



Researching with remote Aboriginal communities of Australia:

A community perspective

Rue Wright Memorial Award

Fitzpatrick E, MacDonald G, Martiniuk A, D'Antoine H,
Oscar J, Lawford T, Carter M, Elliott E

**RACP
CONGRESS
2018**
Sydney
14 – 16 May 2018

www.racpcongress.com.au

A scenic view of a river crossing in the Kimberley region, Australia. The river is calm, reflecting the blue sky and the surrounding greenery. The banks are lined with dense, lush trees and vegetation. In the foreground, the branches of a tree frame the left side of the image, and a large tree trunk is visible on the right. A white vehicle is partially visible on the right bank. The overall atmosphere is peaceful and natural.

Being Respectful of working on country

"It's about being on country, their country, and when you're in that space with them, they become your teachers" (P20)

BMC Medical Ethics (2017) 18(34):1-19

Photo: The Historic Fitzroy Crossing, the Kimberley



The Picture Talk Project

PhD research

1. Systematic Review
2. Research Protocol
3. Interviews with Aboriginal leaders
4. Focus Groups with Aboriginal community members
5. Advocacy for changes in research guidelines
6. Implications for future research



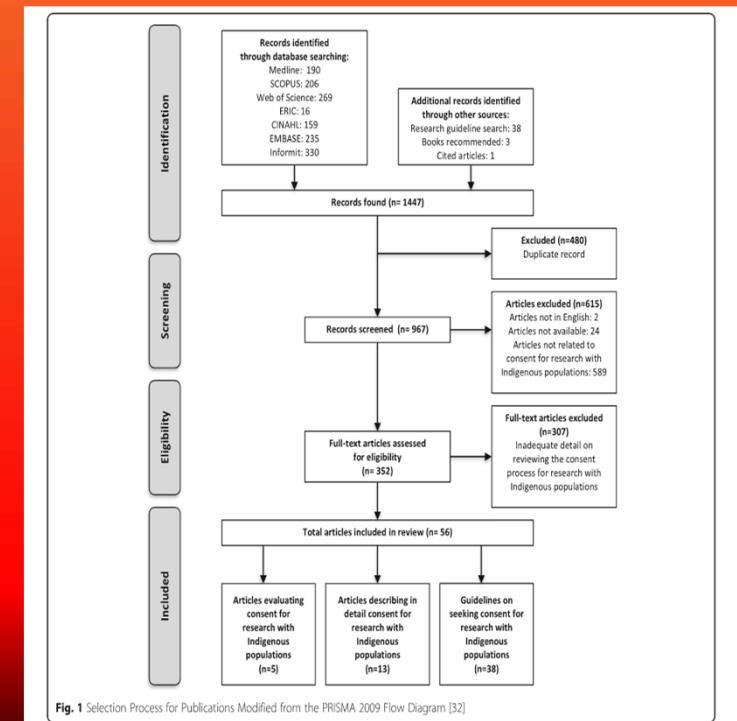
1. The Picture Talk Project: Systematic Review

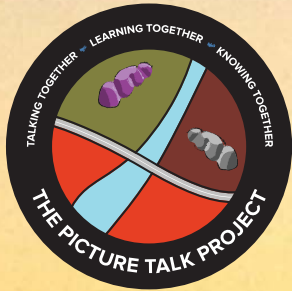
Seeking consent for research with Indigenous communities

Fitzpatrick E, Martiniuk AM, D'Antoine H, Oscar J, Carter M, Elliott E

BMC Medical Ethics (2016) 17:65

- PRISMA Guidelines
 - Full text articles reviewed **n=352**
 - Articles included **n=56**
 - **Evaluate the consent process n=5**
 - **Describe the consent process in detail n=13**
 - **Guidelines reviewed n=38**
- ➡ GAPS in protocols re: consent





The Picture Talk Project Research Team



Marilyn Oscar



Annette Kogolo



Percy Bulagardy



Sandra Nuggett



Joy Nuggett



Leo Thirkall



June Oscar



Maureen Carter



Tom Lawford



Heather D'Anotoine



Alex Martiniuk



Gaynor Macdonald

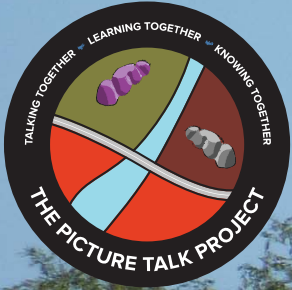


Elizabeth Elliott



Emily Fitzpatrick

Photo: Kimberley Boab at Dawn



2. The Picture Talk Project: Research Protocol

**A qualitative study working together with remote Australian
Aboriginal communities of the Kimberley**

Fitzpatrick E, Martiniuk A, D'Antoine H, Oscar J, Carter M, Lawford T, Elliott E

BMJ Open Dec 2017, 7 (12):1-12 e018452

Photo: Highway through the Kimberley

Language Groups of the Fitzroy Valley



Bunuba



Gooniyandi



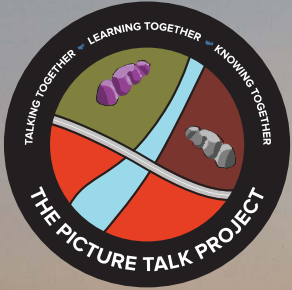
Wangkatjungka



Walmajarri



Photos Courtesy of KALACC



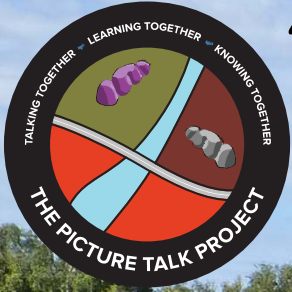
3. The Picture Talk Project: Interviews with Aboriginal Leaders

The Picture Talk Project:

**Starting a Conversation with Community Leaders
on Research with Remote
Aboriginal Communities of Australia**

Fitzpatrick E, MacDonald G, Martiniuk A, D'Antoine H,
Oscar J, Lawford T, Carter M, Elliott E
BMC Medical Ethics (2017) 18(34):1-19

Photo: The Mighty Fitzroy River



4. The Picture Talk Project: Focus Groups with Aboriginal communities

Aboriginal Community Input on Consent for Research

Fitzpatrick E, Martiniuk A, MacDonald G, D'Antoine H, Oscar J, Carter M, Lawford T, Elliott E

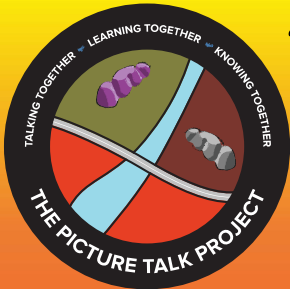




4. The Picture Talk Project: Focus Groups with Aboriginal communities

Focus Group Participants

- **Participants recruited: 26 (3)**
- **Focus Groups n= 6 (of 3-7 participants)**
- Female n=19 73%
- Aboriginal 100% from all language groups
- Preferred language:
 - Kimberley Kriol n=15 58%
 - Standard Australian English n= 2 8%
- Education:
 - University n=1 4%,
 - High school n=9 15%
- Cultural Knowledge:
 - Parent/Grandparent n= 11 43%
 - Elder n=5 19%
 - Cultural advisor n= 4 15%
- **Passive Snowball Recruitment**
- **Culturally Acknowledged Groups**
- **Themes Saturated**



4. The Picture Talk Project: Focus Groups with Aboriginal communities

Consent Materials

Excerpt from The Liliwan Project Participant Information Statement

Marulu (Precious), The Liliwan (little ones) Project
Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study
Stage 2 - Interdisciplinary health and developmental assessments in children



What is the project about?

The project involves health and development checks on children to see which areas they are strong in, and which areas they need more help in.

The checks we do will be similar to what the local children's doctor and Allied health team (Aboriginal health worker, speech and language pathologist, physiotherapist, school nurse, occupational therapist, eye doctor and audiologist) would normally do in the child health clinic. The checks will take around 4 hours and will be spread over 2 visits to the clinic. There are no side effects or risks expected with the checks.

If you agree to participate, your child will be seen by the eye doctor to check their vision and also have their hearing tested. With your permission, we will take a photograph of your child's face to see if they have the special face shape of children with Fetal Alcohol Syndrome. It is important to do this so that we can be sure of the diagnosis and understand the special needs of the child and get help in school or home for them if you think it is needed.

We would like to take a photograph of all the children, even if there was no alcohol used in the pregnancy. If you would like a copy of the photo we will print one out for you to keep. On another visit your child will be checked by a children's doctor for their physical health, including listening to their heartbeat and breathing. The doctor may also ask questions about the pregnancy with this child, and the child's health and development.

The Allied health team will do some tests to see how the child is doing with memory and thinking, their behaviour at school and home, speaking, understanding of language and drawing and how coordinated and strong their muscles are. When we test the language we would like to take a short video of the child telling a story about going bush. The reason for this is so that local Aboriginal people who are experts in language can help to check the child's language including communicating by signing with their lips, eyes, facial expressions and hands.



Photograph of
doctor examination

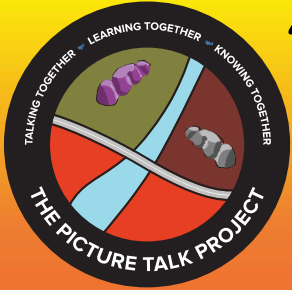


Cartoon created with
Adobe Photoshop CS6



Community Navigator

Participant Information Statement for the Liliwan Project

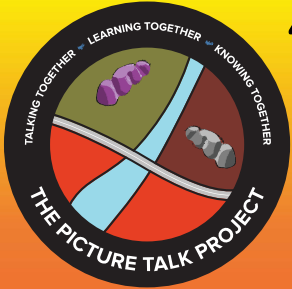


4. The Picture Talk Project: Focus Groups with Aboriginal communities

Focus Group Results:

6 Key Themes:

- 1. Reputation and trust is essential;
- 2. The Community Navigator is Key;
- 3. Pictures give the words meaning;
- 4. Achieving consensus in circles;
- 5. Signing consent;
- 6. Research is needed in the Valley.

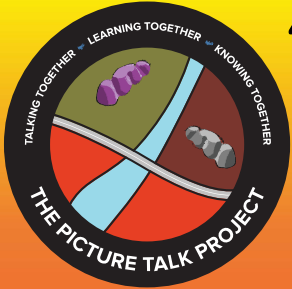


4. The Picture Talk Project: Focus Groups with Aboriginal communities

1. Reputation and Trust is essential

See... you've got the logo. So if they look then they are like ah Lililwan (FG1P1)





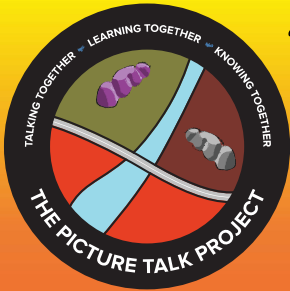
4. The Picture Talk Project: Focus Groups with Aboriginal communities

2. Community Navigator is Key

But if you've got a Community Navigator, you know working alongside of you, then you can give the paper work to everybody. (FG1P1)

As soon as you jump in the car to go see the school or a parent or thing, you let that Community Navigator take the lead. Navigator do all the interpreting from 'go to woah'. (FG4P2)





4. The Picture Talk Project: Focus Groups with Aboriginal communities

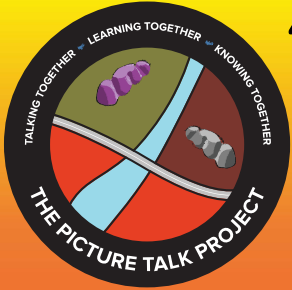
3. Pictures give the words meaning

There's a lot of people just giving out paper to sign, but they don't know what they're signing for. (FG1P1)

If you have local photos...you know they'll feel proud (FG1P1)

I think cartoon is better because pictures say the person has passed away (FG3P2)





4. The Picture Talk Project: Focus Groups with Aboriginal communities

4. Achieving consensus in Circles

FG1P2: *Some of them can't read.*

FG1P1: *Yeah, yeah, maybe talking?*

FG1P3: *You know some of us, some you know,*

FG1P1: *Some can't read*

FG1P3: *Some can't read*

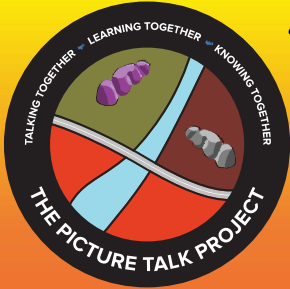
EF: *So without any writing do you think? Just talking*

FG1P1: *Just talking*

FG1P3: *Mhmm*

FG1P2: *Yeah*





4. The Picture Talk Project: Focus Groups with Aboriginal communities

5. Written Consent

- *Probably in the long run better to be on paper just in case. (FG6P1)*
- *See they think every time they sign they get paid for it. (giggling) (FG1P1)*

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Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study
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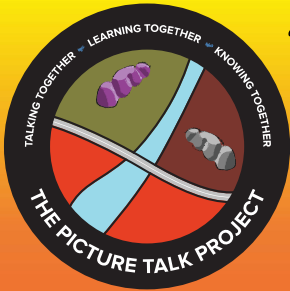
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4. The Picture Talk Project: Focus Groups with Aboriginal communities

6. Research is Needed in the Valley

- FG1P1: *Research is like for finding out things. You know there's something there that's not right. Like mothers were drinking say for example the Lililwan project. Sometimes mothers don't know they are harming their babies cause sometimes they just drink because they like to drink, but they don't know it's gonna to harm their baby or something. That's why maybe kids grew up and have behaviour problem, that's why kids at school, kids growing up with that problem 'cause they had a long time acting up*

Foetal Alcohol Spectrum Disorder study

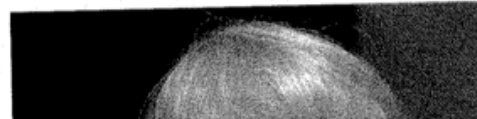
From FaHCSIA

The first Australian study into the prevalence and impact of Foetal Alcohol Spectrum Disorder on Indigenous children will be under-

Other priorities under the Agenda are to strengthen police protection in remote communities, support community led initiatives that heal trauma and change attitudes, and improve coordination of services to

While fewer Indigenous Australians drink alcohol than non-Indigenous Australians, alcohol abuse is a significant issue in Indigenous communities.

A recent study by the Australian





5. The Picture Talk Project: Advocacy for changes in research guidelines

Conducting research together with remote Aboriginal communities

Fitzpatrick EFM, Oscar J, Carter M, Lawford T, Martiniuk AM, D'Antoine H, Elliott EJ

14th National Rural Health Conference Proceedings.

National Rural Health Alliance. Ed. Coleman L. 2017.

Canberra, ACT, Australia. ISSN: 1445 3363



Research protocols and ethical guidelines for research with remote Aboriginal communities should :

- be responsive to the research needs identified by the community.
- require external researchers to collaborate with a nominated representative of the Aboriginal community who holds local respect and has strong cultural knowledge.
- be more flexible in their timelines allowing for unexpected cultural obligations.

➡ **NHMRC Guidelines Consultation**



6. Implications of Research

- Informed Consent?
- Collaborative research partnerships need to be genuine
- Research organisations must have a good reputation and visual identity
- Work alongside someone the community respects and trusts
- Pictures can be used to explain research and assist in obtaining consent
- Despite challenges, Aboriginal people believe research is needed.



Thank you to the Fitzroy Valley community

- Prof E Elliott, Assoc Prof A Martiniuk, Dr G Macdonald, Ms H D'Antoine, Dr J Oscar, Ms M Carter and Mr T Lawford
- AVANT Doctors in Training Fellowship
- University of Sydney Rowan Nicks Russell Drysdale Fellowship
- AFGW Barbara Hale Fellowship



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