Centre for Australian Public Sector Management, Griffith University; 1998.
13. Laycock A, Walker D, Harrison N, Brands J. *Researching Indigenous Health: A practical guide for researchers*, . Melbourne: The Lowitja Institute; 2011.
14. Miller A, Durrheim D. Aboriginal and Torres Strait Islander communities forgotten in new Australian National Action Plan for Human Influenza Pandemic: 'Ask us, listen to us, share with us'. *Med J Aust*. 2010;193(6):316-7.
15. NHMRC, Consumers' Health Forum of Australia. *Statement on Consumer and Community Participation in Health and Medical Research* Canberra: Australian Government; 2001; Available from: [http://www.nhmrc.gov.au/files\\_nhmrc/publications/attachments/r22.pdf](http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/r22.pdf).
16. Couzos S, Lea T, Murray R, Culbond M. 'We are not just participants – we are in charge': The NACCHO Ear Trial and the process for Aboriginal community-controlled health research. *Ethnicity and Health*. 2005;10(2):91-111.
17. Mayo K, Tsey K, the Empowerment Research Team. The research dance: university and community research collaborations at Yarrabah, North Queensland, Australia. *Health Soc Care Comm*. 2009;17(2):133-40.
18. National Health and Medical Research Council. *Keeping Research on Track: a Guide for Aboriginal and Torres Strait Islander Peoples about Health Research*. Canberra: Commonwealth of Australia; 2006.
19. National Health and Medical Research Council. *NHMRC Road Map II: a Strategic Framework for Improving the Health of Aboriginal and Torres Strait Islander People through Research*. Canberra: Commonwealth of Australia; 2010.
20. The Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG) of the NHMRC. *The NHMRC Road Map: A Strategic Framework for Improving*

*Aboriginal and Torres Strait Islander Health Through Research*. Canberra: Australian Government; 2002.

21. Pyett P, Waples-Crowe P, Van Der Sterren A. Engaging with Aboriginal communities in an urban context: some practical suggestions for public health researchers. *Aust N Z J Public Health*. 2009;33(1):51-4.
22. Hayman NE, Askew DA, Spurling GK. From vision to reality: a centre of excellence for Aboriginal and Torres Strait Islander primary health care. *Med J Aust* 2014;200(11):623-4..
23. Askew DA, Schluter PJ, Spurling GKP, Bond CJR, Brown ADH. Urban Aboriginal and Torres Strait Islander children's exposure to stressful events: a cross-sectional study. *Med J Aust*. 2013;199(1):42-5.
24. Coleman J, Spurling G, Askew D, Hayman N. Indigenous Health Checks: The view from the city (Letter to the Editor). *Med J Aust*. 2011;194(10):535-6.
25. Foley W, Houston A. Closing the gap by increasing access to clinical dietetic services for urban Aboriginal and Torres Strait Islander people. *Nutr Diet*. 2014;71(4):216-22.
26. Liddle K, Askew D, Betts K, Noel H, Alati R. Predictors of specialist referral for developmental and behavioural problems in a Queensland urban Aboriginal and Torres Strait Islander community: A cross-sectional study. *Aust Fam Physician*. 2014;43(9):640-3.
27. Maher C, Spurling G, Askew D. Health and well-being of urban Aboriginal and Torres Strait Islander women at their first antenatal visit: a cross-sectional study. *Aust N Z J Obstet Gynaecol*. 2014;54(1):88-90.
28. Abelson J, Forest P, Eyles J, Smit P, E Martin E, Gauvin P. Deliberative about deliberative methods: Issues in the design and evaluation of public participation processes. *Soc Sci & Med*. 2003;57(2): 239-51.
29. Wakefield T. *Citizens Juries: A radical alternative for social research* Guildford: Department of Sociology, University of Surrey; 2002.
30. Mertens DM. *Transformative Research and Evaluation*. New York Guilford Press; 2009.
31. Bell J. Narrative Inquiry: More than just telling stories. *TESOL Quarterly*. 2002;36(2):207-12.
32. Trahar S. Beyond the Story Itself: Narrative inquiry and autoethnography in intercultural research in higher education. *Forum Qual Soc Res [Online]*. 2009; 10(1): Available from: <http://www.qualitative-research.net/index.php/fqs/article/view/1218/2653>.
33. Foley W, Schubert L, Denaro T. Breastfeeding experiences of Aboriginal and Torres Strait Islander mothers in an urban setting in Brisbane. *Breastfeeding Rev*. 2013;21(3):53-61.
34. Brannick T, Coghlan D. In defense of being "Native" The case for insider academic research *Organ Res Methods*. 2007;10(1):59-74.
35. QSR International Pty Ltd. *NVivo qualitative data analysis software; Version 9*. 2010.
36. Gauld S, Smith S, Kendall M. Using participatory action research in community-based rehabilitation for people with acquired brain injury: from service provision to partnership with Aboriginal communities, *Disabil Rehabil*. 2011;33(19-20):1901-11.

37. Jamieson LM, Paradies YC, Eades S, Chong A, Maple-Brown L, Morris P, et al. Ten principles relevant to health research among Indigenous Australian populations. *Med J Aust*. 2012;197(1):16-8.
38. Rae K, Weatherall L, Hollebhone K, Apen K, McLean M, Blackwell C, et al. Developing research in partnership with Aboriginal communities – strategies for improving recruitment and retention. *Rural Remote Health*. 2013;13:1-8.
39. Rumbold A, Cunningham J, Bailie R, Hiller J. Exploring the characteristics of the research workforce in Aboriginal and Torres Strait Islander health. *Aust N Z J Public Health*. 2008;32(1):12-8.
40. Toombs M. Ethical research for Indigenous people by Indigenous researchers. *Aborig Isl Health Work J*. 2012;36(1):24-6.
41. Martin K, Mirraboopa B. 'Ways of knowing, being and doing: A theoretical framework and methods for indigenous research and indigenist re-search'. *J Aust Stud*. 2009;27(76):203-14.
42. Riley T, Hawe P. Researching practice: the methodological case for narrative inquiry. *Health Educ Res*. 2005;20(2):226-36.