Author’s response to reviews

Title: The Picture Talk Project: Aboriginal Community Input on Consent for Research

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Author’s response to reviews:

Reviewer 1:

Thank you so much for such positive, specific and valuable feedback. It is much appreciated by our research team. We have responded to your suggestions as below. The introduction has been reformatted in order to better contextualise this paper and how it sits within The Picture Talk Project. Findings from the Systematic literature review are included followed by the research question, lines 99-149 (inserted text in italics):

The Western approach to research with Indigenous communities is not aligned with Indigenous ways of knowing, doing and being (1,2,3). In response, local Aboriginal leaders invited us to conduct The Picture Talk Project, based in the Fitzroy Valley, The Picture Talk Project aims to explore how to establish strong partnerships and improve the consent process for research with Aboriginal communities. The Picture Talk Project seeks practical advice directly from people living in remote Aboriginal communities of the Kimberley, Australia, asking how researchers should engage in a way that is empowering and culturally respectful. (4,5,6).
The Picture Talk project comprises:

1. A systematic review of research publications which evaluate or describe in detail the consent process for research with Indigenous populations and an evaluation of current research guidelines (3).

2. Interviews with Aboriginal leaders about their understanding and experience with research and community consent (4).

3. Focus groups with Aboriginal community members about their research experiences and the individual consent process (reported here).

4. Feedback to the community and wider scientific audience.

5. Advocacy for policy changes in current guidelines (6).

This paper will focus on part 3: findings from focus group discussions with community members.

This paper explores the question: What do Aboriginal community members of the Fitzroy Valley have to share about past experiences with research, methods for seeking consent, overcoming language and cultural differences, and suggestions for future research?

What we know:

• Few publications evaluate or describe in detail the consent process for research with Indigenous communities (3).

• A study in Alice Springs, Australia revealed that one information session was not enough for Aboriginal participants to give informed consent. Participants preferred information presented in the form of a flipchart by a doctor with an Aboriginal research officer (7).

• Bull (8) found that it was important to Canadian Aboriginal communities that researchers establish reciprocal respectful relationships, seek collective consent, provide the option of oral consent and that research be relevant to the community.

• In the USA, people of the Navajo Nation and interpreters report the consent process for research involved too much scientific and legal jargon and recommended the use of graphics to help explain research concepts in a visual way (9).
A research team in Alberta learned it was insulting to seek consent from community elders after they had already accepted the ceremonious offering of tobacco. In response they designed a method which kept track of oral consent for research (10).

An evaluation of international, national and local ethical research guidelines (3,11-39) revealed that few published guidelines required that researchers provide:

- Access to an interpreter,
- Research information in the participant’s language of preference
- Visual aids for seeking consent
- Consent materials only after input from local Indigenous people.

What this paper adds:

- This is a unique first-hand account of focus group discussions sharing stories about research experiences with members of remote Aboriginal communities of Australia.
- Direct feedback about the standard consent form.
- Suggestions are made for how research information should be communicated.

This paper is contextualised in lines 151-160:

This paper brings to light a number of ethical issues:

- How should consent be sought for research with Indigenous communities?
- How should informed consent be evaluated and by whom?
- Does a power differential remain between the researcher and the researched?
- How important is the trusting relationship with community and the research team?

If consent for research is not obtained freely, without true understanding selection bias may occur in recruitment, affecting study results. Poorly informed consent could potentially cause harm to the individual participant or the community as a whole. By working in partnership with
local Aboriginal communities, The Picture Talk Project research team worked to overcome these issues.

This sentence has been moved to lines: 286-7

The Picture Talk Project is reported in line with the COREQ guidelines for qualitative research (76).

This sentence has been moved to lines: 191-195

“Following the literature review, Aboriginal community leaders were interviewed about how to approach Aboriginal communities for research as stage two of The Picture Talk Project. This advice directly supported the research team’s approach to recruiting community participants for the third stage involving focus groups. By using initial insights from research and applying them to support the design of subsequent stages, grounded theory was applied (57).

Thank you for such positive feedback.

We have reduced the number of quotes attached to each statement and have elaborated on our interpretations.

Lines 339-341:

Having Marninwarntikura’s logo on the research posters, symbolising that leaders of this organisation supported The Picture Talk Project, helped with participant recruitment and seeking consent.

Lines 345-347:

This is a picture of a baby surrounded by different coloured circles which represented the family and community’s responsibility for the health of each child in Fitzroy.

Lines 354-356:

Participants would smile and eyes soften in recognition of the Lililwan Project logo. The body language seemed to convey a positive attitude through the excited manner in which they talked about this project and the high tone of voice.

Lines 364-368:

By repeating the phase “they don’t want to know”, with a low, dismissive tone of voice, the participant makes special emphasis on the point that the young mothers of the community were not likely to be engaged (and hence participate) in a research project if the information they were given was only in the format of a page of typed plain English. By adding the smallest detail such as a Logo, the page held a whole new meaning.
‘Two-way’ is a term used locally when referring to concepts explained from both the Aboriginal and Western world views. In this particular instance, the participant is indirectly pointing out that the information sheet (which is simply adhering to ethics committee standards) is too Westernised. The content is not simplified enough for people whose first language may not be English and do not come from a scientific or legal background. Community members suggested that information could be written in Kimberley Kriol and presented with pictures. Kimberley Kriol is the common language of the area. This community use visual means of communicating much more than the written word.

This participant has given indirect feedback that for next time, in order to minimise the chances of “jealousy” or bias, it would be good to include a variety pictures of people from all of the different language groups.

They suggested a solution to this issue maybe to warn people at the start with a disclaimer that the content may contain photographs of local Aboriginal people that have died:

FG6P2: Maybe you could write up on the front that there is this person in the photos.

This type of warning is often used in public forums and in Australian media when showing films or photographs of Aboriginal Australian people from the past (80).

By using simple computer graphics to capture the images that were in the photographs, the image was made much simpler and easier to see. In addition, subjects can be de-identified so the local child does not have to run the risk of “feeling shame” and also removes the cultural issue of showing photographs of people that have passed away.

Participants were full of ideas and suggestions as to how to present information so that informed consent could be obtained. It was made clear that a single presentation about a research project when seeking consent for participation was not enough.

Because of the relative disadvantage of Indigenous people and entrenched racism in Australia (116) there is often a power differential between the researcher and the researched. The Picture
Talk Project team identified key insights into how to overcome this and best conduct research in Indigenous communities. These include:

• Forming strong, trusting research relationships with Aboriginal leaders and their communities is essential. Seek the support of locally respected organisations.

• Acknowledging the skills and experience that are brought to the team by the Aboriginal research partners.

• Not assuming that communities will prioritise research agendas despite local events, such as cultural mourning practices.

• Employing locally respected Aboriginal people as Community Navigators to introduce you to Aboriginal communities and their leaders, interpret discussions in local language and seek consent for participation in research and evaluate whether consent is informed.

• Clarifying the distinction between research and health service.

• Participants expect to be paid for their time.

• Using pictures and stories to help explain research information. Having a logo for the project.

• Minimising text and jargon in the written consent form. Interpreting into Kriol when possible.

• Consulting the community on how to present the research information.

Reviewer 2:

Our research team are grateful for your valuable feedback. We have responded to your suggestions as below.

The introduction has been reformatted in order to better contextualise this paper and how it sits in The Picture Talk Project, lines 99-160. Please see response to reviewer 1 regarding the introduction.

Picture Talk Project interviews with community leaders informed recruitment of community participants. We have detailed how in lines 191-195.
Following the literature review, Aboriginal community leaders were interviewed about how to approach Aboriginal communities for research as stage two of The Picture Talk Project. This advice directly informed the research team’s approach to recruiting community participants for the third stage involving focus groups. By using initial insights from research and applying them to subsequent stages, grounded theory was applied (57).

Aboriginal community members aged ≥18 years were recruited to Focus Groups through passive snowball sampling (59-61) as recommended by the local Aboriginal leaders on the research leadership team. They were invited to approach the research team if they were interested in participating. Individual consent was sought from participants by a researcher in the presence of a Community Navigator. Working closely with a Community Navigator during each stage of the research process had been highlighted as an essential part of culturally respectful research in The Picture Talk Project interviews with Aboriginal community leaders (4).

Showing respect for the community’s traditional knowledge and local expertise was highlighted as important during interviews with Aboriginal community leaders and this respect was also applied to focus groups. (4)

Having a Community Navigator present to interpret or explain things was also mentioned as important during interviews with Aboriginal community leaders (4).

Participants could nominate the time and the place of the focus group. During interviews with Aboriginal community leaders, it was emphasised that Aboriginal people really valued opportunities to work ‘on country’ (4). ‘On country’ was a term used locally to describe an area which was linked to a group’s ancestral history and holds cultural and spiritual significance (73, 74).

This was in-line with advice provided during interviews with Aboriginal community leaders – one must leave families alone if they have sorry business (4).

The Interview themes have been removed as they are taken out of context. The original point was that “Aboriginal leaders” were comfortable with interviews, but recommended that “Aboriginal community members” would be more comfortable to talk in a group with the peer support. Some Aboriginal leaders were part of the original research team which designed this
project. This advice was taken from the start. This advice was also supported by findings during interviews with 20 Aboriginal leaders in stage 2 of the project.

The word frequency cloud and all text in reference to it have been removed from the paper.

Please refer to response to reviewer 1, Lines:840-855

We did not collect a tally of the preferred method with regard to photographs or cartoons. We have included some more qualifying statements surrounding this topic:

Lines: 453-455

This participant has given indirect feedback that in order to minimise the chances of “jealousy” or bias, it would be good to include a variety pictures of people from all of the different language groups.

Lines: 471-477

They suggested a solution to this issue maybe to warn people at the start with a disclaimer that the content may contain photographs of local Aboriginal people that have died:

FG6P2: Maybe you could write up on the front that there is this person in the photos.

This type of warning is often used in public forums and in Australian media when showing films or photographs of Aboriginal Australian people from the past. (80)

We describe below that the cartoons are likely to be more convenient. Lines: 492-495.

By using simple computer graphics to capture the images that were in the photographs, the image was made much simpler and easier to see. In addition, subjects can be de-identified so the local child does not have to run the risk of “feeling shame” (Butcher) and also removes the cultural issue of showing photographs of people that have passed away.

Later in the discussion, we discuss that medically relevant photographs used in other studies could be very useful. Lines: 716-719

Schoen et al (56) describe a project based in Western Australia working with Aboriginal participants in focus groups evaluating educational resources to be used to promote awareness about diabetic foot care. Photographs of diabetic feet were preferred to cartoons as they appeared more realistic.

We have elaborated further about this particular theme:

Lines: 516-528
Participants often achieved consensus about a certain issue by talking in circles within each focus group. This came about through one person starting to make a statement about a topic, then the next person repeating part of the last few words in agreement and adding it their point of view or knowledge on the subject. The last part of their sentence might then be echoed by the first person or another until silence occurred. Those who did not agree would then have space to speak at this point. Sometimes the conversation flowed as if participants were exploring an idea first, with the pros and cons, before making up their mind on a matter. At other times questions were raised but consensus was not achieved. This process of discussion, debate and decision as a group was repeated with almost every topic raised by the research team. It almost had a rhythm to it with some participants repeating parts of sentences like an echo and nodding together. Even the focus group facilitator EF found herself doing the same where it seemed natural to do so to encourage discussion. This intricate process was like the researchers and focus group participants were sharing a story together, coming to an understanding and knowing together.

Achieving consensus in circles: Aboriginal people of the Valley are community focussed in their way of thinking hence it was natural for focus groups to reach consensus.

Tofoya describes how stories are told in circles in Native American culture (98). A similar thing was witnessed during the focus group discussions from which the theme “achieving consensus in circles” was derived. They hold a different dynamic to interviews in that responses of participants are witnessed and affects the direction of a discussion and flow of ideas and can reveal a wider variety of opinions, values and beliefs of a community (99). This process is akin to “collaborative yarning” described by Bessarab who is an Aboriginal researcher who identifies as Bardi/ Yjindjabandi from the West Kimberley (68). Community consensus was also described in focus group research in Aboriginal communities based in South Australia (Willis). This concept is also similar to “garma” which is a Yolnu word meaning: ‘identifying and respecting difference, while collaborating and building agreed ways of knowing in order to move forward together’ (101,102). This particular theme highlights to Western Researchers a key difference in ways of understanding through an Indigenous knowledge framework. By ‘going with the flow’ of conversation in the focus groups, deeper discussions were able to be held and the same stories were provided with new insights

We have amended this section. Lines: 616-645

When asked what future research the Fitzroy Valley communities need, participants discussed a number of topics. Some participants were overwhelmed by this question:
FG4P2: We’re facing all sorts of issues here. All sorts of problems.

Some participants were concerned about young people and recommended that research focus on how to support their mental health and prevent alcohol, smoking and drug use in the community.

FG2P3: We had a hard time with them sniffing. She said I don’t want to follow them because they will want me to sniff. They will force me to sniff…Show them what happens with smoking. She’s trying to smoke cigarettes.

Focus group participants also suggested researchers should look into how to support the financial stress and mental health of young mothers in the community:

FG3P1: Some are single mothers who are really struggling. I think they need some sort of support. The should do a research on all areas – financial, medical…or mental stress.

Another participant wanted research investigating whether the incidence of lung cancer in people of The Fitzroy Valley was attributable to the asbestos in their houses.

FG1P1: Well there’s a lot of things, you know like, we have people that have cancer especially of the lungs. You know like they have, there’s a big thing about asbestos (86,87). See a lot of our mob have lived in asbestos houses and now it’s like a wake-up call for people to look into it because we may have lost a lot of people to asbestos, you know with cancer of the lungs.

Some participants did not differentiate between the concepts of ‘research question’ and ‘health service’ and proceeded to offer practical advice as to how the community could be supported including building a youth centre, increased health screening for children and improving health literacy.

Lines 783-791:

“When asked about suggestions for research in the future, some participants raised issues which they felt needed more research such as if there is a link between local lung cancer prevalence and asbestos in the houses of the community (86,87). Other participants were concerned about the mental health, smoking, alcohol and drug use of the young people in the community or how to best support the financial and mental stress that young mothers were going through. These topics were raised as issues in the community that they felt needed research however no specific research questions were formulated at the time. In some focus group discussions participants would join the conversation and offer how improved service provision to the community could address issues that were raised. Practical solutions were then explored as to how best support the community.

Lines 816-819:
It was difficult to discuss suggestions for future research projects during the focus group discussions. In order to formulate research questions which addressed community priorities, more discussions would be needed with wider consultation with the people of the Fitzroy Valley and Aboriginal community leaders.

Lines 251-252: We have changed the wording:

Sometimes participants wanted to discuss participation in research with a particular family member or health worker rather than the Community Navigator.

Please refer to response to reviewer 1. Lines 262-263

Line 394-397. We have amended this to caregiver:

Lililwan Project which included photographs of local children demonstrating how they would participate in the various assessments including one photo of a child being examined by the doctor with his caregiver present (36).