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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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1 **Research protocol for The Picture Talk Project: a qualitative study on research and**
2 **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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63   **ARTICLE SUMMARY**

64

65   **Article Focus**

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

75   **Key Messages**

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

80   **Strengths and Limitations of this Study**

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

93

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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 research[3] 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 publications[1]. Few detailed the methods used when seeking consent,

104 including use of videos, flip charts or local researchers to interpret information for Indigenous participants[1].

105 Even fewer evaluated whether this information was understood or presented in a way that is preferred by

106 Indigenous participants[1]. 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 process[5]. Strong trusting relationships between outside researchers and

112 local community partners are essential[5]. 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 process[2].

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120 **Invitation from the Community**

121 Following the Lililwan Project on Fetal Alcohol Spectrum Disorder (FASD) prevalence[6-14] the Picture Talk Project

122 team was invited by Aboriginal leaders of the Fitzroy Valley to explore community understanding of research

123 and consent[2]. 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 issue[11-13]. 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 investigate[11-13]. 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 people[15]. 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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147 and holding focus groups with Aboriginal community members about their experiences with research and the

148 individual consent process. Both groups will be asked how they would like research to be conducted in the

149 future. Findings will be analysed with input from Aboriginal leaders and co-published in peer reviewed

150 journals and a local Fitzroy Valley community report as well as co-presented to the Fitzroy Valley communities

151 and the wider scientific community.

152

153

154 **METHODS AND ANALYSIS**

155

156 **Study Design**

157 Qualitative methods were chosen for the Picture Talk Project to enable deep exploration of participants'

158 perspectives about research and the consent process[16]. The protocol was designed in collaboration with

159 Aboriginal leaders to ensure that local cultural protocols were embedded within each step of the research

160 process. Results will be reported in line with the 32-item checklist for the Consolidated Criteria for Reporting

161 Qualitative research (COREQ)[17]. Semi-structured interviews will be conducted with Aboriginal community

162 leaders and focus groups will be conducted with Aboriginal community members using 'research topic yarning'

163 and 'collaborative yarning'[18,19]. These methods are culturally appropriate for gathering information with

164 Aboriginal people[18]. Focus groups provide a way for participants to validate one another and avoid a potential

165 power imbalance between participants and researchers[18].

166

167 **Setting**

168 The Fitzroy Valley in northern Western Australia has Fitzroy Crossing town at its centre and 45 small

169 communities within a 200km radius[20]. There are four major language groups in these communities, namely

170 Walmajarri, Wangkatjungka, Gooniyandi, and Bunuba as well as Kija, Nikinya language groups[20]. The Fitzroy

171 Valley is home to approximately 4,500, 80% of whom are Aboriginal[20,21]. The whole of the Fitzroy Valley is

172 classified as 'very remote' (ARIA score >9.08-12)[22,23]. Some communities are only accessible via open

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173   (unsealed) roads that are often inaccessible during the annual Wet Season[23]. This setting creates many

174   challenges for both local community members and visiting researchers, with limited access to resources,

175   transportation, emergency services and healthcare. In addition, potential participants are less engaged in

176   research while coping with the extreme heat in the build-up to the Wet Season with days up to 49°C (120°F).

177   Cultural protocols need to be observed such as Lore (taking young members through traditional initiation) and

178   'Sorry Business' (mourning) which impact on the availability of local research team members and potential

179   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, Darwin[28]; 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 Valley[2]. 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

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 communities[17]. 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 NVivo[31]. All non-Aboriginal researchers

213 have received cultural awareness training including from Nindilingarri Cultural Health Services[27] and Aboriginal

214 people in the Fitzroy Valley.

215

Community Navigators

217 Local Aboriginal researchers will be employed and trained as Community Navigators by The Picture Talk

218 Project team[2]. 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 approaches[2]. 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 publications[2]. A similar approach was taken during the Lililwan Project[6].

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 study[2]. During the Lililwan Project, which

239 was overseen by JO and MC, the authors worked closely with Community Navigators and researchers[6-14]. EF

240 and EE are biased towards the success of the Lililwan Project, which they witnessed first-hand[17]. 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 Valley[2]). 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 Project[6], a method suggested by MC[27] as a culturally appropriate way of seeking consent.

259 Community Navigator Sandra Nugget and local artist Neil Carter from KALACC[29] 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 worlds[2]. 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 Park[32]) 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 country[20]. 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 communities[2].

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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280   Western worlds and is nominated to represent and advocate for the community. Community leaders include

281   elders whose positions are based on the cultural hierarchy of the community. It was considered acceptable to

282   invite community leaders to be interviewed by EF in the presence of a Community Navigator[2]. In contrast, it

283   was deemed more culturally acceptable to hold focus groups with Aboriginal community members, rather

284   than interviews, because many community members have had few interactions with research and Western

285   protocols. Some focus groups will include Aboriginal community members who are parents and carers of

286   children of the Fitzroy Valley, some of whom may have participated in the Lililwan Project.

287   All participants will be invited to participate by a Community Navigator. The Community Navigator will be

288   present during all interviews to support participants.

289

290   **Recruitment**

291   Community presentations will be made to key Aboriginal organisations of the Fitzroy Valley and community

292   consent will be requested and granted at these meetings. Recruitment of Aboriginal community leaders will be

293   through purposive sampling, by inviting the participation of Chief Executive Officers of local Aboriginal

294   organisations; chairpersons of communities and language group organisations; as well as cultural elders of

295   each of the language groups[2,16,33,34]. Aboriginal community leaders will be visited by Community Navigators

296   inviting them to learn more about the study. In contrast, because it has been recommended to proceed this

297   way - it will be up to Aboriginal community members to approach the research team if they are interested in

298   being involved in focus groups. The recruitment of community members will be through snowball

299   sampling[16,33,34]. Friends and family members of the Community Navigators; members of local Aboriginal

300   organisations; and other research participants will be invited in person to participate. They will be given time

301   to consider participation and asked to approach the Community Navigator should they agree.

302

303   Potential participants may nominate the time and place that is most convenient for them to be introduced to

304   EF by the Community Navigator. EF and Community Navigators will work together to explain the scope of the

305   research project using a participant information sheet and consent form in plain English and seek signed or

306   verbal consent (witnessed by the Community Navigator) from each participant. They will then collect basic

307   demographic information from each participant including age group, sex, education, language group, language

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308 of preference and cultural knowledge. It will be made clear that participants can decline to participate at any

309 time and if they chose to do so the Community Navigator will investigate why they chose to decline.

310

311 Participants may nominate the Community Navigator they feel most comfortable to work with. Community

312 members participating in focus groups may select which group of participants they would like to share a focus

313 group with. There will be separate focus groups for males and females. The number of participating leaders

314 and community members required for this study will be guided by what is scientifically rigorous yet culturally

315 appropriate. For qualitative research, data will continue to be collected and analysed until all of the themes

316 are 'saturated'[35]. In order to be deemed culturally appropriate it is imperative that a certain number of elders,

317 leaders and community members are consulted from each of the main language groups included, both males

318 and females as guided by the Aboriginal leaders and Community Navigators on the research team.

319

320 **Data Collection**

321 A topic guide will be developed for the interviews and focus groups to ensure steps taken prior to collection of

322 data are consistent (*See Additional Files 1 and 2)*. This will include instructions about when to start the tape

323 recorder if consent is granted. The content of the interview and focus group questions is based on findings

324 from the literature review[1,2]. The research questions were informed by qualitative research methods[16,18,19,33-

325 40]. The language of the questions was guided by JO and MC and the Community Navigators. The delivery of

326 questions will be guided by the Community Navigators at the time of data collection[2].

327

328 **Interviews with leaders**

329 Aboriginal community leaders will participate in semi-structured interviews in the format of 'research topic

330 yarning'. 'Yarning' is an Aboriginal way of conversing and connecting through storytelling[18]. This culturally

331 appropriate method, as described by Dawn Bessarab (an Aboriginal researcher), involves starting the

332 conversation with what she describes as 'social yarning' where the researcher makes casual conversation with

333 the participant in order to find common ground and potential connections through family or community and

334 consequently gain trust and rapport[18]. The researcher will then formalise the conversation by announcing the

335 start of research questions and commence 'research topic yarning' where questions are asked in a semi-

336 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 freely[19]. The focus group will first

350   start with 'social yarning' as described above in order to gain trust and rapport[18]. 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 understandings[18]. 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 knowing[40]. 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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365 All interviews and focus group recordings will be transcribed verbatim and handwritten responses will be

366 typed into Microsoft Word documents. Transcripts will be verified with participants and Community

367 Navigators. Data will be uploaded into NVivo10 qualitative software to facilitate the coding process (31).

368

369 **Data Analysis**

370 A research diary will be kept to record the date, time, duration and setting of each interview and focus group,

371 noting who is present and the first impressions of the research process. Initial codes will be created

372 immediately after each session based on the main topics discussed[33-35,41,42]. Additional notes will be made

373 about current community events such as '*Sorry Business*' (mourning)[25], which can affect participation rates and

374 the mood of participants.

375

376 Individual interviews and focus groups will be analysed separately. A coding topic guide will be created for the

377 initial analysis of transcripts. Transcripts will be uploaded into NVivo10 qualitative software to facilitate

378 coding[31,41]. Coding of data will be conducted line-by-line and derived through deductive and inductive

379 processes using grounded theory[42]. A code hierarchy will be formed from this process and cross-referenced

380 against all transcripts[34,42]. Overarching themes will be synthesised from this analysis and compared back

381 against the data, known as the 'constant comparison method'[34,43]. Rich quotes will be identified to support

382 these themes[31,35,41]. Coding will continue until all themes are saturated and no new information is derived[16,33-

383 35,41-44].

384

385 EF will code all transcripts to ensure coding is consistent. Community Navigators will code random segments of

386 data and this will be verified against coding done by EF to ensure reliability[42]. Research participants will be

387 encouraged to give verbal feedback on findings individually or during community presentations and

388 workshops[17].

389

390

391 **ETHICS APPROVAL AND DISSEMINATION**

392

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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 Integrity[45]. 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.

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455 **Competing Interests**
456 There are no competing interests for any of the authors of this paper.
457

458 **Authors Contributions**
459 Dr Emily Fitzpatrick led the study and the writing of the paper. Prof Elizabeth Elliott initiated and
460 provided oversight to the study and input in its planning, conduct and reporting. Ms June Oscar and
461 Ms Maureen Carter invited this study, advised on the protocol design and are the chief cultural
462 advisors as Aboriginal community leaders of the Fitzroy Valley, The Kimberley and had input into the
463 manuscript. Mr Tom Lawford provided cultural guidance and support from the men's side at the
464 Kimberley Aboriginal Law and Culture Centre and had input into the manuscript. Assoc Prof Alexandra
465 Martiniuk and Ms Heather D'Antoine contributed to the design of the study and the writing of the
466 paper. All authors reviewed and approved the final manuscript.
467

468 **Reporting Guideline**
469 This paper is reported in line with the Consolidated Criteria for Reporting Qualitative Research
470 (COREQ) guidelines. The COREQ check list is shown below in table 1.
471

472 **Figure Legends**
473 Figure 1. The Picture Talk Project Protocol
474 Figure 2. The Picture Talk Project Logo
475

29 June 2017

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573

574

Study Initiation
- Project invited by Aboriginal community leaders of Fitzroy Valley, The Kimberley WA
- Leadership team of 6 chief investigators formed with Aboriginal and non-Aboriginal researchers
- Sytematic literature review confirms the need for the project

Study Design
- Project named by Aboriginal community leader
- The Picture Talk Project is designed in continuous collaboration with all chief investigators, and informed by findings from the literature review

Ethics Approval
- University of Sydney Human Research Ethics Committee
- Western Australian Country Health Services Board
- Western Australian Aboriginal Health Information Ethics Committee
- Kimberley Aboriginal Health Research Planning Forum

Research Team
- Local Aboriginal people, nominated by Aboriginal leaders are employed as Community Navigators on the research team to interpret language and provide cultural guidance at every step of the research process

Community Engagement
- The Picture Talk Project is presented at community meetings with Community Navigators
- A project logo is designed with local artists
- Community Navigators promote project awareness through word of mouth
- Posters about the project distributed in the community

Participant Recruitment
- Participant recruitment through purposive and snowball sampling
- Aboriginal community leaders are invited to participate in interviews
- Aboriginal community members are invited to participate in focus groups

Consent
- Free, prior, informed consent is sought from both the Fitzroy Valley community and individuals, with Community Navigators to interpret language and provide cultural guidance

Interviews and focus groups
- Interviews with Aboriginal leaders by a researcher with a Community Navigator
- Focus groups with Aboriginal community members with a researcher and Community Navigator

Transcription
- Interviews and focus groups are transcribed verbatim
- Transcripts are verified with participants and Community Navigators

Data Analysis
- NVivo 10 Qualitative software is used to facilitate coding and analysis of data
- Themes are extracted from the data with supportive quotations
- Coding and analysis is verified by Community Navigators and Chief Investigators
- Continued consent and ongoing feedback is sought from the community

Publication and Presentation
- A community report is produced and presented to the community summarising research findings
- Continued consent and feedback is sought from the community
- Results are released to the wider Australian community through publications and presentations

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			
Personal characteristics			
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
Relationship with participants			
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			
Theoretical framework			
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
Participant selection			
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
Setting			
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
Data collection			
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			
Data analysis			
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
Reporting			
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.

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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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23 October 2017

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

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30 **Abstract (word count: 291) Article (word count: 5023)**

31

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32 **ABSTRACT**

33

34 **Introduction**

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

39 **Methods and Analysis**

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

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

53 **Ethics and Dissemination**

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

58

59 **Key Words**

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

61

23 October 2017

62 **ARTICLE SUMMARY**

63

64 **Strengths and Limitations of this Study**

65 • This is one of few studies reporting Aboriginal community understanding of research. It is led by a

66 research team that includes Aboriginal leaders, experienced public health researchers and clinicians

67 and is conducted in a way that is respectful and culturally appropriate. We will seek advice on the

68 understanding of research and preferences for community engagement and the process of seeking

69 consent for research directly from Aboriginal leaders and community members.

70 • Local interpreters employed as Community Navigators allow research participants to speak in their

71 language of preference, including all major local languages of the Fitzroy Valley.

72 • Community Navigators provide cultural guidance to visiting researchers to ensure local cultural

73 protocols are observed throughout the research process.

74 • Due to limited capacity and availability of interpreters, data analysis will be conducted in English so

75 some subtleties of local Aboriginal language may have been lost in translation.

76 • This is a relatively small study in a discreet geographical setting, although likely applicable to similar

77 remote communities elsewhere in Australia, findings may not be generalizable to all Indigenous

78 communities.

79

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80 **Research protocol for The Picture Talk Project: a qualitative study on research and consent with**

81 **remote Australian Aboriginal communities**

82

83 **INTRODUCTION**

84

85 When seeking consent for research with Indigenous people, time is rarely taken to reflect on the process[1,2]. If

86 research is not conducted in a culturally respectful way, it can adversely affect participation rates and the

87 quality of the research[3]. Our systematic literature review of research, which describes or evaluates the process

88 for seeking consent and the preference or understanding of the consent process for research with Indigenous

89 communities, identified few relevant publications[1]. Few detailed the methods used when seeking consent,

90 including use of videos, flip charts or local researchers to interpret information for Indigenous participants[1].

91 Even fewer evaluated whether this information was understood or presented in a way that is preferred by

92 Indigenous participants[1]. It should be noted that since there is such variety of Indigenous populations around

93 the world, the United Nations does not have a specific definition for 'Indigenous'[4]. This term will be used when

94 referring to populations in a general sense, however when publications specify the name of a group of people

95 such as 'Aboriginal', that term will be used.

96 Guidelines for research with Indigenous communities recommend that Indigenous community members be

97 involved in all stages of the research process[5]. Strong trusting relationships between outside researchers and

98 local community partners are essential[5]. In this paper we describe the research methods for The Picture Talk

99 Project, a qualitative research project conducted together with remote Aboriginal communities of the Fitzroy

100 Valley in the Kimberley region of Western Australia. In the Picture Talk Project we will interview community

101 leaders about the community engagement and consent process for research, conduct community focus groups

102 about the individual consent process and publish and present findings. We hope The Picture Talk Project will

103 support Indigenous people like those living in the Kimberley to have a more ethical, collaborative experience

104 when participating in research and empower them to guide the research agenda to address community

105 priorities while embedding cultural protocol into each step of the research process[2].

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106   **Invitation from the Community**

107   Following the Lililwan Project on Fetal Alcohol Spectrum Disorder (FASD) prevalence[6-14] the Picture Talk Project

108   team was invited by Aboriginal leaders of the Fitzroy Valley to explore community understanding of research

109   and consent[2]. 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 issue[11-13]. 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   investigate[11-13]. 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 people[15]. 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.

128

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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133 and holding focus groups with Aboriginal community members about their experiences with research and the

134 individual consent process. Both groups will be asked how they would like research to be conducted in the

135 future. Findings will be analysed with input from Aboriginal leaders and co-published in peer reviewed

136 journals and a local Fitzroy Valley community report as well as co-presented to the Fitzroy Valley communities

137 and the wider scientific community.

138

139

140 **METHODS AND ANALYSIS**

141

142 **Study Design**

143 Qualitative methods were chosen for the Picture Talk Project to enable deep exploration of participants'

144 perspectives about research and the consent process[16]. The protocol was designed in collaboration with

145 Aboriginal leaders to ensure that local cultural protocols were embedded within each step of the research

146 process. Results will be reported in line with the 32-item checklist for the Consolidated Criteria for Reporting

147 Qualitative research (COREQ)[17]. Semi-structured interviews will be conducted with Aboriginal community

148 leaders and focus groups will be conducted with Aboriginal community members using 'research topic yarning'

149 and 'collaborative yarning'[18,19]. These methods are considered the best cultural match[20] for gathering

150 information with Aboriginal people[18,19,21]. Focus groups provide a way for participants to validate one another

151 and avoid a potential power imbalance between participants and researchers[18,].

152

153 **Setting**

154 The Fitzroy Valley in northern Western Australia has Fitzroy Crossing town at its centre and 45 small

155 communities within a 200km radius[22]. There are four major language groups in these communities, namely

156 Walmajarri, Wangkatjungka, Gooniyandi, and Bunuba as well as Kija, Nikinya language groups[22]. The Fitzroy

157 Valley is home to approximately 4,500, 80% of whom are Aboriginal[22,23]. The whole of the Fitzroy Valley is

158 classified as 'very remote' (ARIA score >9.08-12)[24,25]. Some communities are only accessible via open

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159   (unsealed) roads that are often inaccessible during the annual Wet Season[25]. This setting creates many

160   challenges for both local community members and visiting researchers, with limited access to resources,

161   transportation, emergency services and healthcare. In addition, potential participants are less engaged in

162   research while coping with the extreme heat in the build-up to the Wet Season with days up to 49°C (120°F).

163   Cultural protocols need to be observed such as Lore (taking young members through traditional initiation) and

164   'Sorry Business' (mourning) which impact on the availability of local research team members and potential

165   participants[2,5,26,27].

166

167   **Study Timeline**

168   The project is being conducted between January 2012 and December 2017 and the project outline is shown in

169   Figure 1. Data collection and verification will occur from 2012 to 2017. Publication and presentation of final

170   results will occur during 2017 and 2018.

171

172   *Insert Figure 1 here*

173

174   **Research Team**

175   A partnership was formed between leaders of the local Aboriginal organisations of the Fitzroy Valley

176   community and academic researchers of organisations based in Sydney and Darwin. The chief investigators of

177   The Picture Talk Project are JO, past Chief Executive Officer (CEO) of Marninwarntikura Women's Resource

178   Centre (MWRC)[28] and MC, CEO of Nindilingarri Cultural Health Services (NCHS)[29] based in the Fitzroy Valley

179   community; HD'A, Aboriginal Researcher, the Menzies School of Research, Darwin[30]; and researchers EE, AM

180   and PhD Student and trainee in paediatrics EF from the University of Sydney who all have experience working

181   in the remote communities of the Fitzroy Valley[2]. The Picture Talk Project protocol was developed in

182   collaboration with all partners. The team received cultural guidance and support from TL, CEO of the

183   Kimberley Aboriginal Law and Culture Centre (KALACC)[31] and Percy Bulagardie and Annette Kogolo from the

184   Kimberley Interpreting Service (KIS)[32], Fitzroy Valley. In addition to Aboriginal leaders overseeing the research

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185 process, local Aboriginal community members are employed as *Community Navigators* to interpret language

186 and provide cultural guidance to EF a Non-Aboriginal researcher.

187

188 **Researcher Skills and Specialised Training**

189 According to the COREQ guidelines it is important to declare the background, qualifications and training of the

190 researchers involved in research with Indigenous communities[17]. The Picture Talk Project constitutes EF's PhD

191 at the University of Sydney, supervised by EE, AM, HD'A and Gaynor Macdonald. EE is a Professor of

192 Paediatrics and Child Health, and Consultant Paediatrician who has worked in the Fitzroy Valley since 2009 and

193 was the Chief Investigator for the Lililwan project. AM is a psychologist and epidemiologist with Inuit family

194 members (Canada). Both work at the University of Sydney. HD'A is an Aboriginal researcher from the

195 Kimberley, a registered nurse, midwife and public health researcher at the Menzies Institute in Darwin. Gaynor

196 Macdonald is an anthropologist at the University of Sydney. EF worked as a researcher on The Lililwan Project

197 research team in 2011. She completed a Health Research Methods and Ethics course at the University of

198 Sydney; and training for qualitative research with QSR International NVivo[33]. All non-Aboriginal researchers

199 have received cultural awareness training including from Nindilingarri Cultural Health Services[27] and Aboriginal

200 people in the Fitzroy Valley.

201

202 **Community Navigators**

203 Local Aboriginal researchers will be employed and trained as Community Navigators by The Picture Talk

204 Project team[2]. A Community Navigator is defined by JO and MC as someone who is Aboriginal, who is local to

205 the community, respected by the community, can interpret language and provide guidance on cultural

206 protocol, and has experience working in both Aboriginal and Western worlds. A different Community

207 Navigator is required for each language group within Fitzroy Crossing. A male Navigator is required when

208 speaking with men and a female Navigator is required for women. Community Navigators guide researchers in

209 cultural protocols regarding kinship ties and skin-name relationships. For example, an Aboriginal man cannot

210 sit in close proximity to his mother-in-law by skin-name relation. Community Navigators on the research team

211 are connected with all four major language groups of the Fitzroy Valley (Walmajarri, Wangkatjungka,

8

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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 approaches[2]. 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 publications[2]. A similar approach was taken during the Lililwan Project[6].

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 study[2]. During the Lililwan Project, which

225 was overseen by JO and MC, the authors worked closely with Community Navigators and researchers[6-14]. EF

226 and EE are biased towards the success of the Lililwan Project, which they witnessed first-hand[17]. 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 Valley[2]). 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   Project[6], a method suggested by MC[29] as a culturally appropriate way of seeking consent.

246   Community Navigator Sandra Nugget and local artist Neil Carter from KALACC[31] 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   worlds[2]. 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 Park[34]) 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 country[22]. 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 communities[2].

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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267   Western worlds and is nominated to represent and advocate for the community. Community leaders include

268   elders whose positions are based on the cultural hierarchy of the community. It was considered acceptable to

269   invite community leaders to be interviewed by EF in the presence of a Community Navigator[2]. In contrast, it

270   was deemed more culturally acceptable to hold focus groups with Aboriginal community members, rather

271   than interviews, because many community members have had few interactions with research and Western

272   protocols[18,19,20,21]. Some focus groups will include Aboriginal community members who are parents and carers

273   of children of the Fitzroy Valley, some of whom may have participated in the Lililwan Project. All participants

274   will be invited to participate by a Community Navigator. The Community Navigator will be present during all

275   interviews and focus groups to support participants.

276

277   **Recruitment**

278   In research with Aboriginal communities both community and individual consent is required in order for the

279   project to proceed.[1] To obtain community consent, presentations will be made to key Aboriginal organisations

280   in the Fitzroy Valley and community consent will be requested and granted from senior community members

281   at these meetings. Individual consent will not be sought until community consent is obtained[1].

282   Recruitment of community leaders will be through purposive sampling[16,35,36]. Aboriginal community leaders

283   will be visited by Community Navigators who will invite them to learn more about the study and to consider

284   participation.

285   In contrast, recruitment of community members will be through passive snowball sampling[16,35,36]. As

286   recommended by the Aboriginal Community leaders JO and MC, who are chief investigators, The Picture Talk

287   Project will be advertised in posters; presented at community meetings and friends and family members of the

288   Community Navigators; members of local Aboriginal organisations; and other research participants will be

289   invited in person to participate. It will be up to Aboriginal community members to approach the research team

290   or community navigators if they are interested in being involved in focus groups. Snowball sampling works well

291   in such a close-knit community, as there is a very strong communication line between families. The

292   composition of focus groups may influence the discussion so groups will by stratified by sex and age in order to

293   encourage active participation from all parties[37.38]. Male participants will be recruited into a separate focus

294   group to females[37], the Community Navigator will also be of the same sex. In addition the Community

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295 Navigator will only work with focus group participants with whom they have good rapport and an established

296 connection through language group or kinship. Participants will be aged 18 years and older. Traditionally, if an

297 Aboriginal elder is present, younger participants let their elder answer questions posed to the group[38]. To

298 encourage active participation of all members, focus groups will include participants of a similar age [38]. If

299 within a community a participant wishes to be accompanied by their elder, the research team will not exclude

300 them from the focus group as a sign of respect. In this way the project is designed to show respect for

301 culturally recognised differences between the sexes and cultural protocols[37].

302 Potential participants may nominate the time and place that is most convenient for them to be introduced to

303 EF by the Community Navigator. EF and Community Navigators will work together to explain the scope of the

304 research project using a participant information sheet and consent form in plain English and seek signed or

305 verbal consent (witnessed by the Community Navigator) from each participant. They will then collect basic

306 demographic information from each participant including age group, sex, education, language group, language

307 of preference and cultural knowledge. It will be made clear that participants can decline to participate at any

308 time and if they chose to do so the Community Navigator will investigate why they chose to decline.

309 Participants may nominate the Community Navigator they feel most comfortable to work with. Community

310 members participating in focus groups may select which group of participants they would like to share a focus

311 group with. The number of participating leaders and community members required for this study will be

312 guided by what is scientifically rigorous yet culturally appropriate. For qualitative research, data will continue

313 to be collected and analysed until all of the themes are 'saturated'[39]. In order to be deemed culturally

314 appropriate it is imperative that a certain number of elders, leaders and community members are consulted

315 from each of the main language groups included, both males and females as guided by the Aboriginal leaders

316 and Community Navigators on the research team. In the Picture Talk Project we aim to interview all the CEOs

317 of the approximately 20 local Aboriginal owned organisations, including elders and chairpersons from all four

318 main language groups. We aim to conduct approximately 6 focus groups with 3 to 8 community members

319 based within local organisations and living in communities in Fitzroy Crossing town, as well as a sample from

320 very remote outlying communities. We aim to conduct at least one group where the participants are male. In

321 addition we aim to recruit participants to focus groups from the four main language groups and a variety of

322 age groups.

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323   We will record whether any focus group participants were involved with The Lililwan Project[6,7] and its consent

324   process because their prior experience may mean they are regarded as experts and that others might feel less

325   likely to contribute. Exact numbers of focus groups will not be set and will be determined by what issues are

326   discussed in each session and the saturation of themes and who is available at the time of data collection.

327

328   **Data Collection**

329   A topic guide will be developed for the interviews and focus groups to ensure steps taken prior to collection of

330   data are consistent (*See Additional Files 1 and 2)*. This will include instructions about when to start the tape

331   recorder if consent is granted. The content of the interview and focus group questions is based on findings

332   from the literature review[1,2]. The research questions were informed by qualitative research methods[16,18,19,33-44]

333   The language of the questions was guided by JO and MC and the Community Navigators. The delivery of

334   questions will be guided by the Community Navigators at the time of data collection[2].

335

336   **Interviews with leaders**

337   Aboriginal community leaders will participate in semi-structured interviews in the format of 'research topic

338   yarning'. 'Yarning' is an Aboriginal way of conversing and connecting through storytelling[18]. This culturally

339   appropriate method, as described by Dawn Bessarab (an Aboriginal researcher), involves starting the

340   conversation with what she describes as 'social yarning' where the researcher makes casual conversation with

341   the participant in order to find common ground and potential connections through family or community and

342   consequently gain trust and rapport[18]. The researcher will then formalise the conversation by announcing the

343   start of research questions and commence 'research topic yarning' where questions are asked in a semi-

344   structured style and any form of response is encouraged, including in a conversational or story-telling format.

345   Aboriginal community leaders will be asked about their experiences with research and the process of

346   community and individual consent. Interview questions *(See Additional File 3)* will be asked in English by EF

347   and interpreted by the Community Navigator into the language preferred by the Aboriginal leader if required.

348   Interviews will be kept flexible and reactive to participants' responses – including both verbal and body

349   language. If the Community Navigator reads that the body language starts to look closed off or disengaged,

350   questions will be asked in a different way. Time will be allowed for silence after a question is asked. With

13

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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.

353

354 **Focus Groups with community members**

355

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 freely[19]. The focus group will first

358 start with 'social yarning' as described above in order to gain trust and rapport[18]. 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 understandings[18]. 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 knowing[44]. 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.

374

375 *Insert Figure 3 here*

376 *Insert Figure 4 here*

377 *Insert Figure 5 here*

378

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 process[33].

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 theory[42]. 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 theory[42] 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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408 EF will code all transcripts to ensure coding is consistent. Community Navigators who are local Aboriginal

409 people will code random segments of data from both the interviews and focus groups and this will be verified

410 against coding done by EF to ensure reliability[46]. Research participants as well as investigators JO and MC will

411 be encouraged to give verbal feedback on findings individually or during community presentations and

412 workshops[17].

413

414

415 **ETHICS APPROVAL AND DISSEMINATION**

416

417 **Core Values**

418 The Picture Talk Project follows guidelines from the Lowitja Institute, AIATSIS and NHMRC Guidelines for

419 conduct of research with Aboriginal and Torres Strait Islander Peoples in order to ensure cultural protocols are

420 respected and embedded into each step of our research process[5,24,49-51]. This project upholds the six core

421 values identified as important when conducting research with Aboriginal communities, namely: Respect,

422 Equality, Reciprocity, Survival and Protection, Responsibility and above all is conducted in the right Spirit and

423 with Integrity[49]. This project seeks to ensure free, prior, informed consent is obtained from all participants and

424 community leaders for all stages of the research.

425

426 **Ethics Committee Approval**

427 Ethics approval was granted by the University of Sydney Human Research Ethics Committee (No. 2012/348,

428 reference:14760), the Western Australian Aboriginal Health Ethics Committee, the Western Australian Country

429 Health Service Ethics Committee (No. 2012:15), and reviewed by the Kimberley Aboriginal Health Planning

430 Forum Research Subcommittee (No. 2012–008).

431

432 **Focus Group Consent**

433 When signing consent to participate in focus groups, participants will be asked to ensure the confidentiality of

434 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 Navigators[5]. 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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487 **Competing Interests**
488 There are no competing interests for any of the authors of this paper.

489
490 **Authors Contributions**
491 Dr Emily Fitzpatrick led the study and the writing of the paper. Prof Elizabeth Elliott initiated and
492 provided oversight to the study and input in its planning, conduct and reporting. Ms June Oscar and
493 Ms Maureen Carter invited this study, advised on the protocol design and are the chief cultural
494 advisors as Aboriginal community leaders of the Fitzroy Valley, The Kimberley and had input into the
495 manuscript. Mr Tom Lawford provided cultural guidance and support from the men's side at the
496 Kimberley Aboriginal Law and Culture Centre and had input into the manuscript. Assoc Prof Alexandra
497 Martiniuk and Ms Heather D'Antoine contributed to the design of the study and the writing of the
498 paper. All authors reviewed and approved the final manuscript.

499
500 **Reporting Guideline**
501 This paper is reported in line with the Consolidated Criteria for Reporting Qualitative Research
502 (COREQ) guidelines.

503
504 **Figure Legends**
505 Figure 1. The Picture Talk Project Protocol
506 Figure 2. The Picture Talk Project Logo
507 Figure 3. Excerpt from the Lililwan Project Participant Information Statement
508 Figure 4. Excerpt from pictorial flip chart used with forms to seek consent for the Lililwan Project
509 Figure 5. Cartoon version of photograph on pictorial flip chart as example of alternative media

510
511 **Consent**
512 Consent for publication in the BMJ was granted by the participants and parent/carer of participants
513 that are in the photograph and depicted in the cartoon in figures 4 and 5 respectively.

514

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Study Initiation
- Picture Talk Project invited by Aboriginal community leaders of Fitzroy Valley, The Kimberley WA
- Leadership team of 6 chief investigators formed with Aboriginal and non-Aboriginal researchers
- Sytematic literature review identifies the need for The Picture Talk Project

Study Design
- The Picture Talk Project is designed in continuous collaboration with all chief investigators, and informed by findings from the literature review

Ethics Approval
- University of Sydney Human Research Ethics Committee
- Western Australian Country Health Services Board
- Western Australian Aboriginal Health Information Ethics Committee
- Kimberley Aboriginal Health Research Planning Forum

Research Team
- Local Aboriginal people, nominated by Aboriginal leaders are employed as Community Navigators on the research team to interpret language and provide cultural guidance at every step of the research process

Community Engagement
- The Picture Talk Project is presented at community meetings with Community Navigators
- A project logo is designed with local artists
- Community Navigators promote project awareness through word of mouth
- Posters about project in the community

Participant Recruitment
- Participant recruitment through purposive and snowball sampling
- Aboriginal community leaders are invited to participate in interviews
- Aboriginal community members are invited to participate in focus groups

Consent
- Free, prior, informed consent is sought from both the Fitzroy Valley community and individuals, with Community Navigators to interpret language and provide cultural guidance

Interviews and focus groups
- Interviews with Aboriginal leaders by a researcher with a Community Navigator
- Focus groups with Aboriginal community members with a researcher and Community Navigator

Transcription
- Interviews and focus groups are transcribed verbatim
- Transcripts are verified with participants and Community Navigators

Data Analysis
- NVivo 10 Qualitative software is used to facilitate coding and analysis of data
- Themes are extracted from the data with supportive quotations
- Coding and analysis is verified by Community Navigators and Chief Investigators
- Continued consent and ongoing feedback is sought from the community

Publication and Presentation
- A community report is produced and presented to the community summarising research findings
- Continued consent and feedback is sought from the community
- Results are released to the wider Australian community through publications and presentations

Figure 1. The Picture Talk Project Protocol
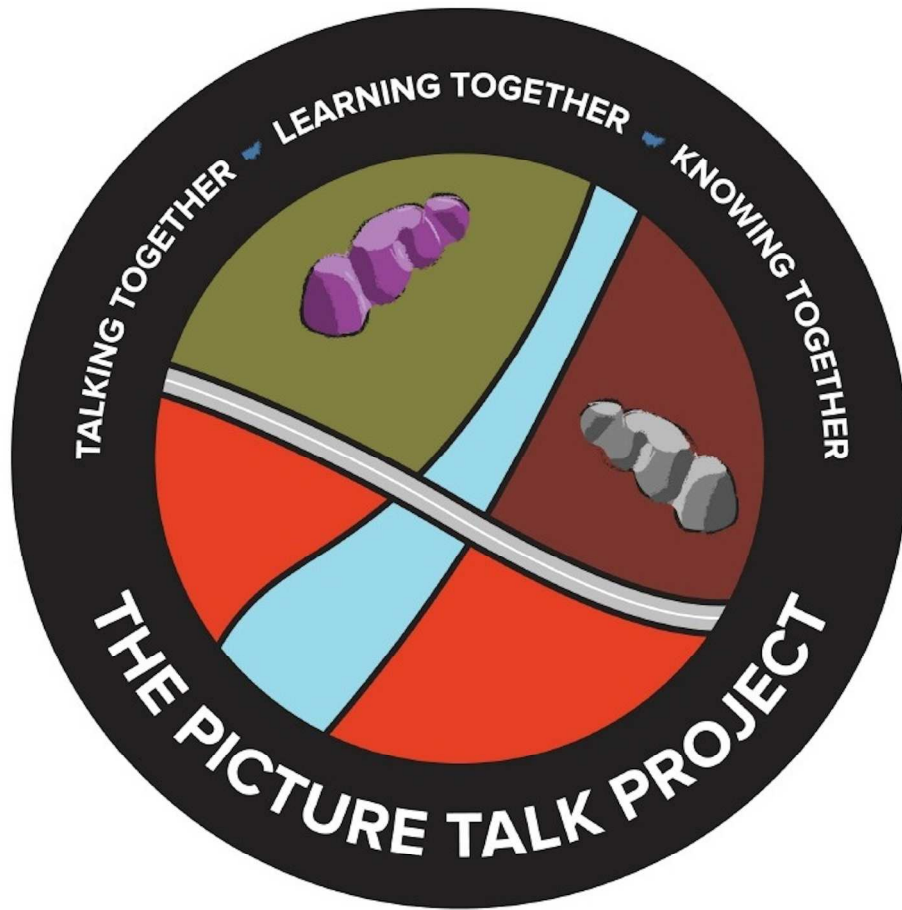
159x252mm (300 x 300 DPI)

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
Version 1   26th March 2012   Page **1** of **1**

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
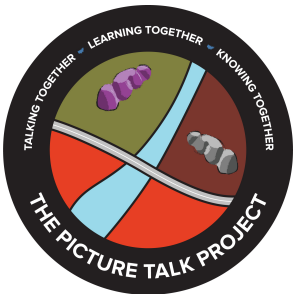
209x297mm (300 x 300 DPI)

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.

Page **1** of **1**

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
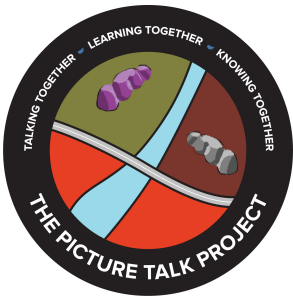
The Picture Talk Project

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?

Page **1** of **1**
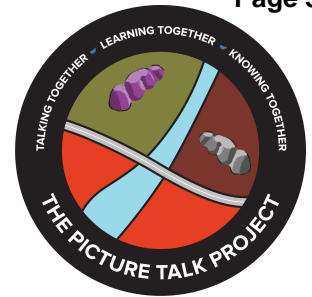
The Picture Talk Project

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 <u>photos</u> 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 <u>cartoons</u> 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			
Personal characteristics			
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?	
Relationship with participants			
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			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
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?	
Setting			
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	
Data collection			
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	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
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?	
Reporting			
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.