



Yarning with remote Aboriginal communities about seeking consent for research, culturally respectful community engagement and genuine research partnerships



Presented by Ms Annette Kogolo
with Dr Emily Fitzpatrick



Connected to Country...



Annette Kogolo



Jila ngapa is living water.

Photo: Purluwala Jila,
Great Sandy Desert



Photo: Karningarra Walmajarri Country, Canning Stock Route
My father's country is Pirlurl, on the Great Sandy Desert



Research with Indigenous People

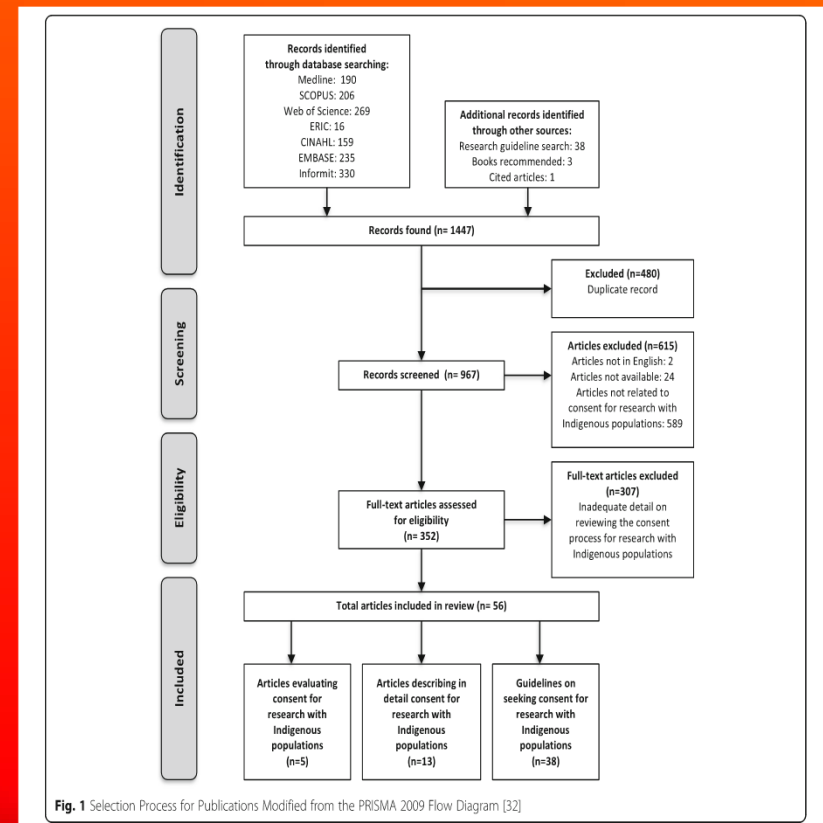
- 370 million Indigenous people in the world
- 90 countries
- Marginalisation > Health and well being
- “*Subjects*” of research in colonised countries
- Rarely benefitted the people
- How far have we come?
 - The “language of inequality” is still used today (L.T.Smith)



Seeking consent for research with Indigenous communities: A Systematic Review

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

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





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Local languages

Visual Aides

Local Advice

	CBD 2002 [7]	UN 2005[8]	UNDRIP 2007[9]	UN 2009[10]	WHO 2009[11]	UN 2013[12]	WMA DOH 2013[13]	WIPO 2015 [14]	NHMRC 2003[49]	NHMRC 2005[50]	CRC TS 2006[51]	NHMRC 2007[52]	CRIAH2008[53]	CSIRO 2009[54]	NHMRC 2010[55]	NHMRC 2010[56]	Lowitja 2011[5]	A/ATSIS 2012[57]	NHMRC 2015[58]	NZ Ministry of Health 2006[59]	PWG 2010[60]	HRC NZ 2010[61]	NEAC 2012[62]	NEAC 2012[63]	AAND 2010[64]	CIHR 2014[65]	The Belmont Report USA 1979[66]	TEC 2014[67]	DK&CRC 2005[68]	DK&CRC 2009 [69]	KLC 2011[70]	KLC IP & TKP 2011[71]	AH&MRC 2013[72]	Ninti One 2015[73]	UoVic 2003 [74]	Nuu-Chah-Nulth 2008 [75]	SNC 2014[76]	Portland Area IHS IRB 2002 [77]																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																																		
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The Lililwan Project

Fetal Alcohol Spectrum Disorder (FASD) prevalence study

- Community initiation, consultation and collaboration
- Community and Individual Consent process was very positive, Participation rate in stage 1 - 97% and stage 2 - 95%
- Highlighted in the 2010 Social Justice Report



The Picture Talk Project

aims to examine the community engagement and consent process



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

Photo: The Mighty Fitzroy River

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



Alexandra Martiniuk



Gaynor Macdonald



Elizabeth Elliott



Emily Fitzpatrick

Aboriginal Community Leaders of the Fitzroy Valley invited researchers from Darwin and Sydney to work in partnership



The Fitzroy Valley

Unique Challenges

The Fitzroy Valley:

- Population 4500
- 95% Aboriginal
- 4 main language groups
- Fitzroy Crossing – main town
- Remote communities hundreds of kilometers on open road
- Cut off annually by flooding in
- “Wet Season” December - March



Language Groups of the Fitzroy Valley



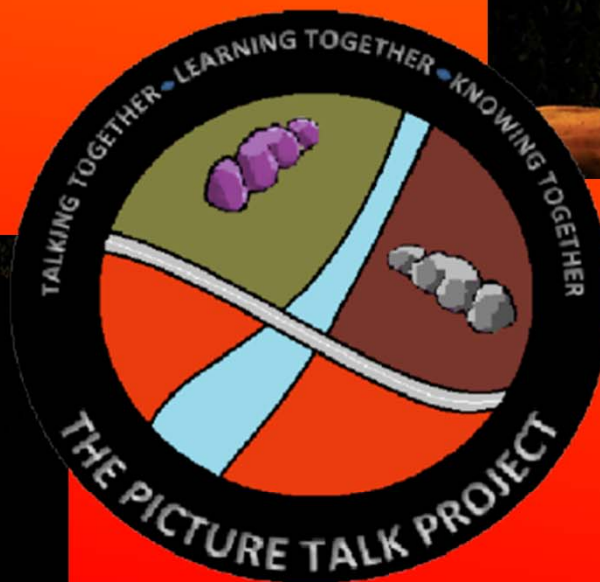
Bunuba



Gooniyandi



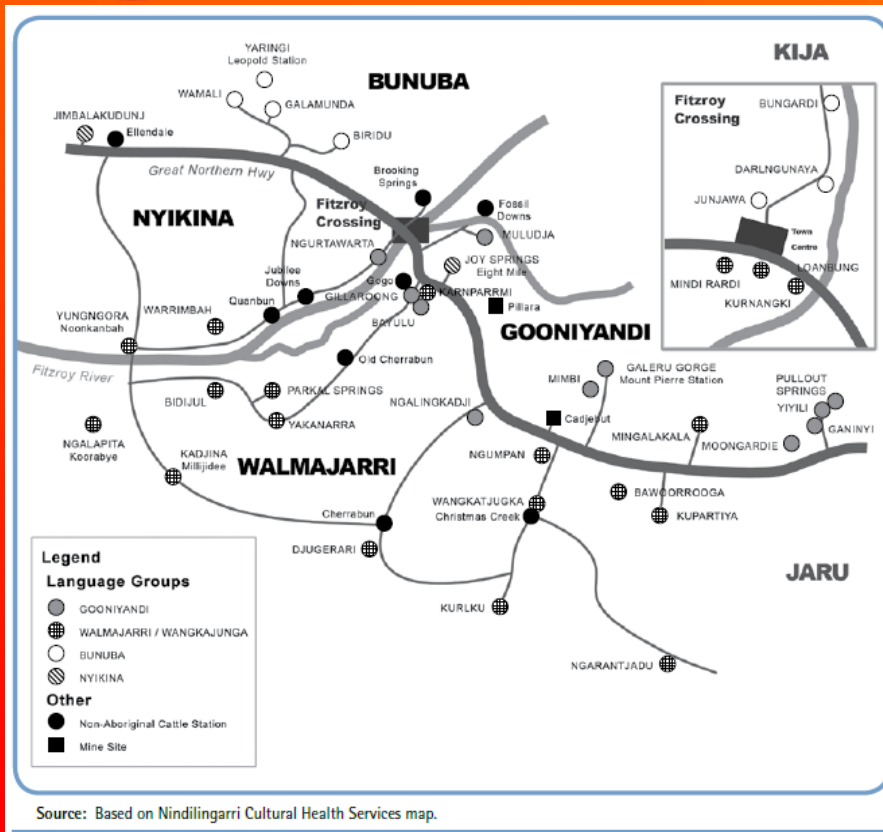
Wangkatjunga



Walmajarri



Engaging Local Organisations





Methods

- Interviews with leaders on community consent
- Focus groups with community members on individual consent.
- With consent, interviews were either written at the time or voice recorded and later transcribed to be analysed by NVivo10 Qualitative Software.



Informed Approach...

QUALITATIVE RESEARCH

➤ Grounded Theory

- Themes are informed by participants
- Minimises assumptions
- Ethically sound and culturally safe

➤ Research Capacity Building

- Immediate Reciprocity and guidance





The Picture Talk Project

- Asking about research:
 - Research experience
 - Importance
 - How could research be conducted?
 - How could information be presented
 - Languages, relationship in research,
 - Ownership of information, intellectual property
 - Protocols: local vs ethics committee



The Picture Talk Project

- Consent:
 - Place, who, witnesses, language, confidentiality
 - How: pictures, talking, story
 - Timing
 - What are we agreeing (consenting) to?
 - Confidentiality,
 - Protecting community,
 - Advocacy, benefits



The Picture Talk Project

- Continued consent
 - Checking in
 - Evaluations
 - Relevancy
- Signing consent
 - Evidence of informed consent
 - Form, audiovisual, witness
 - Copies of evidence/documents



NVivo 10 Qualitative Data Coding

File Query Explore Layout View

Name INT20

- Acknowledgement
- Attitudes
- Communication
- Community
- Culture
- Do things different
- Education
- Expectations
- Funding
- Guidance
- Important
- Intentions
- It Depends
- Offended
- Place
- Politics
- Relationships
- Research
- Responsibility
- Support
- Survival and Protection
- Time
- Two worlds

People can't come in and say we're doing research and then they take it away and the community doesn't own, there's no feedback or anything. That's what happened here in the past. Fitzroy was one of the most researched towns in the Kimberley but where is all that research now? What for, we don't know.

So yeah, community has to have a big say in the research and if the community says no well then so be it. It can't be enforced and you know, using our community navigators is a good way of making sure that the research is done in the right way too amongst Aboriginal people. And that's where the Lililwan Project was so successful cause it's never been done like that before, well the FASD study hasn't happened in this country but the reason it was so successful, because there was a lot of groundwork that took place first. You know what I mean, all that education stuff? And then when JF come on before all of you all turned up, JF went out and talked and the research questions have to be where Aboriginal people can understand it. Like we looked at all of that research question for the Marulu, Lililwan Project and HY, RS and myself sat with JF and we said 'no, no this isn't going to work' so we rephrased all of that whilst the research questions were still there we broke it down where people can understand so the community navigators became a very important part of the research, you know in that study. It was so successful and I think that's the way anyone that's wanting to do research, really has to follow the way the prevalence study happened cause that was really good and the success. From the 147 families that had 7 and 8 year olds, 127 said yes to the study and the biggest part of that was because the team built that relationship before the study happened and all of the team members, you had your cultural advisers/cultural consultants but you all worked in a very respectful way as well. I never heard anyone complaining about it and it's the people. We were so lucky that we had all of you, a good bunch of people that came in to do the study and people can come and do research or say they want to do research, but if you haven't got the right people, it's not going to work either.

So you found your interactions with the Westerners that did come into this community, what did you think about your relationships and the way you interacted with them?

INT20

Coding Density

- Education
- Specific Projects
- Dissemination of information
- Positive
- Respect
- Community Navigator
- Consent
- Research
- Consultation



community
research
likes
knows
people
project
talk
works
good
right
aboriginal
someone
questions
process
approach
day
whole
meetings
make
first
times
respect
another
okay
explain
let
person
in
fitzroy
permission
intruders
give
cultural
country
speaks
means
bunuba
sitting
start
might
interprets
happening
consult
happy
worra
writing
sort
part
even
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name
help
done
word
back
now
places
yep
signing
kartiya
family
side
group
local
taking
information
much
saying
women
differently
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seeing
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involved
language
understand
organisations
engage
myo
western
around
something



Research: Finding Knowledge

"In the past I don't think people who were doing the research felt they had to consult with Aboriginal people... When you think of researchers... going on for years on Aboriginal people.

We're the most researched group in this country and yet nothing's changed.

I believe that if you're going to do research we should see changes or we should benefit you know." (P17)



Photo: Endemic Kimberley Boab Tree



Being Respectful of Aboriginal people

*We all came with a set of skills that
joined part of the jigsaw for that
study and there was the respect
(P20)*





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)*

Photo: Windjana Gorge, Bunuba Country



Being Flexible with Time

“If you want to do research, you can’t just set a timeframe because you’ve got to be respectful of what’s happening around you” (P20)

“Those people on the sorry side, you’ve got to pay respect to them, don’t get them involved with anything.” (P8)





Working Together with Good Communication

*I don't think researchers should do research with any Aboriginal people unless they've engaged fully with the Aboriginal people from the start to the end
(P17)*





Reciprocity: two-way learning

Well first and foremost, preferably engage with an organisation, like you have, and then secondly use youngsters in the process. Not only to transfer your westernised skills but to also utilise their skills in dealing with our members as well (P19)





Communication: Milli milli vs Pictures

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)





Reaching Consent

The community has to have a big say in the research and if the community says 'no' well then so be it (P20)

He's like a key, he is opening the door for you. He helps connect you in the right way. He helps explain why you are here and what you want to do. (P7)

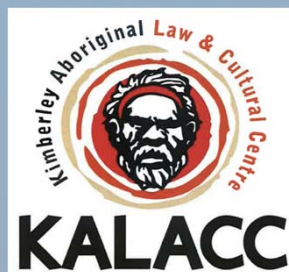




Future Directions

They need a youth centre .. there's no activities for kids at night or weekends.. our people used to take us out fishing and hunting and show us the skills they had (FG6P6)

Photo: Kimberley Boab at Dawn



Thank you to all participants

Rowan Nicks Russell
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Barbara Hale Fellowship
AVANT DiT Scholarship





Painting: Collaborative Artwork from 4 main Language Groups, Mangkaja Art Gallery

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