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Research protocol for The Picture Talk Project: a qualitative study on research and consent with remote Australian Aboriginal communities

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Research protocol for The Picture Talk Project: a qualitative study on research and consent with remote Australian Aboriginal communities

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ABSTRACT**Introduction**

Research with Indigenous populations is not always designed with cultural sensitivity. Few publications evaluate or describing in detail seeking consent for research with Indigenous participants. When potential participants are not engaged in a culturally respectful manner, participation rates and research quality can be adversely affected. It is unethical to proceed with research without truly informed consent.

Methods and Analysis

We describe a culturally appropriate research protocol is invited by Aboriginal communities of the Fitzroy Valley in Western Australia. The Picture Talk Project collaborates in partnership with local Aboriginal leaders who are also chief investigators. We will interview Aboriginal leaders about research, community engagement and the consent process and hold focus groups with Aboriginal community members about individual consent. Cultural protocols will be applied to recruit and conduct research with participants. Transcripts will be analysed using NVivo10 qualitative software and themes synthesised to highlight the key issues raised by the community about the research process.

This protocol will guide future research with the Aboriginal communities of the Fitzroy Valley and may inform the approach to research with other Indigenous communities of Australia or the world. It must be noted, that no community is the same and all research requires local consultation and input. To conduct culturally sensitive research, respected local people from the community who have knowledge of cultural protocol and language are engaged to guide each step of the research process from the project design to the delivery of results.

Ethics and Dissemination

Ethics approval was granted by the University of Sydney Human Research Ethics Committee, the Western Australia Country Health Service Board Research Ethics Committee, The Western Australian Aboriginal Health Information and Ethics Committee and the Kimberley Aboriginal Health Planning Forum Research Sub-Committee. Results will be disseminated through peer review articles, local Fitzroy Valley report and conference presentations.

Key Words

Research Methods, Remote, Aboriginal, Indigenous, Community Engagement, Consent

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ARTICLE SUMMARY

Article Focus

- A qualitative study exploring knowledge about research and preferences for Aboriginal community engagement and the consent process for research that was initiated by and conducted in partnership with Australian Aboriginal leaders.
- To illustrate the value of integrating yarning into research practice. Yarning is a flexible approach that enables Aboriginal people to feel comfortable to talk about their experiences through storytelling. It helps researchers establish trust and rapport with research participants and facilitates conduct of semi-structured interviews and collaboration in focus groups.
- To describe a scientifically rigorous research protocol that embodies respect for Aboriginal language and culture through research partnerships and collaboration.

Key Messages

- Findings from leader’s interviews and focus groups with Aboriginal communities of the Fitzroy Valley will inform future research conduct and ethics protocols.
- This study identifies Aboriginal people’s understanding of research and preferences for community engagement and seeking consent for research and is relevant to Indigenous communities worldwide.

Strengths and Limitations of this Study

- This is the first study on research and consent that is led by a research team that includes Aboriginal leaders, experienced public health researchers and clinicians and seeks advice on research processes directly from Aboriginal leaders and community members.
- Community Navigators provide cultural guidance to visiting researchers to ensure local cultural protocols are observed throughout the research process.
- Local interpreters employed as Community Navigators allow research participants to speak in their language of preference, including all major local languages of the Fitzroy Valley
- Due to limited capacity and availability of interpreters, data analysis will be conducted in English so some subtleties of local Aboriginal language may have been lost in translation.
- This is a relatively small study in a discreet geographical setting. Although likely applicable to similar remote communities elsewhere in Australia, findings may not be generalizable to all Indigenous communities.

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94 **Research protocol for The Picture Talk Project: a qualitative study on research and consent with**
95 **remote Australian Aboriginal communities**

96

97 **INTRODUCTION**

98

99 When seeking consent for research with Indigenous people, time is rarely taken to reflect on the process^{1,2}. If
100 research is not conducted in a culturally respectful way, it can adversely affect participation rates and the
101 quality of the research³ Our systematic literature review of research, which describes or evaluates the process
102 for seeking consent and the preference or understanding of the consent process for research with Indigenous
103 communities, identified few relevant publications¹. Few detailed the methods used when seeking consent,
104 including use of videos, flip charts or local researchers to interpret information for Indigenous participants¹.
105 Even fewer evaluated whether this information was understood or presented in a way that is preferred by
106 Indigenous participants¹. It should be noted that since there is such variety of Indigenous populations around
107 the world, the United Nations does not have a specific definition for 'Indigenous'⁴. This term will be used when
108 referring to populations in a general sense, however when publications specify the name of a group of people
109 such as 'Aboriginal', that term will be used.

110 Guidelines for research with Indigenous communities recommend that Indigenous community members be
111 involved in all stages of the research process⁵. Strong trusting relationships between outside researchers and
112 local community partners are essential⁵. In this paper we describe the research methods for The Picture Talk
113 Project, a qualitative research project conducted together with remote Aboriginal communities of the Fitzroy
114 Valley in the Kimberley region of Western Australia. In the Picture Talk Project we will interview community
115 leaders about the community engagement and consent process for research, conduct community focus groups
116 about the individual consent process and publish and present findings. We hope The Picture Talk Project will
117 support Indigenous people like those living in the Kimberley to have a more ethical, collaborative experience
118 when participating in research and empower them to guide the research agenda to address community
119 priorities while embedding cultural protocol into each step of the research process².

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120 Invitation from the Community

121 Following the Lililwan Project on Fetal Alcohol Spectrum Disorder (FASD) prevalence⁶⁻¹⁴ the Picture Talk Project
122 team was invited by Aboriginal leaders of the Fitzroy Valley to explore community understanding of research
123 and consent². The Lililwan project was initiated after communities leaders noticed that some of their children
124 looked different and had trouble learning, and expressed concern that these children would not remember the
125 dreamtime stories to be passed down to the next generation^{12,13}. Because alcohol use in pregnancy was
126 common they wondered these children might have FASD, so invited researchers to come to the Fitzroy Valley
127 and investigate the issue¹¹⁻¹³. The project was initiated by and conducted in partnership with Aboriginal
128 community leaders following community consultation and agreement that it was an important issue to
129 investigate¹¹⁻¹³. Local Aboriginal researchers were employed as Community Navigators to interpret for those
130 whose first language was not English and provide cultural guidance to the non-Aboriginal researchers^{2,6}.
131 Aboriginal and non-Aboriginal team members guided each other so that the research was both scientifically
132 rigorous and culturally relevant^{2,6}. The Lililwan Project was so well received that in 2010 the Social Justice
133 Commissioner for Aboriginal and Torres Strait Islander people, Mr Michael Gooda, reported that it should set
134 an example for research with Aboriginal people¹⁵. The Picture Talk Project was subsequently initiated, and
135 researchers were invited to reflect with communities of the Fitzroy Valley on how and why the Lililwan Project
136 worked so well and to discuss the processes that should underpin research engagement and consent for the
137 future.

138 Why this study is important

139 This research protocol uses collaborative, culturally respectful, flexible research methods to allow for
140 participants to be in a space where they may speak freely about their experiences and opinions of research.
141 Findings from this study will inform the approach of future studies with Indigenous communities.

142

143 Study Aims

144 The Picture Talk Project is a community-based project conducted with local Aboriginal leaders of the Fitzroy
145 Valley that aims to examine the community engagement and consent process. This will be achieved by
146 interviewing Aboriginal community leaders about community consent and the research engagement process

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and holding focus groups with Aboriginal community members about their experiences with research and the individual consent process. Both groups will be asked how they would like research to be conducted in the future. Findings will be analysed with input from Aboriginal leaders and co-published in peer reviewed journals and a local Fitzroy Valley community report as well as co-presented to the Fitzroy Valley communities and the wider scientific community.

METHODS AND ANALYSIS

Study Design

Qualitative methods were chosen for the Picture Talk Project to enable deep exploration of participants' perspectives about research and the consent process¹⁶. The protocol was designed in collaboration with Aboriginal leaders to ensure that local cultural protocols were embedded within each step of the research process. Results will be reported in line with the 32-item checklist for the Consolidated Criteria for Reporting Qualitative research (COREQ)¹⁷. Semi-structured interviews will be conducted with Aboriginal community leaders and focus groups will be conducted with Aboriginal community members using 'research topic yarning' and 'collaborative yarning'^{18,19}. These methods are culturally appropriate for gathering information with Aboriginal people¹⁸. Focus groups provide a way for participants to validate one another and avoid a potential power imbalance between participants and researchers¹⁸.

Setting

The Fitzroy Valley in northern Western Australia has Fitzroy Crossing town at its centre and 45 small communities within a 200km radius²⁰. There are four major language groups in these communities, namely Walmajarri, Wangkatjungka, Gooniyandi, and Bunuba as well as Kija, Nikinya language groups²⁰. The Fitzroy Valley is home to approximately 4,500, 80% of whom are Aboriginal^{20,21}. The whole of the Fitzroy Valley is classified as 'very remote' (ARIA score >9.08-12)^{22,23}. Some communities are only accessible via open

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(unsealed) roads that are often inaccessible during the annual Wet Season²³. This setting creates many challenges for both local community members and visiting researchers, with limited access to resources, transportation, emergency services and healthcare. In addition, potential participants are less engaged in research while coping with the extreme heat in the build-up to the Wet Season with days up to 49°C (120°F). Cultural protocols need to be observed such as Lore (taking young members through traditional initiation) and 'Sorry Business' (mourning) which impact on the availability of local research team members and potential participants^{2,5,24,25}.

180

181 Study Timeline

182 The project is being conducted between January 2012 and December 2017 and the project outline is shown in
183 Figure 1. Data collection and verification will occur from 2012 to 2017. Publication and presentation of final
184 results will occur during 2017 and 2018.

185

186 *Insert Figure 1 here*

187

188 Research Team

189 A partnership was formed between leaders of the local Aboriginal organisations of the Fitzroy Valley
190 community and academic researchers of organisations based in Sydney and Darwin. The chief investigators of
191 The Picture Talk Project are JO, past Chief Executive Officer (CEO) of Marninwarntikura Women's Resource
192 Centre (MWRC)²⁶ and MC, CEO of Nindilingarri Cultural Health Services (NCHS)²⁷ based in the Fitzroy Valley
193 community; HD'A, Aboriginal Researcher, the Menzies School of Research, Darwin²⁸; and researchers EE, AM
194 and PhD Student and trainee in paediatrics EF from the University of Sydney who all have experience working
195 in the remote communities of the Fitzroy Valley². The Picture Talk Project protocol was developed in
196 collaboration with all partners. The team received cultural guidance and support from TL, CEO of the
197 Kimberley Aboriginal Law and Culture Centre (KALACC)²⁹ and Percy Bulagardie and Annette Kogolo from the
198 Kimberley Interpreting Service (KIS)³⁰, Fitzroy Valley. In addition to Aboriginal leaders overseeing the research

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199 process, local Aboriginal community members are employed as *Community Navigators* to interpret language
200 and provide cultural guidance to EF a Non-Aboriginal researcher.

201

202 **Researcher Skills and Specialised Training**

203 According to the COREQ guidelines it is important to declare the background, qualifications and training of the
204 researchers involved in research with Indigenous communities¹⁷. The Picture Talk Project constitutes EF's PhD
205 at the University of Sydney, supervised by EE, AM, HD'A and Gaynor Macdonald. EE is a Professor of
206 Paediatrics and Child Health, and Consultant Paediatrician who has worked in the Fitzroy Valley since 2009 and
207 was the Chief Investigator for the Lililwan project. AM is a psychologist and epidemiologist with Inuit family
208 members (Canada). Both work at the University of Sydney. HD'A is an Aboriginal researcher from the
209 Kimberley, a registered nurse, midwife and public health researcher at the Menzies Institute in Darwin. Gaynor
210 Macdonald is an anthropologist at the University of Sydney. EF worked as a researcher on The Lililwan Project
211 research team in 2011. She completed a Health Research Methods and Ethics course at the University of
212 Sydney; and training for qualitative research with QSR International NVivo³¹. All non-Aboriginal researchers
213 have received cultural awareness training including from Nindilingarri Cultural Health Services²⁷ and Aboriginal
214 people in the Fitzroy Valley.

215

216 **Community Navigators**

217 Local Aboriginal researchers will be employed and trained as Community Navigators by The Picture Talk
218 Project team². A Community Navigator is defined by JO and MC as someone who is Aboriginal, who is local to
219 the community, respected by the community, can interpret language and provide guidance on cultural
220 protocol, and has experience working in both Aboriginal and Western worlds. A different Community
221 Navigator is required for each language group within Fitzroy Crossing. A male Navigator is required when
222 speaking with men and a female Navigator is required for women. Community Navigators guide researchers in
223 cultural protocols regarding kinship ties and skin-name relationships. For example, an Aboriginal man cannot
224 sit in close proximity to his mother-in-law by skin-name relation. Community Navigators on the research team
225 are connected with all four major language groups of the Fitzroy Valley (Walmajarri, Wangkatjungka,

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226 Gooniyandi, and Bunuba as well as other language groups of the Kimberley such as Nikinya and Kija). This
227 ensures adherence with cultural protocols, while simultaneously allowing Community Navigators to gain
228 experience in Western research approaches². Community Navigators will work in partnership with EF to:
229 recruit participants; seek community and individual consent; conduct interviews and focus groups; verify
230 transcripts and coding; present findings to the Fitzroy Valley Community and report findings through
231 publications². A similar approach was taken during the Lililwan Project⁶.

232

233

234 COMMUNITY ENGAGEMENT AND COMMUNITY CONSENT

235

236 Relationships formed with Aboriginal communities

237 Trusting, respectful relationships were formed between the local Aboriginal Community and Non-Aboriginal
238 researchers over several years prior to the commencement of the study². During the Lililwan Project, which
239 was overseen by JO and MC, the authors worked closely with Community Navigators and researchers⁶⁻¹⁴. EF
240 and EE are biased towards the success of the Lililwan Project, which they witnessed first-hand¹⁷. EF is doing
241 this project is to advocate on behalf of the Aboriginal communities for research methods that are culturally
242 respectful and inclusive. Researchers will make regular trips to the Fitzroy Valley to meet face to face with
243 local Aboriginal research team members and ensure ongoing consent from the community. There will be
244 regular meetings conducted with the key organisations of the Fitzroy Valley, namely: Marninwarntikura
245 Women's Resource Centre; Nindilingarri Cultural Health Services; the Kimberley Aboriginal Law and Culture
246 Centre; Karriyili Adult Education Centre; The Fitzroy Valley Men's Shed; Marra Worra Worra; Mangkatja Art
247 Gallery and the Fitzroy Valley Future Forum. All of these organisations will be engaged and consulted about
248 The Picture Talk Project research protocol over a number of visits. As noted by Mr Harry Yungabun, a local
249 Aboriginal leader, health worker and Community Navigator for The Picture Talk Project: *'Every time you come
250 back, people open up to you more'*.

251

252 Project Identity

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253 Following the Lililwan Project, Aboriginal leaders invited researchers to explore the community's
254 understanding of research and the consent process, including the use of visual aids, for example pictures, to
255 explain the research. The name 'The Picture Talk Project' was given by Marmingee Hand (Aboriginal leader,
256 school teacher and Chairperson of the Walmajarri language group of the Fitzroy Valley²). The name was
257 inspired by the use of pictorial flip cards as a visual aid when seeking consent for research for the Lililwan
258 Project⁶, a method suggested by MC²⁷ as a culturally appropriate way of seeking consent.

259 Community Navigator Sandra Nugget and local artist Neil Carter from KALACC²⁹ worked with EF to design a
260 project logo (Figure 2) and motto : *'Talking together, learning together, knowing together'*². The logo
261 represents all the major language groups and shows the Fitzroy River (blue), the life-force of the town,
262 intersecting with the Great Northern Highway, representing the junction between Aboriginal and Western
263 worlds². The four quadrants represent the main language groups of The Valley – the purple hills to the north
264 are the King Leopold Ranges (soon to be renamed Wilinggin Conservation Park³²) in Bunuba country; the Black
265 Hills of the east represent Gooniyandi country and the Great Sandy Desert in the south represents Walmajarri,
266 Wangkatjungka, Nyikinya and Kija country²⁰. The black band surrounding the logo represents local Aboriginal
267 people whom visitors are required to work with if they wish to enter local Aboriginal communities².

268 This project logo will be used as a visual way of communicating what the project is about and identifying
269 researchers. Through explaining what the logo represents, people will understand the purpose of the research.
270 The logo will be printed on uniforms for research workers and mugs and tote bags to be given to participants.
271 The logo will be used on magnets for project cars and posters for car windows and elsewhere so community
272 onlookers may read about The Picture Talk Project and approach the research team if they wish.

273

274 *Insert Figure 2 here*

275

276 **Participants**

277 There will be two types of participants – Aboriginal community leaders/elders and Aboriginal community
278 members. Aboriginal community leaders of Fitzroy Crossing are defined by JO as any person who is respected
279 by the community, holds local cultural knowledge, has experience working with both the Aboriginal and

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Western worlds and is nominated to represent and advocate for the community. Community leaders include elders whose positions are based on the cultural hierarchy of the community. It was considered acceptable to invite community leaders to be interviewed by EF in the presence of a Community Navigator². In contrast, it was deemed more culturally acceptable to hold focus groups with Aboriginal community members, rather than interviews, because many community members have had few interactions with research and Western protocols. Some focus groups will include Aboriginal community members who are parents and carers of children of the Fitzroy Valley, some of whom may have participated in the Lililwan Project. All participants will be invited to participate by a Community Navigator. The Community Navigator will be present during all interviews to support participants.

289

290 Recruitment

Community presentations will be made to key Aboriginal organisations of the Fitzroy Valley and community consent will be requested and granted at these meetings. Recruitment of Aboriginal community leaders will be through purposive sampling, by inviting the participation of Chief Executive Officers of local Aboriginal organisations; chairpersons of communities and language group organisations; as well as cultural elders of each of the language groups^{2,16,33,34}. Aboriginal community leaders will be visited by Community Navigators inviting them to learn more about the study. In contrast, because it has been recommended to proceed this way - it will be up to Aboriginal community members to approach the research team if they are interested in being involved in focus groups. The recruitment of community members will be through snowball sampling^{16,33,34}. Friends and family members of the Community Navigators; members of local Aboriginal organisations; and other research participants will be invited in person to participate. They will be given time to consider participation and asked to approach the Community Navigator should they agree.

302

Potential participants may nominate the time and place that is most convenient for them to be introduced to EF by the Community Navigator. EF and Community Navigators will work together to explain the scope of the research project using a participant information sheet and consent form in plain English and seek signed or verbal consent (witnessed by the Community Navigator) from each participant. They will then collect basic demographic information from each participant including age group, sex, education, language group, language

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of preference and cultural knowledge. It will be made clear that participants can decline to participate at any time and if they chose to do so the Community Navigator will investigate why they chose to decline.

Participants may nominate the Community Navigator they feel most comfortable to work with. Community members participating in focus groups may select which group of participants they would like to share a focus group with. There will be separate focus groups for males and females. The number of participating leaders and community members required for this study will be guided by what is scientifically rigorous yet culturally appropriate. For qualitative research, data will continue to be collected and analysed until all of the themes are 'saturated'³⁵. In order to be deemed culturally appropriate it is imperative that a certain number of elders, leaders and community members are consulted from each of the main language groups included, both males and females as guided by the Aboriginal leaders and Community Navigators on the research team.

Data Collection

A topic guide will be developed for the interviews and focus groups to ensure steps taken prior to collection of data are consistent (*See Additional Files 1 and 2*). This will include instructions about when to start the tape recorder if consent is granted. The content of the interview and focus group questions is based on findings from the literature review^{1,2}. The research questions were informed by qualitative research methods^{16,18,19,33-40}. The language of the questions was guided by JO and MC and the Community Navigators. The delivery of questions will be guided by the Community Navigators at the time of data collection².

Interviews with leaders

Aboriginal community leaders will participate in semi-structured interviews in the format of 'research topic yarning'. 'Yarning' is an Aboriginal way of conversing and connecting through storytelling¹⁸. This culturally appropriate method, as described by Dawn Bessarab (an Aboriginal researcher), involves starting the conversation with what she describes as 'social yarning' where the researcher makes casual conversation with the participant in order to find common ground and potential connections through family or community and consequently gain trust and rapport¹⁸. The researcher will then formalise the conversation by announcing the start of research questions and commence 'research topic yarning' where questions are asked in a semi-structured style and any form of response is encouraged, including in a conversational or story-telling format.

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337 Aboriginal community leaders will be asked about their experiences with research and the process of
338 community and individual consent. Interview questions (*See Additional File 3*) will be asked in English by EF
339 and interpreted by the Community Navigator into the language preferred by the Aboriginal leader if required.
340 Interviews will be kept flexible and reactive to participants' responses – including both verbal and body
341 language. If the Community Navigator reads that the body language starts to look closed off or disengaged,
342 questions will be asked in a different way. Time will be allowed for silence after a question is asked. With
343 consent, interviews will be either voice recorded or responses hand written and transcribed later into a
344 Microsoft Word document.

345

346 **Focus Groups with community members**

347

348 Aboriginal community members will participate in focus groups in a format similar to 'collaborative yarning'¹⁸,
349 which creates a space in which participants can feel comfortable and speak freely¹⁹. The focus group will first
350 start with 'social yarning' as described above in order to gain trust and rapport¹⁸. The conversation will then be
351 formalised to 'collaborative yarning' within the focus group, which is described as a yarn that occurs between
352 two or more people who are discussing a research topic which may lead to new understandings¹⁸. The
353 advantage of the focus group format is that it creates a forum in which issues arise such as community
354 attitudes, values and beliefs that might not have otherwise been brought to light in a one to one interview^{36,37}.
355 In addition, a focus group creates the capacity for the group to speak with one voice and reach consensus,
356 which is in line with the group-focused Aboriginal way of knowing⁴⁰. Aboriginal community members will be
357 asked about their experiences with research and the individual consent process. They will be provided with an
358 example of a participant information form and consent form that was used with parents and carers of the
359 Lililwan Project and asked to share their thoughts. Focus group questions (*See Additional File 4*) will be
360 conducted in English and interpreted by the Community Navigators into the language preferred by
361 participants. EF and the Community Navigators will facilitate focus groups together, encouraging the quieter
362 participants, and managing the more dominant voices to ensure all participants get to share their opinions.

363

364 **Data Transcription and Processing**

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All interviews and focus group recordings will be transcribed verbatim and handwritten responses will be typed into Microsoft Word documents. Transcripts will be verified with participants and Community Navigators. Data will be uploaded into NVivo10 qualitative software to facilitate the coding process (31).

Data Analysis

A research diary will be kept to record the date, time, duration and setting of each interview and focus group, noting who is present and the first impressions of the research process. Initial codes will be created immediately after each session based on the main topics discussed^{33-35,41,42}. Additional notes will be made about current community events such as 'Sorry Business' (mourning)²⁵, which can affect participation rates and the mood of participants.

Individual interviews and focus groups will be analysed separately. A coding topic guide will be created for the initial analysis of transcripts. Transcripts will be uploaded into NVivo10 qualitative software to facilitate coding^{31,41}. Coding of data will be conducted line-by-line and derived through deductive and inductive processes using grounded theory⁴². A code hierarchy will be formed from this process and cross-referenced against all transcripts^{34,42}. Overarching themes will be synthesised from this analysis and compared back against the data, known as the 'constant comparison method'^{34,43}. Rich quotes will be identified to support these themes^{31,35,41}. Coding will continue until all themes are saturated and no new information is derived^{16,33-35,41-44}.

EF will code all transcripts to ensure coding is consistent. Community Navigators will code random segments of data and this will be verified against coding done by EF to ensure reliability⁴². Research participants will be encouraged to give verbal feedback on findings individually or during community presentations and workshops¹⁷.

ETHICS APPROVAL AND DISSEMINATION

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393 Core Values

394 The Picture Talk Project follows guidelines from the Lowitja Institute, AIATSIS and NHMRC Guidelines for
395 conduct of research with Aboriginal and Torres Strait Islander Peoples in order to ensure cultural protocols are
396 respected and embedded into each step of our research process^{5,24,45-47}. This project upholds the six core
397 values identified as important when conducting research with Aboriginal communities, namely: Respect,
398 Equality, Reciprocity, Survival and Protection, Responsibility and above all is conducted in the right Spirit and
399 with Integrity⁴⁵. This project seeks to ensure free, prior, informed consent is obtained from all participants and
400 community leaders for all stages of the research.

401

402 Ethics Committee Approval

403 Ethics approval was granted by the University of Sydney Human Research Ethics Committee (No. 2012/348,
404 reference:14760), the Western Australian Aboriginal Health Ethics Committee, the Western Australian Country
405 Health Service Research Ethics Committee (No. 2012:15), and the Kimberley Aboriginal Health Planning Forum
406 Research Subcommittee (No. 2012-008).

407

408 Focus Group Consent

409 When signing consent to participate in focus groups, participants will be asked to ensure the confidentiality of
410 discussions. Participants will be informed that they may withdraw from the session at any time but they are
411 not able to request that their answers be erased/destroyed because this would require destroying material
412 provided by others in the group.

413

414 De-identification and Storage of Data

415 Individual participant data will be de-identified and participants will be allocated a study code number. Focus
416 groups will be numbered and participants coded accordingly. Voice recorded material will be transcribed.
417 Quotations used in research reports to capture the rich qualitative data obtained during interviews and focus

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418 groups will be de-identified. Data will be securely stored electronically on a password protected network drive
419 and only nominated study investigators will have access to the data.

420 Throughout the study, hard copy data will be stored securely in a locked filing cabinet in the University of
421 Sydney – Sydney Medical School Discipline of Child and Adolescent Health, Sydney Children's Hospital Network
422 (Westmead) or Marninwarntikura Women's Resource Centre, Fitzroy Valley. At the conclusion of the study all
423 data will reside at the University of Sydney and de-identified data will be accessible to the research community
424 on application.

425 As per guidelines set out by the University of Sydney Human Research Ethics Committee, all data including
426 audio files will be retained for a period of 7 years.

427 **Consent for Dissemination**

428 Community and individual consent will be sought for publication, dissemination and presentation of all aspects
429 of this research to date.

430

431

432 **DISCUSSION**

433

434 Key strengths of this study are that it was prioritised and initiated by the community, will be conducted in
435 partnership with Aboriginal community leaders who are Chief Investigators of this study, and that two thirds of
436 the research team are local Aboriginal people. The Picture Talk Project is designed to be culturally sensitive
437 while maintaining scientific rigor through analysis using grounded theory. This qualitative study will explore
438 how researchers can form collaborative partnerships with Aboriginal communities to ensure that informed
439 consent and respect for Aboriginal culture are embedded at every stage of the process. The Picture Talk
440 Project seeks to embody these values and lead by example. Local interpreters are trained and employed as
441 Community Navigators on the research team to provide guidance in language and cultural protocol throughout
442 the research process - from consent seeking to presentation of results.

443 A limitation of this study is that some nuances of language may be lost through the process of interpreting
444 between local languages and English.

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445 This is this first study with a specific focus on community engagement and the process of seeking consent for
446 research in Aboriginal communities. This research will provide a voice for remote-dwelling Aboriginal people of
447 the Fitzroy Valley, and provide unique insights into understanding of research and preferences about how it
448 should be conducted to embody respect for Aboriginal culture and values.

For peer review only

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Competing Interests

There are no competing interests for any of the authors of this paper.

Authors Contributions

Dr Emily Fitzpatrick led the study and the writing of the paper. Prof Elizabeth Elliott initiated and provided oversight to the study and input in its planning, conduct and reporting. Ms June Oscar and Ms Maureen Carter invited this study, advised on the protocol design and are the chief cultural advisors as Aboriginal community leaders of the Fitzroy Valley, The Kimberley and had input into the manuscript. Mr Tom Lawford provided cultural guidance and support from the men's side at the Kimberley Aboriginal Law and Culture Centre and had input into the manuscript. Assoc Prof Alexandra Martiniuk and Ms Heather D'Antoine contributed to the design of the study and the writing of the paper. All authors reviewed and approved the final manuscript.

Reporting Guideline

This paper is reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines. The COREQ check list is shown below in table 1.

Figure Legends

Figure 1. The Picture Talk Project Protocol

Figure 2. The Picture Talk Project Logo

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References

1. Fitzpatrick EFM MA, D’Antoine H, Oscar J, Carter M, Elliott EJ. Seeking Consent for Research with Indigenous Communities: A Systematic Review. BMC Medical Ethics. 2016.

2. Fitzpatrick EFM, Macdonald G, Martiniuk ALC, D’Antoine H, Oscar J, Carter M, et al. The Picture Talk Project: Starting a Conversation with Community Leaders on Research with Remote Aboriginal Communities of Australia. BMC Med Ethics. 2017;18(1):34.

3. Dodson M, Williamson R. Indigenous peoples and the morality of the Human Genome Diversity Project. Journal of Medical Ethics. 1999;25(2):204-8.

4. UN. State of the World’s Indigenous Peoples. United Nations Division for Social Policy and Development of the Department of Economic and Social Affairs.; 2015.

5. Laycock A, Walker D., Harrison, N., and Brands, J. Researching Aboriginal Health: A Practical Guide for Researchers. Melbourne, Vic, Australia: The Lowitja Institute: Australia’s National Institute for Aboriginal and Torres Strait Islander Research; 2011.

6. Fitzpatrick JP, Elliott EJ, Latimer J, Carter M, Oscar J, Ferreira M, et al. The Lililwan Project: study protocol for a population-based active case ascertainment study of the prevalence of fetal alcohol spectrum disorders (FASD) in remote Australian Aboriginal communities. BMJ Open. 2012;2(3).

7. Fitzpatrick JP, Latimer J, Carter M, Oscar J, Ferreira ML, Carmichael Olson H, et al. Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: the Lililwan Project. J Paediatr Child Health. 2015;51(4):450-7.

8. Fitzpatrick JP, Latimer J, Ferreira ML, Carter M, Oscar J, Martiniuk AL, et al. Prevalence and patterns of alcohol use in pregnancy in remote Western Australian communities: The Lililwan Project. Drug Alcohol Rev. 2015;34(3):329-39.

9. Fitzpatrick JP, Latimer J, Olson HC, Carter M, Oscar J, Lucas BR, et al. Prevalence and profile of Neurodevelopment and Fetal Alcohol Spectrum Disorder (FASD) amongst Australian Aboriginal children living in remote communities. Res Dev Disabil. 2017;65:114-26.

10. Elliott E, Latimer J, Fitzpatrick J, Oscar J, Carter M. There’s hope in the valley. J Paediatr Child Health. 2012;48(3):190-2.

11. Latimer J Elliott E FJea. Marulu: The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation. The George Institute for Global Health; 2010.

12. Hogan M. Yajilarra. A documentary. Fitzroy Crossing, Australia2008.

13. Hogan M. For the Lililwan Project: Marulu. A documentary. Fitzroy Crossing, Australia2009.

14. Tsang TW, Lucas BR, Carmichael Olson H, Pinto RZ, Elliott EJ. Prenatal Alcohol Exposure, FASD, and Child Behavior: A Meta-analysis. Pediatrics. 2016;137(3):e20152542.

15. Gooda M. Chapter 3: From community crisis to community control in the Fitzroy Valley - Social Justice Report 2010 | Australian Human Rights Commission. Canberra, ACT, Australia: Parliament House; 2010.

16. Rice PL, Ezzy, D. Qualitative Research Methods. Melbourne, Victoria: Oxford University Press; 1999.

17. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349-57.

18. Bessarab D, Ng’andu B. Yarning about yarning as a legitimate method in indigenous research. International Journal of Critical Indigenous Studies. 2010;3(1):37-50.

19. Geia LK, Hayes B, Usher K. Yarning/Aboriginal storytelling: towards an understanding of an Indigenous perspective and its implications for research practice. Contemp Nurse. 2013;46(1):13-7.

20. Morphy F. Population, people and place: The Fitzroy Valley Population Project. Centre for Aboriginal Economic Policy Research: Australian National University; 2010 2010-07-01T12:26:09+1000. Contract No.: Working paper 70.

21. ABS. Australian Bureau of Statistics Census QuickStats: Fitzroy Crossing. 2011.

22. AIHW. Rural, Regional and Remote Health: A Guide to Remoteness Classifications. In: Unit LFArH, editor. Canberra, Australia2004.

23. DHAC. Measuring Remoteness Accessibility/Remoteness Index of Australia (ARIA). 2001.

24. AIATSIS. Guidelines for Ethical Research in Indigenous Studies Australia: Australian Institute of Aboriginal and Torres Strait Islander Studies; 2012.

25. Wynne-Jones M HA, Byers D, Stanley D, Edwige V, Brideson T Aboriginal grief and loss: a review of the literature. Australian Indigenous Health Bulletin. 2016;16(3):1-9.

29 June 2017

- 532 26. MWRC. Marninwarntikura Women's Resource Centre Fitzroy Crossing, Australia [Available from: <https://www.mwrc.com.au/>.]
- 533
- 534 27. NCHS. Nindilinggarri Cultural Health Services Fitzroy Crossing, Australia [Available from: <http://www.nindilinggarri.org.au/>.]
- 535
- 536 28. MSHR. Menzies School of Health Research, Darwin, Australia [Available from: <http://www.menzies.edu.au/>.]
- 537
- 538 29. KALACC. Kimberley Aboriginal Law and Culture Centre Fitzroy Crossing, Australia [Available from: <http://www.kalacc.org.au/>.]
- 539
- 540 30. KIS. Kimberley Interpreting Service [Available from: <http://www.kimberleyinterpreting.org.au/>.]
- 541 31. QSR. NVivo 10 Qualitative Software [Available from: <http://www.qsrinternational.com/>.]
- 542 32. New national park for the north Kimberley [press release]. Australia2017.
- 543 33. Sobo EJ. Culture and Meaning in Health Services Research: A Practical Field Guide. Walnut Creek, California: Left Coast Press; 2009.
- 544
- 545 34. Crabtree B MW. Doing Qualitative Research: Research Methods of Primary Care. Newbury Park, CA: Sage Publications; 1992.
- 546
- 547 35. Green J, Thorogood N. Qualitative methods for health research. London: SAGE; 2004.
- 548 36. Christopher S, Watts, V., McCormick, A.K.H.G., Young, S. Building and maintaining trust in a community-based participatory research partnership. . American Journal of Public Health. 2008;98(8):1398-406.
- 549
- 550 37. Coreil J. Group interview methods in community health research. Med Anthropol. 1995;16(3):193-210.
- 551
- 552 38. Fereday J, Muir-Cochrane, E. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. . International Journal of Qualitative Methods. 2008;5(1):80-92.
- 553
- 554 39. Liamputtong P, Ezzy, D. Qualitative research methods. 2nd ed. Oxford, UK: Oxford University Press; 2005.
- 555
- 556 40. Willis E, Pearce, M., Jenkin, T. Adapting focus group methods to fit Aboriginal community-based research. Qualitative Research Journal. 2005;5(2):112-23.
- 557
- 558 41. Bazeley P. Qualitative Data Analysis with Nvivo. London: Sage; 2007.
- 559
- 560 42. Bradley EH, Curry, L.A., Devers, K.J. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. . Health Services Research. 2007;42:1758-72.
- 561
- 562 43. Strauss A, Corbin, J. The Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park, CA: Sage Publishing; 1990.
- 563
- 564 44. Hannes K, Lockwood, C. Synthesizing Qualitative Research: Choosing the right approach. London, United Kingdom: Wiley-Blackwell; 2012.
- 565
- 566 45. NHMRC. Values and Ethics: Guidelines for Conduct of Aboriginal and Torres Strait Islander Health Research. In: Council NHaMR, editor. Australia2003.
- 567
- 568 46. NHMRC. Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander People About Health Research and Ethics. In: Council NHaMR, editor. Australia2005.
- 569
- 570 47. NHMRC. Road Map II: A strategic framework for improving Aboriginal and Torres Strait Islander Health Through Research. In: Council NHaMR, editor. Australia2010.
- 571
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Figure 1 The Picture Talk Project Research Protocol



Figure 2. The Picture Talk Project Logo

COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	11-13
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	8&9
Occupation	3	What was their occupation at the time of the study?	7&8
Gender	4	Was the researcher male or female?	8
Experience and training	5	What experience or training did the researcher have?	8&9
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	9
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	10&11
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	9
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	2&14
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	11
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	11
Sample size	12	How many participants were in the study?	12
Non-participation	13	How many people refused to participate or dropped out? Reasons?	11
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	11
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	13
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	11&12
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	12
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	12&13
Field notes	20	Were field notes made during and/or after the inter view or focus group?	14
Duration	21	What was the duration of the inter views or focus group?	14
Data saturation	22	Was data saturation discussed?	11&14
Transcripts returned	23	Were transcripts returned to participants for comment and/or	14

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	14
Description of the coding tree	25	Did authors provide a description of the coding tree?	14
Derivation of themes	26	Were themes identified in advance or derived from the data?	14
Software	27	What software, if applicable, was used to manage the data?	14
Participant checking	28	Did participants provide feedback on the findings?	14
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	14
Data and findings consistent	30	Was there consistency between the data presented and the findings?	14
Clarity of major themes	31	Were major themes clearly presented in the findings?	14
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	14

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

BMJ Open

Research protocol for The Picture Talk Project: a qualitative study on research and consent with remote Australian Aboriginal communities

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Primary Subject Heading:	Research methods
Secondary Subject Heading:	Qualitative research, Health policy, Global health, Communication, Health services research
Keywords:	Aboriginal, Indigenous, Australia, QUALITATIVE RESEARCH, Consent, Community

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Manuscripts

23 October 2017

Research protocol for The Picture Talk Project: a qualitative study on research and consent with remote Australian Aboriginal communities

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ABSTRACT**Introduction**

Research with Indigenous populations is not always designed with cultural sensitivity. Few publications evaluate or describe in detail seeking consent for research with Indigenous participants. When potential participants are not engaged in a culturally respectful manner, participation rates and research quality can be adversely affected. It is unethical to proceed with research without truly informed consent.

Methods and Analysis

We describe a culturally appropriate research protocol is invited by Aboriginal communities of the Fitzroy Valley in Western Australia. The Picture Talk Project is a partnership with local Aboriginal leaders who are also chief investigators. We will interview Aboriginal leaders about research, community engagement and the consent process and hold focus groups with Aboriginal community members about individual consent. Cultural protocols will be applied to recruit and conduct research with participants. Transcripts will be analysed using NVivo10 qualitative software and themes synthesised to highlight the key issues raised by the community about the research process.

This protocol will guide future research with the Aboriginal communities of the Fitzroy Valley and may inform the approach to research with other Indigenous communities of Australia or the world. It must be noted, that no community is the same and all research requires local consultation and input. To conduct culturally sensitive research, respected local people from the community who have knowledge of cultural protocol and language are engaged to guide each step of the research process from the project design to the delivery of results.

Ethics and Dissemination

Ethics approval was granted by the University of Sydney Human Research Ethics Committee, the Western Australia Country Health Service Ethics Committee, the Western Australian Aboriginal Health Ethics Committee and reviewed by the Kimberley Aboriginal Health Planning Forum Research Sub-Committee. Results will be disseminated through peer review articles, local Fitzroy Valley report and conference presentations.

Key Words

Research Methods, Remote, Aboriginal, Indigenous, Community Engagement, Consent

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ARTICLE SUMMARY

Strengths and Limitations of this Study

- This is one of few studies reporting Aboriginal community understanding of research. It is led by a research team that includes Aboriginal leaders, experienced public health researchers and clinicians and is conducted in a way that is respectful and culturally appropriate. We will seek advice on the understanding of research and preferences for community engagement and the process of seeking consent for research directly from Aboriginal leaders and community members.
- Local interpreters employed as Community Navigators allow research participants to speak in their language of preference, including all major local languages of the Fitzroy Valley.
- Community Navigators provide cultural guidance to visiting researchers to ensure local cultural protocols are observed throughout the research process.
- Due to limited capacity and availability of interpreters, data analysis will be conducted in English so some subtleties of local Aboriginal language may have been lost in translation.
- This is a relatively small study in a discreet geographical setting, although likely applicable to similar remote communities elsewhere in Australia, findings may not be generalizable to all Indigenous communities.

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Research protocol for The Picture Talk Project: a qualitative study on research and consent with remote Australian Aboriginal communities

INTRODUCTION

When seeking consent for research with Indigenous people, time is rarely taken to reflect on the process^{1,2}. If research is not conducted in a culturally respectful way, it can adversely affect participation rates and the quality of the research³. Our systematic literature review of research, which describes or evaluates the process for seeking consent and the preference or understanding of the consent process for research with Indigenous communities, identified few relevant publications¹. Few detailed the methods used when seeking consent, including use of videos, flip charts or local researchers to interpret information for Indigenous participants¹. Even fewer evaluated whether this information was understood or presented in a way that is preferred by Indigenous participants¹. It should be noted that since there is such variety of Indigenous populations around the world, the United Nations does not have a specific definition for 'Indigenous'⁴. This term will be used when referring to populations in a general sense, however when publications specify the name of a group of people such as 'Aboriginal', that term will be used.

Guidelines for research with Indigenous communities recommend that Indigenous community members be involved in all stages of the research process⁵. Strong trusting relationships between outside researchers and local community partners are essential⁵. In this paper we describe the research methods for The Picture Talk Project, a qualitative research project conducted together with remote Aboriginal communities of the Fitzroy Valley in the Kimberley region of Western Australia. In the Picture Talk Project we will interview community leaders about the community engagement and consent process for research, conduct community focus groups about the individual consent process and publish and present findings. We hope The Picture Talk Project will support Indigenous people like those living in the Kimberley to have a more ethical, collaborative experience when participating in research and empower them to guide the research agenda to address community priorities while embedding cultural protocol into each step of the research process².

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106 **Invitation from the Community**

107 Following the Lililwan Project on Fetal Alcohol Spectrum Disorder (FASD) prevalence⁶⁻¹⁴ the Picture Talk Project
108 team was invited by Aboriginal leaders of the Fitzroy Valley to explore community understanding of research
109 and consent². The Lililwan project was initiated after communities leaders noticed that some of their children
110 looked different and had trouble learning, and expressed concern that these children would not remember the
111 dreamtime stories to be passed down to the next generation^{12,13}. Because alcohol use in pregnancy was
112 common, they wondered if these children might have FASD, so invited researchers to come to the Fitzroy
113 Valley and investigate the issue¹¹⁻¹³. The project was initiated by and conducted in partnership with Aboriginal
114 community leaders following community consultation and agreement that it was an important issue to
115 investigate¹¹⁻¹³. Local Aboriginal researchers were employed as Community Navigators to interpret for those
116 whose first language was not English and provide cultural guidance to the non-Aboriginal researchers^{2,6}.
117 Aboriginal and non-Aboriginal team members guided each other so that the research was both scientifically
118 rigorous and culturally relevant^{2,6}. The Lililwan Project was so well received that in 2010 the Social Justice
119 Commissioner for Aboriginal and Torres Strait Islander people, Mr Michael Gooda, reported that it should set
120 an example for research with Aboriginal people¹⁵. The Picture Talk Project was subsequently initiated, and
121 researchers were invited to reflect with communities of the Fitzroy Valley on how and why the Lililwan Project
122 worked so well and to discuss the processes that should underpin research engagement and consent for the
123 future.

124 **Why this study is important**

125 This research protocol uses collaborative, culturally respectful, flexible research methods to allow for
126 participants to be in a space where they may speak freely about their experiences and opinions of research.
127 Findings from this study will inform the approach of future studies with Indigenous communities.

129 **Study Aims**

130 The Picture Talk Project is a community-based project conducted with local Aboriginal leaders of the Fitzroy
131 Valley that aims to examine the community engagement and consent process. This will be achieved by
132 interviewing Aboriginal community leaders about community consent and the research engagement process

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and holding focus groups with Aboriginal community members about their experiences with research and the individual consent process. Both groups will be asked how they would like research to be conducted in the future. Findings will be analysed with input from Aboriginal leaders and co-published in peer reviewed journals and a local Fitzroy Valley community report as well as co-presented to the Fitzroy Valley communities and the wider scientific community.

METHODS AND ANALYSIS

Study Design

Qualitative methods were chosen for the Picture Talk Project to enable deep exploration of participants' perspectives about research and the consent process¹⁶. The protocol was designed in collaboration with Aboriginal leaders to ensure that local cultural protocols were embedded within each step of the research process. Results will be reported in line with the 32-item checklist for the Consolidated Criteria for Reporting Qualitative research (COREQ)¹⁷. Semi-structured interviews will be conducted with Aboriginal community leaders and focus groups will be conducted with Aboriginal community members using 'research topic yarning' and 'collaborative yarning'^{18,19}. These methods are considered the best cultural match²⁰ for gathering information with Aboriginal people^{18,19,21}. Focus groups provide a way for participants to validate one another and avoid a potential power imbalance between participants and researchers¹⁸.

Setting

The Fitzroy Valley in northern Western Australia has Fitzroy Crossing town at its centre and 45 small communities within a 200km radius²². There are four major language groups in these communities, namely Walmajarri, Wangkatjungka, Gooniyandi, and Bunuba as well as Kija, Nikinya language groups²². The Fitzroy Valley is home to approximately 4,500, 80% of whom are Aboriginal^{22,23}. The whole of the Fitzroy Valley is classified as 'very remote' (ARIA score >9.08-12)^{24,25}. Some communities are only accessible via open

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(unsealed) roads that are often inaccessible during the annual Wet Season²⁵. This setting creates many challenges for both local community members and visiting researchers, with limited access to resources, transportation, emergency services and healthcare. In addition, potential participants are less engaged in research while coping with the extreme heat in the build-up to the Wet Season with days up to 49°C (120°F). Cultural protocols need to be observed such as Lore (taking young members through traditional initiation) and 'Sorry Business' (mourning) which impact on the availability of local research team members and potential participants^{2,5,26,27}.

Study Timeline

The project is being conducted between January 2012 and December 2017 and the project outline is shown in Figure 1. Data collection and verification will occur from 2012 to 2017. Publication and presentation of final results will occur during 2017 and 2018.

Insert Figure 1 here

Research Team

A partnership was formed between leaders of the local Aboriginal organisations of the Fitzroy Valley community and academic researchers of organisations based in Sydney and Darwin. The chief investigators of The Picture Talk Project are JO, past Chief Executive Officer (CEO) of Marninwarntikura Women's Resource Centre (MWRC)²⁸ and MC, CEO of Nindilingarri Cultural Health Services (NCHS)²⁹ based in the Fitzroy Valley community; HD'A, Aboriginal Researcher, the Menzies School of Research, Darwin³⁰; and researchers EE, AM and PhD Student and trainee in paediatrics EF from the University of Sydney who all have experience working in the remote communities of the Fitzroy Valley². The Picture Talk Project protocol was developed in collaboration with all partners. The team received cultural guidance and support from TL, CEO of the Kimberley Aboriginal Law and Culture Centre (KALACC)³¹ and Percy Bulagardie and Annette Kogolo from the Kimberley Interpreting Service (KIS)³², Fitzroy Valley. In addition to Aboriginal leaders overseeing the research

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process, local Aboriginal community members are employed as *Community Navigators* to interpret language and provide cultural guidance to EF a Non-Aboriginal researcher.

Researcher Skills and Specialised Training

According to the COREQ guidelines it is important to declare the background, qualifications and training of the researchers involved in research with Indigenous communities¹⁷. The Picture Talk Project constitutes EF's PhD at the University of Sydney, supervised by EE, AM, HD'A and Gaynor Macdonald. EE is a Professor of Paediatrics and Child Health, and Consultant Paediatrician who has worked in the Fitzroy Valley since 2009 and was the Chief Investigator for the Lililwan project. AM is a psychologist and epidemiologist with Inuit family members (Canada). Both work at the University of Sydney. HD'A is an Aboriginal researcher from the Kimberley, a registered nurse, midwife and public health researcher at the Menzies Institute in Darwin. Gaynor Macdonald is an anthropologist at the University of Sydney. EF worked as a researcher on The Lililwan Project research team in 2011. She completed a Health Research Methods and Ethics course at the University of Sydney; and training for qualitative research with QSR International NVivo³³. All non-Aboriginal researchers have received cultural awareness training including from Nindilingarri Cultural Health Services²⁷ and Aboriginal people in the Fitzroy Valley.

Community Navigators

Local Aboriginal researchers will be employed and trained as Community Navigators by The Picture Talk Project team². A Community Navigator is defined by JO and MC as someone who is Aboriginal, who is local to the community, respected by the community, can interpret language and provide guidance on cultural protocol, and has experience working in both Aboriginal and Western worlds. A different Community Navigator is required for each language group within Fitzroy Crossing. A male Navigator is required when speaking with men and a female Navigator is required for women. Community Navigators guide researchers in cultural protocols regarding kinship ties and skin-name relationships. For example, an Aboriginal man cannot sit in close proximity to his mother-in-law by skin-name relation. Community Navigators on the research team are connected with all four major language groups of the Fitzroy Valley (Walmajarri, Wangkatjungka,

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212 Gooniyandi, and Bunuba as well as other language groups of the Kimberley such as Nikinya and Kija). This
213 ensures adherence with cultural protocols, while simultaneously allowing Community Navigators to gain
214 experience in Western research approaches². Community Navigators will work in partnership with EF to:
215 recruit participants; seek community and individual consent; conduct interviews and focus groups; verify
216 transcripts and coding; present findings to the Fitzroy Valley Community and report findings through
217 publications². A similar approach was taken during the Lililwan Project⁶.

218

219

220 COMMUNITY ENGAGEMENT AND COMMUNITY CONSENT

221

222 Relationships formed with Aboriginal communities

223 Trusting, respectful relationships were formed between the local Aboriginal Community and Non-Aboriginal
224 researchers over several years prior to the commencement of the study². During the Lililwan Project, which
225 was overseen by JO and MC, the authors worked closely with Community Navigators and researchers⁶⁻¹⁴. EF
226 and EE are biased towards the success of the Lililwan Project, which they witnessed first-hand¹⁷. EF is doing
227 this project to advocate on behalf of the Aboriginal communities for research methods that are culturally
228 respectful and inclusive. A provisional budget and flexible timeline has been developed to account for any
229 unexpected expenses or delays. EF will make regular trips to the Fitzroy Valley to meet face to face with local
230 Aboriginal research team members and ensure ongoing consent from the community. There will be regular
231 meetings conducted with the key organisations of the Fitzroy Valley, namely: Marninwarntikura Women's
232 Resource Centre; Nindilingarri Cultural Health Services; the Kimberley Aboriginal Law and Culture Centre;
233 Karriyili Adult Education Centre; The Fitzroy Valley Men's Shed; Marra Worra Worra; Mangkatja Art Gallery
234 and the Fitzroy Valley Future Forum. All of these organisations will be engaged and consulted about The
235 Picture Talk Project research protocol over a number of visits. As noted by Mr Harry Yungabun, a local
236 Aboriginal leader, health worker and Community Navigator for The Picture Talk Project: *'Every time you come
237 back, people open up to you more'*.

238

239 Project Identity

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240 Following the Lililwan Project, Aboriginal leaders invited researchers to explore the community's
241 understanding of research and the consent process, including the use of visual aids, for example pictures, to
242 explain the research. The name 'The Picture Talk Project' was given by Marmingee Hand (Aboriginal leader,
243 school teacher and Chairperson of the Walmajarri language group of the Fitzroy Valley²). The name was
244 inspired by the use of pictorial flip cards as a visual aid when seeking consent for research for the Lililwan
245 Project⁶, a method suggested by MC²⁹ as a culturally appropriate way of seeking consent.

246 Community Navigator Sandra Nugget and local artist Neil Carter from KALACC³¹ worked with EF to design a
247 project logo (Figure 2) and motto : *'Talking together, learning together, knowing together'*². The logo
248 represents all the major language groups and shows the Fitzroy River (blue), the life-force of the town,
249 intersecting with the Great Northern Highway, representing the junction between Aboriginal and Western
250 worlds². The four quadrants represent the main language groups of The Valley – the purple hills to the north
251 are the King Leopold Ranges (soon to be renamed Wilinggin Conservation Park³⁴) in Bunuba country; the Black
252 Hills of the east represent Gooniyandi country and the Great Sandy Desert in the south represents Walmajarri,
253 Wangkatjungka, Nyikinya and Kija country²². The black band surrounding the logo represents local Aboriginal
254 people whom visitors are required to work with if they wish to enter local Aboriginal communities².

255 This project logo will be used as a visual way of communicating what the project is about and identifying
256 researchers. Through explaining what the logo represents, people will understand the purpose of the research.
257 The logo will be printed on uniforms for research workers and mugs and tote bags to be given to participants.
258 The logo will be used on magnets for project cars and posters for car windows and elsewhere so community
259 onlookers may read about The Picture Talk Project and approach the research team if they wish.

260

261 *Insert Figure 2 here*

262

263 **Participants**

264 There will be two types of participants – Aboriginal community leaders/elders and Aboriginal community
265 members. Aboriginal community leaders of Fitzroy Crossing are defined by JO as any person who is respected
266 by the community, holds local cultural knowledge, has experience working with both the Aboriginal and

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Western worlds and is nominated to represent and advocate for the community. Community leaders include elders whose positions are based on the cultural hierarchy of the community. It was considered acceptable to invite community leaders to be interviewed by EF in the presence of a Community Navigator². In contrast, it was deemed more culturally acceptable to hold focus groups with Aboriginal community members, rather than interviews, because many community members have had few interactions with research and Western protocols^{18,19,20,21}. Some focus groups will include Aboriginal community members who are parents and carers of children of the Fitzroy Valley, some of whom may have participated in the Lililwan Project. All participants will be invited to participate by a Community Navigator. The Community Navigator will be present during all interviews and focus groups to support participants.

Recruitment

In research with Aboriginal communities both community and individual consent is required in order for the project to proceed.¹ To obtain community consent, presentations will be made to key Aboriginal organisations in the Fitzroy Valley and community consent will be requested and granted from senior community members at these meetings. Individual consent will not be sought until community consent is obtained¹. Recruitment of community leaders will be through purposive sampling^{16,35,36}. Aboriginal community leaders will be visited by Community Navigators who will invite them to learn more about the study and to consider participation. In contrast, recruitment of community members will be through passive snowball sampling^{16,35,36}. As recommended by the Aboriginal Community leaders JO and MC, who are chief investigators, The Picture Talk Project will be advertised in posters; presented at community meetings and friends and family members of the Community Navigators; members of local Aboriginal organisations; and other research participants will be invited in person to participate. It will be up to Aboriginal community members to approach the research team or community navigators if they are interested in being involved in focus groups. Snowball sampling works well in such a close-knit community, as there is a very strong communication line between families. The composition of focus groups may influence the discussion so groups will be stratified by sex and age in order to encourage active participation from all parties^{37,38}. Male participants will be recruited into a separate focus group to females³⁷, the Community Navigator will also be of the same sex. In addition the Community

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Navigator will only work with focus group participants with whom they have good rapport and an established connection through language group or kinship. Participants will be aged 18 years and older. Traditionally, if an Aboriginal elder is present, younger participants let their elder answer questions posed to the group³⁸. To encourage active participation of all members, focus groups will include participants of a similar age³⁸. If within a community a participant wishes to be accompanied by their elder, the research team will not exclude them from the focus group as a sign of respect. In this way the project is designed to show respect for culturally recognised differences between the sexes and cultural protocols³⁷.

Potential participants may nominate the time and place that is most convenient for them to be introduced to EF by the Community Navigator. EF and Community Navigators will work together to explain the scope of the research project using a participant information sheet and consent form in plain English and seek signed or verbal consent (witnessed by the Community Navigator) from each participant. They will then collect basic demographic information from each participant including age group, sex, education, language group, language of preference and cultural knowledge. It will be made clear that participants can decline to participate at any time and if they chose to do so the Community Navigator will investigate why they chose to decline.

Participants may nominate the Community Navigator they feel most comfortable to work with. Community members participating in focus groups may select which group of participants they would like to share a focus group with. The number of participating leaders and community members required for this study will be guided by what is scientifically rigorous yet culturally appropriate. For qualitative research, data will continue to be collected and analysed until all of the themes are 'saturated'³⁹. In order to be deemed culturally appropriate it is imperative that a certain number of elders, leaders and community members are consulted from each of the main language groups included, both males and females as guided by the Aboriginal leaders and Community Navigators on the research team. In the Picture Talk Project we aim to interview all the CEOs of the approximately 20 local Aboriginal owned organisations, including elders and chairpersons from all four main language groups. We aim to conduct approximately 6 focus groups with 3 to 8 community members based within local organisations and living in communities in Fitzroy Crossing town, as well as a sample from very remote outlying communities. We aim to conduct at least one group where the participants are male. In addition we aim to recruit participants to focus groups from the four main language groups and a variety of age groups.

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We will record whether any focus group participants were involved with The Lililwan Project^{6,7} and its consent process because their prior experience may mean they are regarded as experts and that others might feel less likely to contribute. Exact numbers of focus groups will not be set and will be determined by what issues are discussed in each session and the saturation of themes and who is available at the time of data collection.

Data Collection

A topic guide will be developed for the interviews and focus groups to ensure steps taken prior to collection of data are consistent (*See Additional Files 1 and 2*). This will include instructions about when to start the tape recorder if consent is granted. The content of the interview and focus group questions is based on findings from the literature review^{1,2}. The research questions were informed by qualitative research methods^{16,18,19,33-44}. The language of the questions was guided by JO and MC and the Community Navigators. The delivery of questions will be guided by the Community Navigators at the time of data collection².

Interviews with leaders

Aboriginal community leaders will participate in semi-structured interviews in the format of 'research topic yarning'. 'Yarning' is an Aboriginal way of conversing and connecting through storytelling¹⁸. This culturally appropriate method, as described by Dawn Bessarab (an Aboriginal researcher), involves starting the conversation with what she describes as 'social yarning' where the researcher makes casual conversation with the participant in order to find common ground and potential connections through family or community and consequently gain trust and rapport¹⁸. The researcher will then formalise the conversation by announcing the start of research questions and commence 'research topic yarning' where questions are asked in a semi-structured style and any form of response is encouraged, including in a conversational or story-telling format. Aboriginal community leaders will be asked about their experiences with research and the process of community and individual consent. Interview questions (*See Additional File 3*) will be asked in English by EF and interpreted by the Community Navigator into the language preferred by the Aboriginal leader if required. Interviews will be kept flexible and reactive to participants' responses – including both verbal and body language. If the Community Navigator reads that the body language starts to look closed off or disengaged, questions will be asked in a different way. Time will be allowed for silence after a question is asked. With

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351 consent, interviews will be either voice recorded or responses hand written and transcribed later into a
352 Microsoft Word document.

354 **Focus Groups with community members**

356 Aboriginal community members will participate in focus groups in a format similar to 'collaborative yarning'¹⁸,
357 which creates a space in which participants can feel comfortable and speak freely¹⁹. The focus group will first
358 start with 'social yarning' as described above in order to gain trust and rapport¹⁸. The conversation will then be
359 formalised to 'collaborative yarning' within the focus group, which is described as a yarn that occurs between
360 two or more people who are discussing a research topic which may lead to new understandings¹⁸. The
361 advantage of the focus group format is that it creates a forum in which issues arise such as community
362 attitudes, values and beliefs that might not have otherwise been brought to light in a one to one interview^{40,41}.
363 In addition, a focus group creates the capacity for the group to speak with one voice and reach consensus,
364 which is in line with the group-focused Aboriginal way of knowing⁴⁴. Aboriginal community members will be
365 asked about their experiences with research and the individual consent process. Focus group participants will
366 be provided with an example of a participant information statement and (Figure 3) as well as an excerpt from
367 the pictorial flip chart (Figure 4) that was used with parents and carers in the Lililwan Project and asked to
368 share their thoughts and preference. In addition, focus group participants will be asked to comment on a
369 newly created cartoon version (Figure 5) of the photographs shown in figure 3 as a potential medium for
370 future consent materials. Focus group questions (*See Additional File 4*) will be spoken in English and
371 interpreted by the Community Navigators into the language preferred by participants. EF and the Community
372 Navigators will facilitate focus groups together, encouraging the quieter participants, and managing the more
373 dominant voices to ensure all participants can share their opinions.

375 *Insert Figure 3 here*

376 *Insert Figure 4 here*

377 *Insert Figure 5 here*

379 **Data Transcription and Processing**

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380 All interviews and focus group recordings will be transcribed verbatim and handwritten responses will be
381 typed into Microsoft Word documents. Transcripts will be verified with participants and Community
382 Navigators. Data will be uploaded into NVivo10 qualitative software to facilitate the coding process³³.
383
384 **Data Analysis**
385 A research diary will be kept by EF to record the date, time, duration and setting of each interview and focus
386 group, noting who is present and the first impressions of the research process. Initial codes will be created by
387 EF immediately after each session based on the main topics discussed^{35-39,45,46}. Additional notes will be made
388 by EF about current community events such as 'Sorry Business' (mourning)²⁷, which can affect participation
389 rates and the mood of participants.
390
391 Transcripts from individual interviews and focus groups will be analysed separately by EF. A coding topic guide
392 will be created by EF for the initial analysis of transcripts. Transcripts will be uploaded into NVivo10 qualitative
393 software to facilitate coding^{33,45}. Coding of data will be conducted by EF line-by-line and derived through
394 deductive and inductive processes using grounded theory⁴². When using NVivo software, one unit of analysis
395 from the data is called a node. This node might be "River" which is coded when participants discuss the river. A
396 node hierarchy will be formed using this process and cross-referenced against all transcripts^{36,46}. The node
397 hierarchy is developed when nodes are collapsed into each other if they are similar and divided if there is
398 enough data for them to be declared two entities. These top-level nodes will then be reviewed along with their
399 linked text. Following this, overarching themes will be synthesised from this analysis and compared back
400 against the data, known as the 'constant comparison method'^{36,47}. Rich quotes from participants will be
401 identified to support these themes^{33,39,45}. Coding will continue until all themes are saturated and no new
402 information is derived^{16,35-39,45-49}. In addition, key lessons learned from the content within the initial interviews
403 and focus groups will be employed when engaging with the participants for subsequent interviews or focus
404 groups. In this way a further layer of grounded theory⁴² will be applied to ensure that knowledge gained about
405 culturally respectful research is put into practice with the continued guidance of the Community Navigator
406 working along side EF.
407

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EF will code all transcripts to ensure coding is consistent. Community Navigators who are local Aboriginal people will code random segments of data from both the interviews and focus groups and this will be verified against coding done by EF to ensure reliability⁴⁶. Research participants as well as investigators JO and MC will be encouraged to give verbal feedback on findings individually or during community presentations and workshops¹⁷.

ETHICS APPROVAL AND DISSEMINATION

Core Values

The Picture Talk Project follows guidelines from the Lowitja Institute, AIATSIS and NHMRC Guidelines for conduct of research with Aboriginal and Torres Strait Islander Peoples in order to ensure cultural protocols are respected and embedded into each step of our research process^{5,24,49-51}. This project upholds the six core values identified as important when conducting research with Aboriginal communities, namely: Respect, Equality, Reciprocity, Survival and Protection, Responsibility and above all is conducted in the right Spirit and with Integrity⁴⁹. This project seeks to ensure free, prior, informed consent is obtained from all participants and community leaders for all stages of the research.

Ethics Committee Approval

Ethics approval was granted by the University of Sydney Human Research Ethics Committee (No. 2012/348, reference:14760), the Western Australian Aboriginal Health Ethics Committee, the Western Australian Country Health Service Ethics Committee (No. 2012:15), and reviewed by the Kimberley Aboriginal Health Planning Forum Research Subcommittee (No. 2012-008).

Focus Group Consent

When signing consent to participate in focus groups, participants will be asked to ensure the confidentiality of discussions. Participants will be informed that they may withdraw from the session at any time but they are

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435 not able to request that their answers be erased/destroyed because this would require destroying material
436 provided by others in the group.

437

438 **De-identification and Storage of Data**

439 Individual participant data will be de-identified and participants will be allocated a study code number. Focus
440 groups will be numbered and participants coded accordingly. Voice recorded material will be transcribed.
441 Quotations used in research reports to capture the rich qualitative data obtained during interviews and focus
442 groups will be de-identified. Data will be securely stored electronically on a password protected network drive
443 and only nominated study investigators will have access to the data.

444 Throughout the study, hard copy data will be stored securely in a locked filing cabinet in the University of
445 Sydney – Sydney Medical School Discipline of Child and Adolescent Health, Sydney Children’s Hospital Network
446 (Westmead) or Marninwarntikura Women’s Resource Centre, Fitzroy Valley. At the conclusion of the study all
447 data will reside at the University of Sydney and de-identified data will be accessible to the research community
448 on application.

449 As per guidelines set out by the University of Sydney Human Research Ethics Committee, all data including
450 audio files will be retained for a period of 7 years.

451 **Consent for Dissemination**

452 Community and individual consent will be sought for publication, dissemination and presentation of all aspects
453 of this research to date.

454

455

456 **DISCUSSION**

457

458 Key strengths of this study are that it was prioritised and initiated by the community, will be conducted in
459 partnership with Aboriginal community leaders who are Chief Investigators of this study, and that two thirds of
460 the research team are local Aboriginal people. The Picture Talk Project is designed to be culturally sensitive
461 while maintaining scientific rigor through analysis using grounded theory. This qualitative study will explore

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462 how researchers can form collaborative partnerships with Aboriginal communities to ensure that informed
463 consent and respect for Aboriginal culture are embedded at every stage of the process. The Picture Talk
464 Project seeks to embody these values and lead by example. Local interpreters are trained and employed as
465 Community Navigators on the research team to provide guidance in language and cultural protocol throughout
466 the research process - from consent seeking to presentation of results. It must be noted that the Picture Talk
467 project is an exemplar of a research framework working with communities. Cultural protocols may vary from
468 one community to another and it is important to be flexible and respond to needs identified by the
469 Community Navigators⁵. For example there may be "Sorry Business" (mourning for a death in the family) about
470 which the Community Navigator but not the researcher is aware. A particular family or community might have
471 a special ritual associated with mourning for their loss that takes a set amount of time and this might delay
472 research. A limitation of this study is that some nuances of language may be lost through the process of
473 interpreting between local languages and English.
474 This is this first study with a specific focus on community engagement and the process of seeking consent for
475 research in Aboriginal communities. This research will provide a voice for remote-dwelling Aboriginal people of
476 the Fitzroy Valley, and provide unique insights into understanding of research and preferences about how it
477 should be conducted to embody respect for Aboriginal culture and values. Aboriginal communities are not
478 against research itself but want research that is conducted in the right way. Following the successful Lililwan
479 Project, the Picture Talk Project was proposed by Aboriginal community members and is a 'community driven'
480 partnership with external researchers.

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Competing Interests

There are no competing interests for any of the authors of this paper.

Authors Contributions

Dr Emily Fitzpatrick led the study and the writing of the paper. Prof Elizabeth Elliott initiated and provided oversight to the study and input in its planning, conduct and reporting. Ms June Oscar and Ms Maureen Carter invited this study, advised on the protocol design and are the chief cultural advisors as Aboriginal community leaders of the Fitzroy Valley, The Kimberley and had input into the manuscript. Mr Tom Lawford provided cultural guidance and support from the men’s side at the Kimberley Aboriginal Law and Culture Centre and had input into the manuscript. Assoc Prof Alexandra Martiniuk and Ms Heather D’Antoine contributed to the design of the study and the writing of the paper. All authors reviewed and approved the final manuscript.

Reporting Guideline

This paper is reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

Figure Legends

- Figure 1. The Picture Talk Project Protocol
- Figure 2. The Picture Talk Project Logo
- Figure 3. Excerpt from the Lililwan Project Participant Information Statement
- Figure 4. Excerpt from pictorial flip chart used with forms to seek consent for the Lililwan Project
- Figure 5. Cartoon version of photograph on pictorial flip chart as example of alternative media

Consent

Consent for publication in the BMJ was granted by the participants and parent/carer of participants that are in the photograph and depicted in the cartoon in figures 4 and 5 respectively.

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References

1. Fitzpatrick EFM MA, D'Antoine H, Oscar J, Carter M, Elliott EJ. Seeking Consent for Research with Indigenous Communities: A Systematic Review. *BMC Medical Ethics*. 2016.
2. Fitzpatrick EFM, Macdonald G, Martiniuk ALC, D'Antoine H, Oscar J, Carter M, et al. The Picture Talk Project: Starting a Conversation with Community Leaders on Research with Remote Aboriginal Communities of Australia. *BMC Med Ethics*. 2017;18(1):34.
3. Dodson M, Williamson R. Indigenous peoples and the morality of the Human Genome Diversity Project. *Journal of Medical Ethics*. 1999;25(2):204-8.
4. UN. State of the World's Indigenous Peoples. United Nations Division for Social Policy and Development of the Department of Economic and Social Affairs.; 2015.
5. Laycock A, Walker D., Harrison, N., and Brands, J. Researching Aboriginal Health: A Practical Guide for Researchers. Melbourne, Vic, Australia: The Lowitja Institute: Australia's National Institute for Aboriginal and Torres Strait Islander Research; 2011.
6. Fitzpatrick JP, Elliott EJ, Latimer J, Carter M, Oscar J, Ferreira M, et al. The Lililwan Project: study protocol for a population-based active case ascertainment study of the prevalence of fetal alcohol spectrum disorders (FASD) in remote Australian Aboriginal communities. *BMJ Open*. 2012;2(3).
7. Fitzpatrick JP, Latimer J, Carter M, Oscar J, Ferreira ML, Carmichael Olson H, et al. Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: the Lililwan Project. *J Paediatr Child Health*. 2015;51(4):450-7.
8. Fitzpatrick JP, Latimer J, Ferreira ML, Carter M, Oscar J, Martiniuk AL, et al. Prevalence and patterns of alcohol use in pregnancy in remote Western Australian communities: The Lililwan Project. *Drug Alcohol Rev*. 2015;34(3):329-39.
9. Fitzpatrick JP, Latimer J, Olson HC, Carter M, Oscar J, Lucas BR, et al. Prevalence and profile of Neurodevelopment and Fetal Alcohol Spectrum Disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Res Dev Disabil*. 2017;65:114-26.
10. Elliott E, Latimer J, Fitzpatrick J, Oscar J, Carter M. There's hope in the valley. *J Paediatr Child Health*. 2012;48(3):190-2.
11. Latimer J Elliott E FJea. Marulu: The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation. The George Institute for Global Health; 2010.
12. Hogan M. Yajilarra. A documentary. Fitzroy Crossing, Australia2008.
13. Hogan M. For the Lililwan Project: Marulu. A documentary. Fitzroy Crossing, Australia2009.
14. Tsang TW, Lucas BR, Carmichael Olson H, Pinto RZ, Elliott EJ. Prenatal Alcohol Exposure, FASD, and Child Behavior: A Meta-analysis. *Pediatrics*. 2016;137(3):e20152542.
15. Gooda M. Chapter 3: From community crisis to community control in the Fitzroy Valley - Social Justice Report 2010 | Australian Human Rights Commission. Canberra, ACT, Australia: Parliament House; 2010.
16. Rice PL, Ezzy, D. Qualitative Research Methods. Melbourne, Victoria: Oxford University Press; 1999.
17. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-57.
18. Bessarab D, Ng'andu B. Yarning about yarning as a legitimate method in indigenous research. *International Journal of Critical Indigenous Studies*. 2010;3(1):37-50.
19. Geia LK, Hayes B, Usher K. Yarning/Aboriginal storytelling: towards an understanding of an Indigenous perspective and its implications for research practice. *Contemp Nurse*. 2013;46(1):13-7.
20. Manley AJ, Begay and Cornell S. What is cultural match and why is it so important? Native Nations Institute for Leadership, Management, and Policy (University of Arizona) and Harvard Project on American Indian Economic Development. 2008.
- http://fngovernance.org/resources_docs/Why_Is_Cultural_Match_So_Important_Presentation.pdf (Accessed on 7th Sep 2017)
21. Willis E, Pearce M, and Jenkin T. Adapting Focus Group Methods to Fit Aboriginal Community-based Research. *Qualitative Research Journal*. 2005;5(2):112-123.
- <http://search.informit.com.au.ezproxy1.library.usyd.edu.au/documentSummary;dn=126368218286278;res=IELHSS> ISSN: 1443-9883. (Accessed 7th Sep 2017).
22. Morphy F. Population, people and place: The Fitzroy Valley Population Project. Centre for Aboriginal Economic Policy Research: Australian National University; 2010 2010-07-01T12:26:09+1000. Contract No.: Working paper 70.

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57
58
59
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572 23. ABS. Australian Bureau of Statistics Census QuickStats: Fitzroy Crossing. 2011.

573 24. AIHW. Rural, Regional and Remote Health: A Guide to Remoteness Classifications. In: Unit LFArH,
574 editor. Canberra, Australia2004.

575 25. DHAC. Measuring Remoteness Accessibility/Remoteness Index of Australia (ARIA). 2001.

576 26. AIATSIS. Guidelines for Ethical Research in Indigenous Studies Australia: Australian Institute of
577 Aboriginal and Torres Strait Islander Studies; 2012.

578 27. Wynne-Jones M HA, Byers D, Stanley D, Edwige V, Brideson T Aboriginal grief and loss: a review of the
579 literature. Australian Indigenous Health Bulletin. 2016;16(3):1-9.

580 28. MWRC. Marninwarntikura Women's Resource Centre Fitzroy Crossing, Australia [Available from:
581 <https://www.mwrc.com.au/>.

582 29. NCHS. Nindilingarri Cultural Health Services Fitzroy Crossing, Australia [Available from:
583 <http://www.nindilingarri.org.au/>.

584 30. MSHR. Menzies School of Health Research, Darwin, Australia [Available from:
585 <http://www.menzies.edu.au/>.

586 31. KALACC. Kimberley Aboriginal Law and Culture Centre Fitzroy Crossing, Australia [Available from:
587 <http://www.kalacc.org.au/>.

588 32. KIS. Kimberley Interpreting Service [Available from: <http://www.kimberleyinterpreting.org.au/>.

589 33. QSR. NVivo 10 Qualitative Software [Available from: <http://www.qsrinternational.com/>.

590 34. New national park for the north Kimberley [press release]. Australia2017.

591 35. Sobo EJ. Culture and Meaning in Health Services Research: A Practical Field Guide. Walnut Creek,
592 California: Left Coast Press; 2009.

593 36. Crabtree B MW. Doing Qualitative Research: Research Methods of Primary Care. Newbury Park, CA:
594 Sage Publications; 1992.

595 37. Cuneen, C. Criminology, criminal justice and Indigenous people: A dysfunctional relationship. Current
596 Issues Crim. Just. 2008; 20: 323.

597 38. McGregor, A. Doing groups: Situating knowledge and creating stories.
598 Australian Geographer. 2004; 35(2), 141–149.

599 39. Green J, Thorogood N. Qualitative methods for health research. London: SAGE; 2004.

600 40. Christopher S, Watts, V., McCormick, A.K.H.G., Young, S. Building and maintaining trust in a
601 community-based participatory research partnership. . American Journal of Public Health.
602 2008;98(8):1398-406.

603 41. Coreil J. Group interview methods in community health research. Med Anthropol. 1995;16(3):193-
604 210.

605 42. Fereday J, Muir-Cochrane., E. Demonstrating rigor using thematic analysis: A hybrid approach of
606 inductive and deductive coding and theme development. . International Journal of Qualitative
607 Methods. 2008;5(1):80-92.

608 43. Liamputtong P, Ezzy, D. Qualitative research methods. 2nd ed. Oxford, UK: Oxford University Press;
609 2005.

610 44. Willis E, Pearce, M., Jenkin, T. Adapting focus group methods to fit Aboriginal community-based
611 research. Qualitative Research Journal. 2005;5(2):112-23.

612 45. Bazeley P. Qualitative Data Analysis with Nvivo. London: Sage; 2007.

613 46. Bradley EH, Curry, L.A., Devers, K.J. Qualitative data analysis for health services research: developing
614 taxonomy, themes, and theory. . Health Services Research. 2007;42:1758-72.

615 47. Strauss A, Corbin, J. The Basics of Qualitative Research: Grounded Theory Procedures and Techniques.
616 Newbury Park, CA: Sage Publishing; 1990.

617 48. Hannes K, Lockwood, C. Synthesizing Qualitative Research: Choosing the right approach. London,
618 United Kingdom: Wiley-Blackwell; 2012.

619 49. NHMRC. Values and Ethics: Guidelines for Conduct of Aboriginal and Torres Strait Islander Health
620 Research. In: Council NHaMR, editor. Australia2003.

621 50. NHMRC. Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander People About
622 Health Research and Ethics. In: Council NHaMR, editor. Australia2005.

623 51. NHMRC. Road Map II: A strategic framework for improving Aboriginal and Torres Strait Islander
624 Health Through Research. In: Council NHaMR, editor. Australia2010.

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Figure 1. The Picture Talk Project Protocol

159x252mm (300 x 300 DPI)

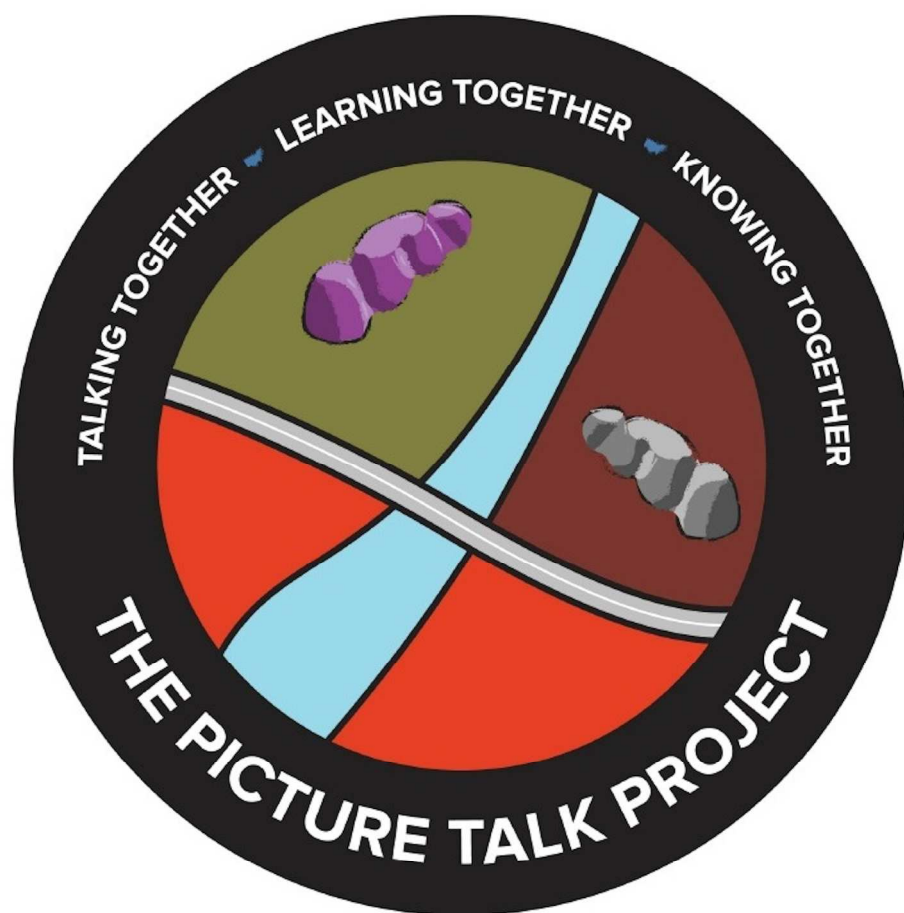


Figure 2. The Picture Talk Project Logo

281x278mm (300 x 300 DPI)

The Picture Talk Project
Appendix 9

Excerpt from The Lililwan Project Participant Information Statement

Marulu (Precious), The Lililwan (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.

Excerpt from The Lililwan Project Participant Information Statement
The Picture Talk Project. Developing Culturally Appropriate Communication Methods for
Seeking Consent for Research with Aboriginal Communities of the Fitzroy Valley
26th March 2012

Version 1

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Figure 3. Excerpt from the Lililwan Project Participation Information Statement

152x233mm (300 x 300 DPI)

Children’s Doctor Check-up



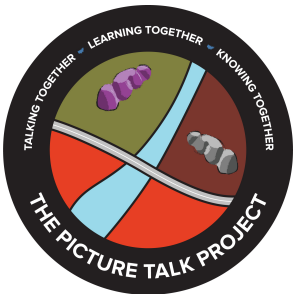
Figure 4. Excerpt from pictorial flip chart used with forms to seek consent for the Lililwan Project
209x297mm (300 x 300 DPI)

Children's Doctor Check-up



Figure 5. Cartoon version of photograph on pictorial flip chart as example of alternative media

209x297mm (300 x 300 DPI)



The Picture Talk Project

INTERVIEW TOPIC GUIDE

A. Interview Preparation

- Ensure consent and demographics form filled in and language preference noted
- Check recording device/ batteries / room availability
- Quiet setting, ensure interviewee is comfortable
- Explain the purpose of the interview
- Address terms of confidentiality (who has access to answers and analysis)
- Explain the format of the interview – the type of interview and its nature
- Indicate how long the interview usually takes
- Ask if there are any questions before the interview starts
- Ask permission to record the interview

B. Start interview

- Note the time, date, location and attendees of interview
- Thank participant for taking the time to do this interview
- Use standardised open ended topic questions
(Open ended, neutral and clear questions)

C. Close interview

- Check if participant has any other information to add
- Thank participant for their time and note the end of the interview.
- Write any observational notes immediately from interview experience.
- Add to any notes taken within interview.



The Picture Talk Project

FOCUS GROUP TOPIC GUIDE

A. Focus Group Preparation

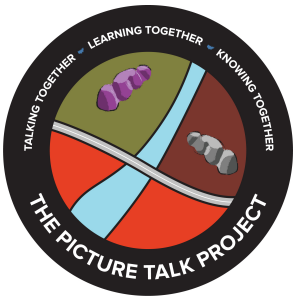
- Ensure consent is given and language preference/ need for interpreter is noted prior to commencement / demographics form filled out/name tags
- Check both recording devices (extra device for backup)/ batteries / room availability
- Quiet setting, ensure interviewee(s) is/are comfortable
- Introduce Focus Group Moderator explain the role
- Introduce Community Navigator and explain role as a language and cultural interpreter. If they have any questions later can ask them.
- Explain the purpose of the focus group
- Emphasise that the information discussed that day will be de-identified and that group participants must keep the discussion confidential.
- Explain the format of the focus group
- Indicate how long the focus group usually takes
- Ask if there are any questions before the focus group starts
- Remind participants that this is a recording and information will be transcribed. Ask permission to record the focus group. Start recording

B. Start Focus Group

- Note the time, date, location focus group code and the number of people attending the focus group
- Thank participants for taking the time to do the focus group
- Invite participants to introduce themselves around the group
- Set house rules
 - o House Rules will be set at the start of every focus group:
 1. Everyone's opinion is important.
 2. If someone has a different view we want to hear this too.
 3. There are no right or wrong answers, this is not a test.
 4. Please let one person speak at a time.
 5. If another language is spoken, please allow extra time for the Community Navigator to interpret into English before the next person speaks.
- Refer to *Focus Group Questions*

C. Close the Focus Group

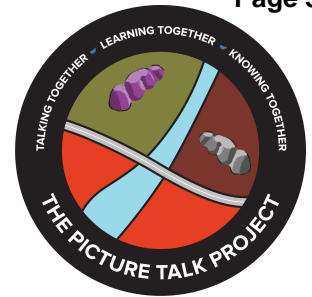
- Summarise discussion's main themes to confirm with participants that nothing was missed.
- Thank participants and Community Navigator for their time,
- Close discussion. Turn off tape



The Picture Talk Project

INTERVIEW QUESTIONS

1. How do you think permission should be granted for research with the Aboriginal communities of the Fitzroy Valley?
2. What do you think about the way research projects approach this process?
3. Does this process respect Aboriginal culture?
4. What do researchers need to know when consulting communities and their leaders to see if they can do a project?
5. How do researchers approach a community?
6. How do they start communication with the community leader?
7. What steps need to be taken to ask permission from a community leader?
8. Is permission from the community leader enough to start a project or does permission need be sought from the community? If so, how is this done?
9. Who do researchers approach first for the Fitzroy Valley?
10. Are there any organisations that need to be involved?
11. Which leaders do they need to talk to?
12. Do they have to talk to all the leaders for every project?
13. How much information should a project give when talking about a proposed research project?
14. How should this information be delivered?
15. Can you tell me from your experience an example of a research project that worked well with the Fitzroy Valley Communities? What made it a good?
16. Can you tell me from your experience an example of a research project that did not work well with the Fitzroy Valley Communities? What was not so good?
17. If permission is granted for a project, how long does the permission last?
18. Do researchers need to “check in” that the leaders are happy with the project? How often? How do they do this?
19. Do you have any things you think researchers should NOT do?
20. Is there any other information you would like to share?



The Picture Talk Project

FOCUS GROUP QUESTIONS

1. What is your understanding of research?
2. Has anyone had any experience with a research project?
3. If someone was to come to ask you to take part in a research project, where is the place you would feel most comfortable to talk about it?
4. *Who would you talk to if you wanted to know more about the project or join in?*
5. Would you prefer to have a local Aboriginal person who has been given knowledge about the project to help explain/discuss it with you rather than an outside person?
6. How much detail about a project would you want before giving consent?
7. What would you think about receiving information about research that is given to you written in English?
8. Is it better to have the information about research provided by talking or writing?
9. Would you prefer to give permission by *saying* it's ok or would you rather *sign* a paper? Or some other way?
10. What do you think about using photographs or pictures?

These photos were used in the Lililwan Project to explain about the Kids health check. (*Hand around the flip chart, also have a copy of one page in hand*)

They have also been made into cartoons on the computer. (*Hand around chart, hold corresponding page to photo example in hand*)

11. How would you explain what is happening in the picture using your own words?
12. I have seen some researchers use stories to help explain their study. What do you think about this?
13. What research projects do you think the Fitzroy Valley needs?
14. Would anybody like to make any further comments, questions or suggestions?

COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.