

RESEARCH ARTICLE

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Development of a reliable questionnaire to assist in the diagnosis of fetal alcohol spectrum disorders (FASD)

James P Fitzpatrick^{1,2,3*}, Jane Latimer^{1,2}, Manuela Ferreira^{1,2}, Alexandra LC Martiniuk^{1,2,4,5}, Elizabeth Peadon^{2,3}, Maureen Carter⁶, June Oscar^{7,8}, Emily Carter^{6,7}, Meredith Kefford⁹, Rhonda Shandley⁶, Harry Yungabun⁶ and Elizabeth J Elliott^{1,2,3}

Abstract

Background: A battery of clinical assessments was used in the Lililwan* Project, Australia's first population-based Fetal Alcohol Spectrum Disorders (FASD) prevalence study, conducted in the remote Fitzroy Valley, Western Australia. One objective was to develop and assess test-retest reliability of an acceptable questionnaire for collecting health information in remote Aboriginal communities feasible for use in the Lililwan Project.

Methods: A questionnaire was developed by paediatricians to assist in diagnosis of FASD. Content was based on a literature review of FASD diagnostic criteria, existing questionnaires and risk factors for FASD and birth defects. Aboriginal community members, including qualified Aboriginal language interpreters, adapted the questionnaire to ensure language and cultural components were appropriate for use in the Fitzroy Valley. Locally developed pictorial aids were used for gathering accurate information on alcohol use. Aboriginal 'community navigators' assisted researchers to translate the questions into Kimberley Kriol or local Aboriginal languages depending on participant preference.

A subset of 14 questions was assessed for test-retest reliability in 30 parents/carers of children in the Lililwan Project cohort, who were interviewed by one rater using the entire questionnaire, then by a second rater who repeated 14 critical questions at least 6 hours later.

Results: The full questionnaire contained 112 items and took 50 minutes to administer. For a subset of 14 items from the full questionnaire percent exact agreement between raters ranged from 59-100%, and was below 70% for only 1 question. Test-retest reliability was excellent (Kappa 0.81-1.00) for 5 items, substantial (Kappa 0.61-0.80) for 5 items, and moderate, fair or slight (Kappa \leq 0.60) for the remaining 4 items tested. Test-retest reliability for questions relating to alcohol use in pregnancy was excellent. When questions had moderate, fair or slight agreement, information was obtained from alternate sources e.g. medical records. Qualitative feedback from parents/carers confirmed acceptability of the questionnaire.

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* Correspondence: jfitzpatrick@georgeinstitute.org.au

¹The George Institute for Global Health, PO Box M201 Missenden Rd, Sydney 2050, Australia

²Sydney Medical School, University of Sydney, Sydney, Australia

Full list of author information is available at the end of the article

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Conclusions: This questionnaire had acceptable test-retest reliability and could be used to collect demographic, socio-cultural and biomedical information relevant to the diagnosis of FASD in Aboriginal communities throughout Australia and elsewhere. Community input is crucial when developing and administering questionnaires for use in cross-cultural contexts.

*Lililwan is a Kimberley Kriol word meaning 'all the little ones'. Kimberley Kriol is the main language spoken by Aboriginal people in the Fitzroy Valley.

Keywords: Fetal alcohol syndrome (FAS), Fetal alcohol spectrum disorders (FASD), Aboriginal and Torres Strait Islander, Indigenous, Questionnaire development, Diagnosis, Reliability testing, Reproducibility of results, Test-retest, Percent exact agreement

Background

In remote Aboriginal communities of the Fitzroy Valley historical trauma, chronic alcohol oversupply, high-risk patterns of alcohol consumption and the devastating effects of alcohol on the developing fetus threaten the continuation of language and culture (personal communication, June Oscar 2011). Alcohol is teratogenic and exposure *in utero* can cause a spectrum of lifelong physical, neurological and cognitive abnormalities termed fetal alcohol spectrum disorders (FASD), including specific diagnoses of fetal alcohol syndrome (FAS), partial FAS (pFAS) and neurodevelopmental disorder - alcohol exposed (ND/AE) [1].

In 2007, the Fitzroy Valley communities introduced local alcohol restrictions, with immediate and enduring social and health benefits [2]. Until recently few people in the Fitzroy Valley communities were aware of the effects of alcohol on the developing fetus. Since 2008 a concerted FASD awareness raising campaign has laid the foundation for FASD prevention.

This campaign is part of a sophisticated strategy to address FASD, [3] including partnering with leading research organisations The George Institute for Global Health and Sydney Medical School, The University of Sydney, to conduct Australia's first population-based FASD prevalence study: The Lililwan Project [4-6]. This paper describes the development of a reliable questionnaire for use in the Lililwan Project.

Alcohol exposure *in utero* is the most common preventable cause of intellectual impairment, and international estimates of FAS prevalence range from a median of 0.27 cases per 1,000 people in surveillance studies, to a median of 8.5 cases per 1,000 people using active case ascertainment methods [7]. Studies in some high-risk communities that include all diagnoses on the FASD spectrum (FAS, pFAS, ND-AE) report a median prevalence of 19.0 cases per 1,000 people [7]. Communities where high-risk drinking is common, including some Fitzroy Valley communities, are expected to have high FASD prevalence rates. In Australia the prevalence of FASD is unknown and there

are few FASD screening programs or diagnostic clinics [8,9]. Diagnosis of FASD requires a comprehensive history and a multidisciplinary clinical and developmental assessment [10]. A comprehensive history includes details of prenatal alcohol exposure, other pregnancy complications and exposures, birth, development, health and social/environmental conditions. Multidisciplinary clinical/developmental assessment identifies dysmorphology and growth impairment, central nervous system structure/function and differential diagnoses [10].

Prenatal alcohol exposure data is key in diagnosis of FASD. A number of tools have been developed for gathering alcohol exposure and comprehensive history data for the purpose of FASD diagnosis. FASD researchers in the Collaborative Initiative on FASD (CIFASD) have developed a standard vocabulary for alcohol exposure variables with the aim of gathering comparable data from multiple sites [11]. The University of Washington (UW) 4-digit diagnostic code [12] includes a 'new patient information form' to document demographics, growth, health, schooling, environmental stressors and alcohol exposure *in utero*. A series of 14 questions document alcohol exposure prior to and during pregnancy and evidence of maternal alcohol dependency.

Researchers at the University of New Mexico developed an extensive (240 item) questionnaire for use in FASD prevalence studies in rural South African communities [13]. This questionnaire includes demographic, health and antenatal items with a particular focus on family structure and household stressors including employment status, household occupancy and income, and domestic violence. Questions about maternal nutrition lead into a comprehensive series of questions about alcohol use.

While suitable for use in their intended target populations, none of the existing questionnaires are appropriate for use in remote Australian Aboriginal communities. Our questionnaire required a standardised approach to administration, tailored language with meaningful local terminology, and detailed questions on language groupings and environmental conditions including early life

trauma. Additionally, specific pictorial aides were used to display local alcohol brands and improve accuracy of alcohol use reporting. This questionnaire enables history taking as part of an assessment battery to accurately establish FASD prevalence in these communities.

Objectives

The objectives of this study were to:

1. Develop a comprehensive, culturally acceptable questionnaire feasible for use in the Lililwan project to collect demographic, socio-cultural, antenatal and biomedical data from parents/carers of children born in 2002 or 2003 and living in the Fitzroy Valley in 2010 or 2011.
2. Evaluate the test-retest reliability of this questionnaire.

Methods

Setting

The setting for this work is the remote Fitzroy Valley of North Western Australia, including Fitzroy Crossing town and approximately 45 remote communities representing the language groups of the Bunuba, Walmajarri/Wangkatjungka, Gooniyandi and Nyikina peoples [14]. The Fitzroy Valley is approximately 2,500 km North of Perth, and 400 km East of Broome, and includes communities within a radius of 200 km from Fitzroy Crossing town. The total population of the Fitzroy Valley is 4,500, approximately 80% being Aboriginal [14]. Kimberley Kriol is the most commonly spoken language but traditional Aboriginal languages and Standard Australian English are also used.

Questionnaire development

A questionnaire (Additional file 1) was created to collect accurate information about pregnancy, child health and development in a cohort of predominately Aboriginal participants in the Lililwan Project FASD prevalence study. The questionnaire was initially developed in Sydney, Australia by general paediatricians with experience in FASD diagnosis and research and a paediatric advanced trainee with experience working with remote Aboriginal communities in the Fitzroy Valley. Content was informed by a literature review of FASD diagnostic criteria and existing questionnaires [12,15-19] with consideration of potential antenatal and environmental influences on child development, [20-23] maternal risk factors for birth defects, and risk factors for FASD [24-27].

The information gathered, when used in the context of a comprehensive clinical assessment enables a FASD diagnosis to be made by application of various international FASD diagnostic criteria. These include the Canadian Guidelines for the diagnosis of FASD [15],

University of Washington 4-Digit Diagnostic Code, [12] Institute of Medicine FASD diagnostic criteria, [28] clarified Institute of Medicine FASD diagnostic criteria, [17] and the Centers for Disease Control Guidelines – FAS [29].

Refining the questionnaire

From February - April 2010 researchers worked with an Aboriginal leader from Fitzroy Crossing to ensure that the questions contained in the questionnaire were culturally appropriate for use in Aboriginal communities in the Fitzroy Valley. The questionnaire was then refined in consultation with three local Aboriginal community members - 'community navigators' - on the research team. Input was sought from an Aboriginal representative of the Kimberley Interpreting Service (a regional Aboriginal language centre). The questionnaire was modified to take into account cultural and language considerations.

Sensitive questions about the father (which it was thought could cause female participants to feel uncomfortable) were removed. Similarly, it was advised that during interviews, questions about 'women's business' (e.g. history of miscarriage, complications in pregnancy or details of mode of delivery) should not be asked in the presence of males. In order to make the interview process as non-threatening as possible, questions were ordered so that they 'flowed' intuitively and so that participants could anticipate the type of question that was to follow. Script was incorporated in the questionnaire to reassure participants that confidentiality would be maintained and families and children would not be identified in stored data or publications.

Language considerations included using plain English throughout, substituting local terms 'grog' for alcohol, 'kid' for child, and asking who 'grew them up' for who raised the child. The questionnaire was always administered in the presence of a community navigator who was able to explain questions in Kimberley Kriol or a local Aboriginal language as required and to interpret the responses.

Scripting around sensitive questions about alcohol

A preamble was inserted prior to sensitive questions, including about alcohol use in pregnancy, and consent to continue was verbally re-established at that time:

"The next questions are about if you drank grog before and during the pregnancy with this kid, is that OK? Answering these questions might be a bit hard, but it's really important that you're honest about it. It's not about shame or blame, but about helping kids who need help to be as good as they can be. If you start to feel upset we can stop."

Development and use of pictorial communication aids to quantify alcohol consumption

Questions about alcohol consumption specifically quantified the amount, timing and frequency of alcohol use in pregnancy, including episodes of 'binge' drinking. Reported intake was converted into standard drink equivalents to enable risk stratification using questions adapted from the Alcohol Use Disorders Identification Test screening system (AUDIT-C) [30]. While there are various definitions of 'binge' drinking, we used more than 6 standard drinks per occasion to provide a conservative estimate in communities with known high risk drinking patterns. Items relating to alcohol use in the 3 months before pregnancy and indicators of maternal alcohol dependence (e.g. alcohol-related injury or illness) were included. To improve participant recall of alcohol use in the index pregnancy 7-8 years prior, pictorial communication aids were developed using local alcohol brands so that the type and volume of alcohol consumption could be accurately described (Figures 1 and 2).

Scripting around sensitive questions about the home environment

The questionnaire includes items relating to environmental exposures at home and early life trauma (including financial troubles, food insecurity, overcrowding and domestic violence) that may contribute to learning and behavioural impairment. A preamble was scripted prior to these sensitive questions to gain agreement to continue:

"The next questions are about things that could have made this kid worry or feel sad while they were growing up. We know these questions might be hard for you. Is it OK to keep going?" Questions included:

"Are there times when adults in this kid's house worry about not having enough money (or food)?" and "Do adults or parents fight a lot at home?"

Leaving people feeling 'safe' and 'good'

A concluding script prompted the rater to express their appreciation. Participants were reassured that the study would contribute to improving child health services in the community and that responses would remain confidential. Feedback was sought from participants on how the interview could be improved:

"Thank you so much for being part of this interview. Nindilingarri [Cultural Health Services], Marninwarntikura [Womens Resource Centre] and other organisations will work hard to make sure this project helps all children in the Fitzroy Valley. The information that you give us is confidential between you and the Lililwan Project workers. Were there any problems with this interview? How do you think we could do it better?"

Two raters were trained to administer the questionnaire as a structured interview in Fitzroy Crossing over a one-week period in May 2010. Raters were a paediatric advanced trainee and a volunteer with health service experience. Raters were partnered with two local Aboriginal 'community navigators'. Raters formed two working pairs, with the non-Aboriginal rater asking questions in person, in plain English and recording verbal responses on the questionnaire, and the 'community navigator' interpreting as required. Interviews were not audio or video recorded.



Figure 1 Pictorial aid for 'type' of alcohol consumed.



Figure 2 Pictorial aid for 'size' of alcoholic beverages consumed.

Pilot reliability testing

Prior to full reliability testing, inter- and intra-rater reliability was assessed in a pilot study with ten participants. Participants were a convenience sample from one remote community in the Fitzroy Valley, a sub-sample of the total Lililwan Project cohort. The same 12 questions were scored twice within the same interview in person, by two raters. Inter-rater reliability was assessed as the responses were scored by two independent raters, and intra-rater reliability was assessed as 12 questions were repeated within the same interview. The aim of this pilot was to inform the design and selection of questions for the main reliability study and to provide important information that would inform any necessary retraining of the raters.

Full reliability testing

Between 25th May and 15th July 2010 a convenience sample, from 9 communities in the Fitzroy Valley, of 30 parents/carers of children in the Lililwan project cohort was recruited. Participants were predominately birth mothers (n=22), the remainder being aunts (n=5), 1 grandmother, 1 father and 1 guardian. None of this sample had participated in pilot reliability testing.

In order to assess test-retest reliability a subset of 14 questions from the original 112 item questionnaire was identified to be asked on a second occasion (questions 23, 32, 32(d), 32(e), 34, 37, 38, 39, 42, 43, 57, 58, 66, 67). (Table 1) We decided to evaluate the reliability of 14 questions (as opposed to the entire questionnaire) due to time limitations imposed by the difficulty in locating and re-interviewing participants in very remote communities. These questions were selected as they related to the pregnancy, particularly antenatal complications and

alcohol exposure [30], and information about current development and educational status. Twelve of the 14 questions had been assessed in the pilot reliability study.

Briefly, one rater interviewed a participant using the full 112 item questionnaire, and after a minimum of 6 hours the other rater repeated a portion of the interview using the selected subset of 14 questions. The two raters were blinded to each other's scores. Scores from each rater were compared to determine inter-rater agreement and test-retest reliability. A minimum 6-hour period between first and repeat interview was used to minimise recall bias while balancing the practicality of locating highly mobile participants for re-interview. Full questionnaire interviews took approximately 45-60 minutes to complete, with repeat interview with 14 questions taking approximately 15 minutes. All recruited participants completed the interviews.

Statistical analysis

In addition to percent exact agreement between the pairs of raters, Kappa values were calculated for all 14 questions, except for questions 42 and 43 which have ordered categories necessitating calculation of weighted Kappas using quadratic weighting. Quadratic weighting was used since the differences between the 'upper' categories were deemed to be more important than the differences between the 'lower' categories. [31,32]. Interpretation of the strength of agreement was based on the system proposed by Landis and Koch: [33] a Kappa value of 0.81-1.00 is excellent agreement, 0.61-0.80 indicates substantial agreement, 0.41-0.60 moderate agreement, 0.21-0.40 fair agreement, 0.00-0.20 slight agreement and less than 0.00 poor agreement. All statistical analyses were performed

Table 1 Test-retest reliability assessment of 14 important questions (N=30 caregivers)

Level of agreement of specific questions	Percent exact agreement	Kappa value	95% CI
Excellent agreement (Kappa 0.81-1.00)			
Q34 Pregnancy: smoking during pregnancy n=27	100%	1.00	1.00 to 1.00
Q38 Pregnancy: alcohol use during pregnancy n=27	100%	1.00	1.00 to 1.00
Q42 Pregnancy: number of drinks on a typical day n=25	96%	0.99*	0.97 to 1.00
Q43 Pregnancy: frequency of drinking alcohol n=24	83%	0.98 *	0.96 to 1.00
Q66 Child: development behind children of same age n=30	90%	0.81	0.60 to 1.00
Substantial agreement (Kappa 0.61-0.80)			
Q37 Pre-pregnancy: alcohol use before pregnancy n=27	89%	0.76	0.52 to 1.00
Q32d Pregnancy: infections during pregnancy n=27	89%	0.75	0.48 to 1.00
Q67 Child: areas of developmental delay n=28	82%	0.74	0.56 to 0.92
Q39 Pregnancy: trimester alcohol consumed n=27	81%	0.73	0.54 to 0.91
Q58 Child: specifics of medical problems requiring care in question 57 n=23	87%	0.72	0.49 to 0.94
Moderate agreement (Kappa 0.41-0.60)			
Q32e Pregnancy: hospital admissions during pregnancy n=27	81%	0.60	0.30 to 0.89
Q57 Child: long term medical problems requiring care n=30	77%	0.55	0.31 to 0.79
Fair agreement (Kappa 0.21-0.40)			
Q32 Pregnancy: medical problems during pregnancy n=27	59%	0.39	0.16 to 0.63
Slight agreement (Kappa 0.00-0.20)			
Q23 Child: learning or behavioral support in school n=30	73%	0.03	-0.14 to 0.20

n= number of respondents to each question *For Q42 and Q43 a quadratic weighted Kappa was used.

using MedCalc for Windows, version 12.6.0.0 (MedCalc Software, Ostend, Belgium). We calculated that 40 participants would need to be interviewed on two occasions to provide sufficient power for a Kappa value of 0.70, with 95% confidence intervals ranging from 0.50 to 0.90.

STROBE guidelines for reporting observational studies were used [34].

Ethics approval

Ethics approval for this study was granted by the University of Sydney Human Research Ethics Committee (Approval number 12527), the Western Australian Aboriginal Health Information and Ethics Committee (Approval number 271-01/10), the Western Australian Country Health Service Board Research Ethics Committee (Approval number 2010:01), and the Kimberley Aboriginal Health Planning Forum Research Sub-committee (Approval number 2010-001). Written consent was obtained from all participants prior to participation in the study.

Results

Questionnaire development

The interview includes 112 questions (some with sub-questions) about child demographics, schooling, language, place of residence, living conditions, prenatal exposures (including alcohol, illicit drugs and medications), birth and neonatal history, early life trauma, health and

educational outcomes and family characteristics. It also includes items to determine risk levels of alcohol consumption, birth defects, developmental problems, and syndromes with features similar to FAS. The entire questionnaire is included at Additional file 1.

Pilot reliability testing

The average Kappa value for inter-rater reliability was 0.95 (range 0.77-1.00), indicating excellent agreement [33]. Kappa values for intra-rater reliability were consistently greater than or equal to 0.63, indicating substantial or excellent agreement in all but two questions (Q 66 and Q67). For these two questions the language used to clarify questions was modified, and raters were trained to standardise the way questions were asked and the information recorded, prior to full reliability testing.

Full reliability testing

A total of 30 participants were recruited for the full reliability study (22 mothers, 5 aunts, 1 grandmother, 1 father, 1 guardian). Median time between first and second interview was 525 hours (mean=157 hours, range 6-1056 hours). As shown in Table 1, the agreement ranged from 59-100%, and was below 70% for question 32 (medical problems during pregnancy agreement=59%).

Kappa values for test-retest reliability ranged from 0.03 to 1.00. (Table 1) Five questions had Kappa values

indicating excellent agreement (Kappa 0.81-1.00). Five questions had substantial agreement (Kappa 0.61-0.80). Four questions had moderate, fair or slight agreement including questions 32e (hospital admissions during pregnancy), 57 (child's long term medical problems requiring care), 32 (medical problems during pregnancy) and 23 (learning or behavioral support in school). The discrepancy between the Kappa value of 0.03 and the percent exact agreement of 73% for question 23 reflects the 'base rate problem' relevant for a question with a high prevalence of 'no' responses. For example where prevalence is high the agreement needs to be close to 100% for the Kappa to reflect higher agreement [35].

Qualitative feedback

Qualitative data about the acceptability of the questionnaire was gathered from participants by asking: "Were there any problems with this interview, and how do you think we could do it better?" 98% of respondents gave positive feedback including: "The Lililwan Project is a good thing, it'll help with kids who have FASD and problems with learning. It is so important that kids are given a chance - it's not their fault if they are born with problems." In 2% of cases feedback was not positive and comments included: "The timing of interview was not good, it should have been on another day" and "I am sick of being asked questions with no help for the problems I want help with. My immediate issue is around violence - no-one is able to help." Where carers raised issues such as violence, researchers recommended local services and made referrals with the carer's consent if appropriate.

Discussion and conclusions

Questionnaire development

We have developed a comprehensive and reliable questionnaire for history taking relevant to making FASD diagnoses in Aboriginal communities. Diagnosis of FASD requires collection of accurate information relating to pregnancy exposures, birth, health and developmental outcomes in addition to a multidisciplinary clinical assessment. Our questionnaire considers language and cultural sensitivities and is acceptable to participants. It would be applicable for use in other remote Aboriginal communities in Australia and in communities elsewhere in which high risk alcohol use is prevalent.

Pilot and full reliability testing

Pilot reliability testing confirmed substantial or excellent inter- and intra-rater agreement in 10 out of 12 questions tested. It also informed rater training in standardisation of language used and interview technique. In full reliability testing, we assessed the test-retest reliability in a

subset of 14 important items from the questionnaire and found Kappa values >0.60 in ten out of 14 questions. The finding of Kappa values of ≤ 0.60 in the remaining 4 questions could be explained either by inconsistency in raters recording, or inconsistency of answers provided by the participant. We hypothesise that the error was more likely to arise from recall bias or participants lacking the information required to answer the questions than from rater error. For instance parents/carers may be unaware of details of support provided in the school setting and those who are not biological mothers may be unaware of problems during the mother's pregnancy. Rater error was minimised by the use of a pilot study that provided further information for training raters ensuring a standardised interview and data recording technique. Local Aboriginal community navigators were present to interpret in local languages.

For the questions with Kappa values ≤ 0.60 we elected to obtain the information from an alternative source (e.g. school or hospital records) rather than by interview. This procedure was followed for the entire Lililwan FASD prevalence study cohort. For example, accurate information about learning and/or behavioural support at school was obtained from the school, rather than the parent/carer. Similarly, problems or hospital admissions during pregnancy were identified through a review of antenatal records for each mother, and details of childhood medical problems from the child's medical records.

Notably the Kappa values indicated excellent agreement for questions relating to alcohol use in pregnancy. The exception was question 39 (trimester alcohol consumed in pregnancy, Kappa 0.73) for which substantial agreement was found. This supports our expectation that alcohol use would be reported accurately by birth mothers. Our findings are consistent with evidence from other studies indicating that retrospective reporting of alcohol consumption is more accurate than reporting at the time of pregnancy [36-39]. For instance, one study showed that the predictive validity of retrospective reporting of alcohol use (5 years after pregnancy) is high in relation to craniofacial anomalies, and higher than antenatal reporting in relation to other alcohol-related anomalies [38]. Similarly, alcohol consumption reported 14 years after a pregnancy was more predictive of behavioural problems in teenagers than reports of consumption at the time of pregnancy [37]. Taken together these findings suggest that retrospective reporting is likely to yield valid data on prenatal alcohol exposure.

To encourage participants to accurately report alcohol use during pregnancy, we took great care to emphasise confidentiality and minimise the potential for feelings of guilt or shame. One quarter of respondents were carers rather than birth mothers. We believe their responses to questions about the mother's alcohol use in pregnancy

are accurate because the carers interviewed were usually family members and lived in or near the birth mother's household. In remote Aboriginal communities with close kinship networks and overcrowded living conditions the drinking behaviour of pregnant women is frequently observed and known by the wider community.

Other groups have reported validation or language modification of questionnaires used in FASD diagnosis. The University of Washington 'new patient information form' was designed for caregivers in a general United States population to self-complete. It identifies unique patterns of exposure that differentiate FAS from Alcohol Related Neurodevelopmental Disorder and correlate significantly with underlying structural and functional brain abnormalities [1,40-42]. The questionnaire used by the University of New Mexico in South African FASD prevalence studies includes 'script' to introduce sensitive questions and confirm consent. The questionnaire takes into account the local cultural and language context and when used is administered in Afrikaans, the primary regional language [13]. Our study is the first to report development and reliability testing of a tool for use in Australian Aboriginal communities.

Our findings are comparable or superior to test-retest reliability of the Alcohol Use Disorder Identification Test (AUDIT), a questionnaire commonly used clinically and in research relating to alcohol use. In a general population sample of 457 people in Sweden, intra-class correlation coefficients on ten individual items ranged from 0.29 to 0.80, and the Kappa value was 0.69 for agreement at a predetermined 'risk cut-off score' [43]. Interestingly, many tests in common clinical use show only fair inter-rater agreement. A study of specialist cardiorespiratory physical therapists in Canada showed only fair agreement (Kappa 0.26) on clinical interpretation for auscultation of breath sounds [44]. Similarly, a recent study of orthopedic surgeons about the nature of upper arm (humerus) fractures based on a variety of imaging methods, showed slight agreement on the classification of the fracture (Kappas ranged from 0.06-0.14) and fair agreement on the recommended treatment option (Kappas ranged from 0.28-0.33) [45].

A strength of our study is that the questionnaire was developed from a comprehensive literature review and modified with input from the Aboriginal community and local language interpreters to refine its language and content. Importantly, questions were included to allow application of a validated assessment tool for alcohol exposure risk (AUDIT-C) [30] and existing FASD diagnostic criteria [12,15,17]. Another strength of this study was reporting both agreement and Kappa to take into account chance agreement or disagreement between raters.

One limitation of the study is that reliability testing was only performed in a subset of questions used. This

was due to logistical difficulties in locating participants for re-interview, including the remote location, lack of transport, lack of telephones in most households and high mobility between residences. We originally estimated that we would need 40 subjects to provide sufficient power for the reliability study. Our ability to recruit only 30 subjects resulted in larger but acceptable 95% confidence intervals. Recall bias may affect the accuracy of responses to questions relating to past events (up to 8 years previously in this study). This may have been the case for questions 32 and 32e that related to problems in the pregnancy.

Future research may include assessment of the validity of this questionnaire by examining associations between items in the diagnostic questionnaire and consequent FASD diagnosis. This would identify specific items with predictive validity for FASD diagnosis that could be included in a short version of the questionnaire for the purpose of screening or more targeted history taking.

This study demonstrates that a questionnaire that is based on existing literature can be modified for use in Australian Aboriginal communities with unique cultural and language characteristics. Furthermore, we report acceptable test-retest reliability of a subset of items on this questionnaire. The process followed to refine this questionnaire could be used in other populations with unique cultural and language characteristics.

Additional file

Additional file 1: The Lillilwan Project – FASD Diagnostic Questionnaire.

Competing interest

The authors declare that they have no competing interests.

Authors' contribution

JL, JPF, MF, EJE, MC, and JO consulted with the participant communities, conceived of and designed the study, and obtained ethics approval for the study. EP conducted the literature review and created the first draft of the questionnaire. EJE and JPF reviewed and created the second and further drafts of the questionnaire. MC, EC, HY and RS further refined the questionnaire for language and cultural appropriateness. MF and JL designed reliability protocols and databases for the diagnostic questionnaire. JPF, HY, RS and MK conducted participant recruitment and data collection. MF and ALCM analysed the data and contributed to interpretation of results. JPF wrote the initial drafts of the manuscript. MC, JO, EC, HY and RS are Aboriginal community members from the Fitzroy Valley. JPF, JL, MC, JO and EJE are Chief Investigators on the study. MK is a volunteer with Indigenous Community Volunteers. JO is a Master's candidate with the University of Notre Dame, Broome, Western Australia. JPF is a PhD candidate with The University of Sydney, New South Wales. All authors read, edited and approved the final manuscript.

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Author details

¹The George Institute for Global Health, PO Box M201 Missenden Rd, Sydney 2050, Australia. ²Sydney Medical School, University of Sydney, Sydney, Australia. ³The Sydney Children's Hospital Network (Westmead), Westmead, Australia. ⁴Sunnybrook Research Institute, Toronto, Canada. ⁵Dalla Lana School of Public Health, University of Toronto, Toronto, Canada. ⁶Nindilinggarri Cultural Health Services, Fitzroy Crossing, Australia. ⁷Marninwarntikura Women's Resource Centre, Fitzroy Crossing, Australia. ⁸School of Arts and Science, University of Notre Dame, Broome, Australia. ⁹Indigenous Community Volunteers, Perth, Australia.

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References

1. Astley S: **Diagnosing fetal alcohol spectrum disorders (FASD)**. In *Prenatal alcohol Use and fetal alcohol spectrum disorders: diagnosis, assessment and New directions in research and multimodal treatment*. Edited by Adobato S, Cohen DE. Oak Park, Illinois: Bentham Science Publishers Ltd; 2011:3–29.
2. Kinnane S, Farringdon F, Henderson-Yates L, Parker H: *An evaluation of the effects of alcohol restrictions in Fitzroy Crossing relating to measurable health and social outcomes, community perceptions and alcohol related behaviours after a 12 month period*. Western Australian: Drug and Alcohol Authority; 2009. ISBN 978-1-876684-419.
3. Gooda M: **From community crisis to community control in the Fitzroy Valley**. In *2010 Social justice report, aboriginal and torres strait islander social justice commissioner*. Sydney: Australian Human Rights Commission; 2010:67–120. ISSN 1873-6482.
4. Latimer J, Elliott EJ, Carter M, Oscar J, Ferreira M, Fitzpatrick JP, Kefford M, O'Brien J: *Marulu: the lililwan project. Fetal alcohol spectrum disorders prevalence study in the Fitzroy Valley. A community consultation*. The George Institute for Global Health; 2010. ISBN 978-0-646-53390-2.
5. Fitzpatrick JP, Elliott EJ, Latimer J, Carter M, Oscar J, Ferreira M, Carmichael Olson H, Lucas B, Doney R, Salter C, et al: **The Lililwan project: study protocol for a population based, active case ascertainment study of the prevalence of fetal alcohol spectrum disorders (FASD) in remote australian aboriginal communities**. *BMJ Open* 2012, **2**(3):1–11.
6. Elliott EJ, Latimer J, Fitzpatrick JP, Oscar J, Carter M: **There's hope in the valley**. *J Paediatr Child Health* 2012, **48**(Suppl 3):190–192.
7. May PA, Gossage JP, Kalberg WO, Robinson LK, Buckley D, Manning M, Hoyme HE: **Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies**. *Dev Disabil Res Rev* 2009, **15**(Suppl 3):176–192.
8. Peardon E, Fremantle E, Bower C, Elliott EJ: **International survey of diagnostic services for children with fetal alcohol spectrum disorders**. *BMC Pediatr* 2008, **8**:12.
9. Mutch R, Peardon EM, Elliott EJ, Bower C: **Need to establish a national diagnostic capacity for foetal alcohol spectrum disorders**. *J Paediatr Child Health* 2009, **45**(Suppl 3):79–81.
10. Astley SJ, Clarren SK: **Diagnosing the full spectrum of fetal alcohol-exposed individuals: introducing the 4-digit diagnostic code**. *Alcohol* 2000, **35**(Suppl 4):400–410.
11. Arenson AD, Bakhireva LN, Chambers CD, Deximo CA, Foroud T, Jacobson JL, Jacobson SW, Jones KL, Mattson SN, May PA, et al: **Implementation of a shared data repository and common data dictionary for fetal alcohol spectrum disorders research**. *Alcohol* 2010, **44**(Suppl 7–8):643–647.
12. Astley SJ: *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-digit Diagnostic Code*. 3rd edition. Seattle WA: University of Washington Publication Services; 2004:114.
13. May PA, Gossage JP, Marais AS, Adnams CM, Hoyme HE, Jones KL, Robinson LK, Khaole NC, Snell C, Kalberg WO, et al: **The epidemiology of fetal alcohol syndrome and partial FAS in a South African community**. *Drug Alcohol Depend* 2007, **88**(Suppl 2–3):259–271.
14. Morphy F: *Population, people and place: the fitzroy valley population project*. Canberra: Australian National University; 2010:1–77. ISBN 0 7315 4969 4.
15. Chudley AE, Conry J, Cook JL, Look C, Rosales T, LeBlanc N: **Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis**. *CMAJ* 2005, **172**(Suppl 5):S1–S21.
16. Poitra BA, Marion S, Dionne M, Wilkie E, Dauphinais P, Wilkie-Pepion M, Martsolf JT, Klug MG, Burd L: **A school-based screening program for fetal alcohol syndrome**. *Neurotoxicol Teratol* 2003, **25**(Suppl 6):725–729.
17. Hoyme HE, May PA, Kalberg WO, Kodituwakku P, Gossage JP, Trujillo PM, Buckley DG, Miller JH, Aragon AS, Khaole N, et al: **A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: clarification of the 1996 institute of medicine criteria**. *Pediatrics* 2005, **115**(1):39–47.
18. Bertrand J, Floyd LL, Weber MK: **Guidelines for identifying and referring persons with fetal alcohol syndrome**. *MMWR Recomm Rep* 2005, **54**(RR-11):1–14.
19. Howe CJB, Frederick C, Stratton, Kathleen R: *Fetal alcohol syndrome: diagnosis, epidemiology, prevention, and treatment*. Washington, D.C: National Academy Press; 1996.
20. Sood B, Delaney-Black V, Covington C, Nordstrom-Klee B, Ager J, Templin T, Janisse J, Martier S, Sokol RJ: **Prenatal alcohol exposure and childhood behavior at age 6 to 7 years: I. dose-response effect**. *Pediatrics* 2001, **108**(Suppl 2):E34.
21. Western Australian Aboriginal Child Health Survey - Household survey forms: *Perth*. Perth Australia: Telethon Institute for Child Health Research; 1999.
22. Footprints in Time: *The longitudinal study of indigenous children (LSIC)*. Canberra: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA); 2008.
23. Growing Up in Australia: *The longitudinal study of Australian children (LSAC)*. Canberra: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), the Australian Institute of Family Studies (AIFS) and the Australian Bureau of Statistics (ABS); 2003.
24. May PA, Gossage JP, Marais AS, Hendricks LS, Snell CL, Tabachnick BG, Stellavato C, Buckley DG, Brooke LE, Viljoen DL: **Maternal risk factors for fetal alcohol syndrome and partial fetal alcohol syndrome in South Africa: a third study**. *Alcohol Clin Exp Res* 2008, **32**(Suppl 5):738–753.
25. May PA, Gossage JP, Brooke LE, Snell CL, Marais AS, Hendricks LS, Croxford JA, Viljoen DL: **Maternal risk factors for fetal alcohol syndrome in the Western cape province of South Africa: a population-based study**. *Am J Public Health* 2005, **95**(Suppl 7):1190–1199.
26. Astley SJ, Bailey D, Talbot C, Clarren SK: **Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: I. Identification of high-risk birth mothers through the diagnosis of their children**. *Alcohol Alcohol* 2000, **35**(Suppl 5):499–508.
27. Astley SJ, Bailey D, Talbot C, Clarren SK: **Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS**. *Alcohol Alcohol* 2000, **35**(Suppl 5):509–519.
28. Stratton K, Howe C, Battaglia F: *Fetal alcohol syndrome: diagnosis, epidemiology, prevention, and treatment*. Washington: Institute of Medicine and National Academy Press; 1996.
29. National Center on Birth Defects and Developmental Disabilities: *Fetal alcohol syndrome: guidelines for referral and diagnosis*. Atlanta GA: Centres for Disease Control and Prevention; 2004.
30. Bush K, Kivlahan DR, McDonnell MB, Fihn SD, Bradley KA: **The AUDIT alcohol consumption questions (AUDIT-C): an effective brief screening test for problem drinking. Ambulatory care quality improvement project (ACQUIP). alcohol Use disorders identification test**. *Arch Intern Med* 1998, **158**(Suppl 16):1789–1795.
31. Norman GR, Streiner DL: *Biostatistics: the bare essentials*. 3rd edition. Ontario: BC Decker Inc.; 2008.
32. Shrout PE, Fleiss JL: **Intraclass correlations: uses in assessing rater reliability**. *Psychol Bull* 1979, **86**(Suppl 2):420–428.

33. Landis JR, Koch GG: **The measurement of observer agreement for categorical data.** *Biometrics* 1977, **33**(Suppl 1):159–174.
34. STROBE Statement: *Strengthening the reporting of observational studies in epidemiology.*. Available at: <http://www.strobe-statement.org/>. Accessed December 2012.
35. Wood J: *Understanding and computing Cohen's kappa: a tutorial.* *WebPsychEmpiricist*. 2007. <http://wpe.info/vault/wood07/Wood07.pdf>.
36. Jacobson SW, Jacobson JL, Sokol RJ, Martier SS, Ager JW, Kaplan MG: **Maternal recall of alcohol, cocaine, and marijuana use during pregnancy.** *Neurotoxicol Teratol* 1991, **13**(5):535–540.
37. Hannigan JH, Chiodo LM, Sokol RJ, Janisse J, Ager JW, Greenwald MK, Delaney-Black V: **A 14-year retrospective maternal report of alcohol consumption in pregnancy predicts pregnancy and teen outcomes.** *Alcohol* 2010, **44**(7–8):583–594.
38. Ernhart CB, Morrow-Tlucak M, Sokol RJ, Martier S: **Underreporting of alcohol use in pregnancy.** *Alcohol Clin Exp Res* 1988, **12**(4):506–511.
39. Alvik A, Haldorsen T, Groholt B, Lindemann R: **Alcohol consumption before and during pregnancy comparing concurrent and retrospective reports.** *Alcohol Clin Exp Res* 2006, **30**(3):510–515.
40. Astley SJ: **Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the washington state fetal alcohol syndrome diagnostic & prevention network.** *Can J Clin Pharmacol* 2010, **17**(1):e132–e164.
41. Astley SJ, Aylward EH, Olson HC, Kerns K, Brooks A, Coggins TE, Davies J, Dorn S, Gendler B, Jirikowic T, et al: **Magnetic resonance imaging outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders.** *Alcohol Clin Exp Res* 2009, **33**(10):1671–1689.
42. Astley SJ, Olson HC, Kerns K, Brooks A, Aylward EH, Coggins TE, Davies J, Dorn S, Gendler B, Jirikowic T, et al: **Neuropsychological and behavioral outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders.** *Can J Clin Pharmacol* 2009, **16**(1):e178–e201.
43. Selin KH: **Test-retest reliability of the alcohol use disorder identification test in a general population sample.** *Alcohol Clin Exp Res* 2003, **27**(9):1428–1435.
44. Brooks D, Wilson L, Kelsey C: **Accuracy and reliability of 'specialized' physical therapists in auscultating tape-recorded lung sounds.** *Physiother Can* 1993, **45**(1):21–24.
45. Foroohar A, Tosti R, Richmond JM, Gaughan JP, Ilyas AM: **Classification and treatment of proximal humerus fractures: inter-observer reliability and agreement across imaging modalities and experience.** *J Orthop Surg Res* 2011, **6**:38.

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DATE

CHILD ID.....

THE LILILWAN PROJECT – INTERVIEW FORM

FILL IN BEFORE THE INTERVIEW STARTS - This page will be detached and stored separately so that the identity of the child and parent/carer is kept secret.

Which community is the interview being conducted at? _____

Names of person/people collecting information (interviewer/s):

First person: _____

Second person: _____

Name of study child: _____

Age and D.O.B. of study child: _____

Is child under DCP care? Yes No **If yes, DCP staff member must be at the interview.**

If yes, Name of DCP staff member: _____

CONFIDENTIALITY

The information you give us is confidential between you and the Lirilwan Project workers. What you say will be put only on this form without giving it to anyone else outside.

Every person doing these interviews had to sign a confidentiality form saying we are not allowed to tell anyone about what you have told us.

When we finish interviewing you, your name will be taken off and replaced with a number so nobody will know whose form it is. Your name or the child's name will not be used, only the number (ID number). The forms will be securely locked up.

Name of person / people being interviewed (interviewee/s):

What is the name of each person being interviewed, and how are each of you related to this child?

First person **First name(s)** _____

Last name(s) _____

Second person **First name(s)** _____

Last name(s) _____

Relationship to child? Stepmother Foster mother Adoptive mother Auntie Grandmother Sister
 Birth father Stepfather Foster father Adoptive father Grandfather Brother
 Uncle Cousin Carer DCP worker
 Other (specify): _____

Third Person **First name(s)** _____

Last name(s) _____

Relationship to child? Stepmother Foster mother Adoptive mother Auntie Grandmother Sister
 Birth father Stepfather Foster father Adoptive father Grandfather Brother
 Uncle Cousin Carer DCP worker
 Other (specify): _____

What language do you prefer to do the interview in? _____

Is it OK to do the interview in English with the community navigator helping to explain the questions?

If interpreter required what language/day/place/time has interview been booked for? _____

DATE

CHILD ID.....

PAGE 2

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DATE

CHILD ID.....

PART 1 – GENERAL INFORMATION ABOUT YOU AND YOUR FAMILY

1	Mother's details	Mother's current age at time of interview: ____ years How old are you now? Date of birth: / / What is your date of birth?
2	Father's details	Father's current age at time of interview: ____ years How old is the father now? Date of birth: / / What is his date of birth?
3	Study ID number: _____ Date of birth: / / _____	Girl or Boy (circle)
4	Is this child of Aboriginal, Torres Strait or South Sea Islander origin?	<input type="checkbox"/> Aboriginal <input type="checkbox"/> Torres Strait <input type="checkbox"/> South Sea Islander <input type="checkbox"/> Neither <input type="checkbox"/> Unknown Go to next Q Go to Q 10 Go to Q 10
IF ABORIGINAL		
5	What's the child's (biological) father's language group?	<input type="checkbox"/> Bunuba <input type="checkbox"/> Nykina <input type="checkbox"/> Goonyandi <input type="checkbox"/> Unknown <input type="checkbox"/> Walmajarri/ Wangkatjungka <input type="checkbox"/> Other (specify):
6	What's your (the child's mother's) language group?	<input type="checkbox"/> Bunuba <input type="checkbox"/> Nykina <input type="checkbox"/> Goonyandi <input type="checkbox"/> Unknown <input type="checkbox"/> Walmajarri/ Wangkatjungka <input type="checkbox"/> Other (specify):
7	What's the child's language group?	<input type="checkbox"/> Bunuba <input type="checkbox"/> Nykina <input type="checkbox"/> Goonyandi <input type="checkbox"/> Unknown <input type="checkbox"/> Walmajarri/ Wangkatjungka <input type="checkbox"/> Other (specify):
8	What's the main language this child speaks at home?	<input type="checkbox"/> Bunuba <input type="checkbox"/> Nykina <input type="checkbox"/> Kriol <input type="checkbox"/> Goonyandi <input type="checkbox"/> Unknown <input type="checkbox"/> English <input type="checkbox"/> Other (specify):
9	What other languages does this child speak or understand?	<input type="checkbox"/> Bunuba <input type="checkbox"/> Nykina <input type="checkbox"/> Kriol <input type="checkbox"/> Goonyandi <input type="checkbox"/> Unknown <input type="checkbox"/> English <input type="checkbox"/> Walmajarri/ Wangkatjungka Now go to Q 14
IF NOT ABORIGINAL		
10	Where were you (the child's mother) born?	<input type="checkbox"/> Australia <input type="checkbox"/> Other (specify):
11	What is your ethnicity/cultural background? (Where did your family originate from?)	<input type="checkbox"/> Australian <input type="checkbox"/> Pacific Islander <input type="checkbox"/> Maori <input type="checkbox"/> Middle Eastern <input type="checkbox"/> Chinese <input type="checkbox"/> Japanese <input type="checkbox"/> Filipino <input type="checkbox"/> Indonesian <input type="checkbox"/> Other Asian <input type="checkbox"/> African <input type="checkbox"/> Dutch <input type="checkbox"/> English <input type="checkbox"/> French <input type="checkbox"/> German <input type="checkbox"/> Italian <input type="checkbox"/> New Zealand <input type="checkbox"/> Scottish <input type="checkbox"/> Irish <input type="checkbox"/> Indian subcontinent <input type="checkbox"/> Latin American <input type="checkbox"/> Other (specify):
12	Where was this child's (biological) father born?	<input type="checkbox"/> Australia <input type="checkbox"/> Other (specify):
13	What is this child's father's ethnicity/cultural background?	<input type="checkbox"/> Australian <input type="checkbox"/> Pacific Islander <input type="checkbox"/> Maori <input type="checkbox"/> Middle Eastern <input type="checkbox"/> Chinese <input type="checkbox"/> Japanese <input type="checkbox"/> Filipino <input type="checkbox"/> Indonesian <input type="checkbox"/> Other Asian <input type="checkbox"/> African <input type="checkbox"/> Dutch <input type="checkbox"/> English <input type="checkbox"/> French <input type="checkbox"/> German <input type="checkbox"/> Italian <input type="checkbox"/> New Zealand <input type="checkbox"/> Scottish <input type="checkbox"/> Irish <input type="checkbox"/> Indian subcontinent <input type="checkbox"/> Latin American <input type="checkbox"/> Other (specify):
14	Where does this child live mainly?	<input type="checkbox"/> Fitzroy Town <input type="checkbox"/> Wangkatjungka <input type="checkbox"/> Other (specify): <input type="checkbox"/> Bayulu <input type="checkbox"/> Yakanarra <input type="checkbox"/> Unknown <input type="checkbox"/> Noonkanbah
15	Where will this child be mainly living in the dry season?	<input type="checkbox"/> Fitzroy Town <input type="checkbox"/> Wangkatjungka <input type="checkbox"/> Other (specify): <input type="checkbox"/> Bayulu <input type="checkbox"/> Yakanarra <input type="checkbox"/> Unknown <input type="checkbox"/> Noonkanbah
16	Where will this child be mainly living in the wet season?	<input type="checkbox"/> Fitzroy Town <input type="checkbox"/> Wangkatjungka <input type="checkbox"/> Other (specify): <input type="checkbox"/> Bayulu <input type="checkbox"/> Yakanarra <input type="checkbox"/> Unknown <input type="checkbox"/> Noonkanbah

DATE

CHILD ID.....

PART 2 – SCHOOLING AND EDUCATION

Now we want to ask about this child's schooling.

17	What school does (CHILD) attend? Which school does this child normally go to?	<input type="checkbox"/> Fitzroy Crossing <input type="checkbox"/> Wangkatjungka <input type="checkbox"/> Other (specify):	<input type="checkbox"/> Bayulu <input type="checkbox"/> Yakanarra <input type="checkbox"/> None	<input type="checkbox"/> Noonkanbah		
18	What grade is (CHILD) in? What grade is this child in at school now?	<input type="checkbox"/> Not at school <input type="checkbox"/> Grade 2 <input type="checkbox"/> Other (specify):	<input type="checkbox"/> Pre-school <input type="checkbox"/> Grade 3	<input type="checkbox"/> Grade 1		
19	What other school(s) does (CHILD) attend during different seasons? (tick all that apply) What other school(s) does this child sometimes go to (this year)? (Tick all the other schools they go to)	<input type="checkbox"/> Fitzroy Crossing <input type="checkbox"/> Wangkatjungka <input type="checkbox"/> Other (specify):	<input type="checkbox"/> Bayulu <input type="checkbox"/> Yakanarra <input type="checkbox"/> None	<input type="checkbox"/> Noonkanbah		
20	How many schools has (CHILD) attended since starting school? – not counting pre-school How many schools has this child gone to since starting school?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5 or more
21	How often does (CHILD) attend school? How often does this child attend school?	<input type="checkbox"/> Not at all <input type="checkbox"/> Little bit (2-3 days/week) <input type="checkbox"/> Most days (4-5 days/week)	<input type="checkbox"/> Not much (1 day/week)	Go to next Q Go to Q23		
22	If they attend school less than 4-5 days per week, why does (CHILD) miss school? (tick all that apply) Why is this child missing school? (maybe just one reason or more than one)	<input type="checkbox"/> Family/personal reasons <input type="checkbox"/> Skipping school <input type="checkbox"/> School expulsion <input type="checkbox"/> Unknown (specify):	<input type="checkbox"/> Illness <input type="checkbox"/> Suspension <input type="checkbox"/> Cultural reasons <input type="checkbox"/> Other reasons			
23	Does (CHILD) receive learning or behaviour support at school? Is (CHILD) in a special class? Does this child have someone like a special education aide working with them in the classroom because they need extra help? If they do, how much of the time do they get extra help?	<input type="checkbox"/> No <input type="checkbox"/> Yes (specify what help they get):	<input type="checkbox"/> Unknown			

PART 3 – YOUR PREGNANCIES AND BIRTHS

Now we'd like to ask a bit about the times you have been pregnant. Is that ok?

24	How many children have you given birth to altogether? How many babies have you had altogether?	Number:		
25	How many pregnancies have you had? Did you lose any babies before they were born? If you have, do you know why you lost them?	<input type="checkbox"/> Don't want to answer <input type="checkbox"/> Lost ___ babies before birth (number) <input type="checkbox"/> Miscarriage <input type="checkbox"/> Abortion / termination <input type="checkbox"/> Unknown <input type="checkbox"/> Other (specify):		
26	Was (CHILD) a twin or triplet or more? Was this child a twin or triplet or more?	<input type="checkbox"/> No <input type="checkbox"/> Quadruplet	<input type="checkbox"/> Twin <input type="checkbox"/> Unknown	<input type="checkbox"/> Triplet
27	How many children were born before (CHILD)? How many of your children are older than this child?	Number:		
28	How many children were born after (CHILD)? How many of your children are younger than this child?	Number:		

Now we want to ask about when you were pregnant with this child. Is that ok?

29	Where did you live when you were pregnant with (CHILD)? Where were you living when you were pregnant with this child? (tick all the places)	<input type="checkbox"/> Fitzroy Crossing <input type="checkbox"/> Wangkatjungka <input type="checkbox"/> Other (specify):	<input type="checkbox"/> Bayulu <input type="checkbox"/> Yakanarra <input type="checkbox"/> Unknown	<input type="checkbox"/> Noonkanbah
30	Did you have any check ups during the pregnancy? Did you have any check ups during the pregnancy?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
31	If yes, how far along in the pregnancy was the first check up? If yes, how far along in the pregnancy was the first check up?	<input type="checkbox"/> First 3 months <input type="checkbox"/> Last 3 months	<input type="checkbox"/> Second 3 months <input type="checkbox"/> Unknown	

DATE

CHILD ID.....

ANTENATAL COMPLICATIONS:

Any problems or special things during the pregnancy

32	Did you have any problems in the pregnancy with (CHILD)? Did you have any problems in the pregnancy with this child?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown	
	If yes, what were the problems? (specify all that apply): If yes, what problems did you have? - maybe one or more than one problem	High blood pressure	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
		Diabetes	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
		Premature rupture of membranes (waters broke early)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
		Infections	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
		Hospital admission	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
		Anaemia (low iron)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
Other (Please specify):					

OTHER ANTENATAL MEDICATIONS AND EXPOSURES:

The next questions are about medicines and drugs in the pregnancy with this child

33	Were you on any medications during the pregnancy with (CHILD)? Did you take any medicines during the pregnancy with this child?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Iron supplements / Iron medicine?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Folic acid / Folic acid or folate?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Phenytoin (Dilantin) / The medicine for fits called Phenytoin (Dilantin)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Valproate (Epilim) / Another medicine for fits called Sodium Valproate (Epilim)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Any other medication during this pregnancy? Did you take any other medicines while you were pregnant with this child?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
Please specify medication. If yes, what medicine?				
34	Did you smoke during this pregnancy? Did you smoke while you were pregnant with this child?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
35	Did you chew tobacco during this pregnancy? Did you chew tobacco while you were pregnant with this child?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
36	Did you take any of these drugs during the pregnancy with (CHILD)? Did you take any drugs like the ones below during the pregnancy?			
	Methadone for heroin addiction	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Marijuana (Ganja)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Sniffing solvents e.g. petrol, paint thinner, deodorant spray	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Heroin	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Cocaine	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
	Speed or Ice	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
Other (specify):				

ANTENATAL ALCOHOL EXPOSURE:The next questions are about if you drank alcohol/grog before and during the pregnancy with this child, is that ok? Answering these questions might be a bit hard, but it's really important that you're honest about it. It's not about shame or blame, but about helping children who need help to be as good as they can be. If you start to feel upset we can stop.

37	Did you drink any alcohol in the 3 months BEFORE the pregnancy with (CHILD)? Did you drink any alcohol/grog in the 3 months BEFORE you were pregnant with this child?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
38	Did you drink any alcohol DURING this pregnancy? Did you drink any alcohol/grog WHILE you were pregnant with this child?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
39	If yes, in which trimester(s) was alcohol consumed (tick all that apply) If you did drink, how far along in the pregnancy were you when you were drinking? Did you drink in the first three months, the second three months, the last three months, or all the way through?	<input type="checkbox"/> First 3 months <input type="checkbox"/> Second 3 months <input type="checkbox"/> Last 3 months <input type="checkbox"/> During the entire pregnancy <input type="checkbox"/> Unknown		
40	What type of alcohol did you usually drink? What type of alcohol/grog did you usually drink? Use picture of local drink cans / bottles to specify:	<input type="checkbox"/> Full strength beer <input type="checkbox"/> Port/liqueur <input type="checkbox"/> Mid strength beer <input type="checkbox"/> Spirits <input type="checkbox"/> Light beer <input type="checkbox"/> Premixed spirits <input type="checkbox"/> Wine <input type="checkbox"/> Other (specify):		

DATE

CHILD ID.....

41	Were you drinking cans, bottles, glasses? What size did you usually drink? Use picture of local drink cups / cans / bottles	<input type="checkbox"/> Cans <input type="checkbox"/> Stubbies <input type="checkbox"/> Long necks <input type="checkbox"/> Schooner glass <input type="checkbox"/> Middy glass <input type="checkbox"/> Wine glass <input type="checkbox"/> Beer bottles <input type="checkbox"/> Other (specify):
42	How many alcoholic drinks did you have on a typical day when drinking? On the days when you did drink, how many drinks would you have on each day?	<input type="checkbox"/> 1 - 2 <input type="checkbox"/> 3 - 4 <input type="checkbox"/> 5 - 6 <input type="checkbox"/> 7 - 9 <input type="checkbox"/> 10 or more <input type="checkbox"/> Unknown
43	On average how often did you have a drink containing alcohol? When pregnant with this child how often did you drink alcohol/grog?	<input type="checkbox"/> Never <input type="checkbox"/> Less than once a month <input type="checkbox"/> Once a month <input type="checkbox"/> Once every two weeks <input type="checkbox"/> Once a week <input type="checkbox"/> 2 or 3 times a week <input type="checkbox"/> Daily or almost daily
44	When you were pregnant, how often did you have 6 or more alcoholic drinks on one occasion? During the whole pregnancy how often did you have 6 or more drinks of alcohol/grog at one time?	<input type="checkbox"/> Never <input type="checkbox"/> Less than once a month <input type="checkbox"/> Once a month <input type="checkbox"/> Once every 2 weeks <input type="checkbox"/> Once a week <input type="checkbox"/> 2 or 3 times a week <input type="checkbox"/> Daily or almost daily
45	Will you drink alcohol if you become pregnant again? If you are pregnant again would you drink alcohol/grog during your pregnancy?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know / maybe
46	How sure are you about your answers to these questions about alcohol? We know it might be hard to remember about grog back before this child was born. Can you say how sure you are about what you've told us?	<input type="checkbox"/> Very sure <input type="checkbox"/> Fairly sure <input type="checkbox"/> Not so sure

PART 4 – THE BIRTH OF THIS CHILD

Now we'd like to ask you about when this child was born.

47	Where was (CHILD) born? Where was this child born?	<input type="checkbox"/> Derby <input type="checkbox"/> Fitzroy <input type="checkbox"/> Perth <input type="checkbox"/> Darwin <input type="checkbox"/> Other (specify):
48	How was (CHILD) born? How was this child born?	<input type="checkbox"/> Normal vaginal delivery <input type="checkbox"/> Vacuum extraction <input type="checkbox"/> Forceps <input type="checkbox"/> Elective Caesarean <input type="checkbox"/> Emergency Caesarean <input type="checkbox"/> Other (specify):
49	How far along in the pregnancy were you when (CHILD) was born? Was the child born early / at the due date / after the due date?	<input type="checkbox"/> Early (how early?) _____ weeks <input type="checkbox"/> Late (how late?) _____ weeks <input type="checkbox"/> On time <input type="checkbox"/> Unknown

PART 5 – GROWTH AND DEVELOPMENT – GROWING UP

The next questions are about the child's development. Development means things like playing sport, writing, talking and making friends. We want to know if you think this child is different from the other children.

We also want to know if this child has been sick from the baby time upward. Is it OK to keep asking questions?

57	Does (CHILD) have any long-term medical problems requiring ongoing care, including mental health or behavioural problems? Does this child have any long-term medical problems that need ongoing care, including mental health or behavioural problems?	<input type="checkbox"/> Yes If yes, go to next Q <input type="checkbox"/> No <input type="checkbox"/> Unknown If no or unknown, go to Q 59
58	If yes, specify the problem/s? (all that apply) What kind of problems does this child have? Please tell us about all the medical problems. (Run through checklist)	Please specify: <input type="checkbox"/> Cardiovascular (heart) <input type="checkbox"/> Ear, nose and throat <input type="checkbox"/> Endocrine (like diabetes or hormones) <input type="checkbox"/> Gastrointestinal (inside stomach) <input type="checkbox"/> Neurological (brain, nerves, spine) <input type="checkbox"/> Respiratory / lung <input type="checkbox"/> Skin <input type="checkbox"/> Mental health or behavioural problems <input type="checkbox"/> Other (specify):
59	What regular medicines does (CHILD) currently take? Is this child taking any tablets or medicines for a long time? If yes, what tablets or medicines do they take?	<input type="checkbox"/> None/no <input type="checkbox"/> Unknown <input type="checkbox"/> Yes (Please list):
60	Has (CHILD) had any hospital admissions? Has this child ever been in hospital? (apart from when they were born)	<input type="checkbox"/> Yes If yes, go to next Q <input type="checkbox"/> No <input type="checkbox"/> Unknown If no or unknown, go to Q 62
61	If yes, why was (CHILD) admitted, and which hospital/s? If yes, why was this child admitted to hospital? Which hospital were they in?	Problem: Hospital/s:
62	Has (CHILD) had a serious head injury? Has this child ever had a serious head injury?	<input type="checkbox"/> Yes If yes, go to next Q <input type="checkbox"/> No <input type="checkbox"/> Unknown If no or unknown, go to Q 64
63	If yes, what happened to (CHILD)? If they had a head injury, what happened?	<input type="checkbox"/> Loss of consciousness (knocked out) <input type="checkbox"/> Admitted to hospital <input type="checkbox"/> Skull fracture <input type="checkbox"/> Bleeding inside the head <input type="checkbox"/> Other (please specify):
64	Has (CHILD) ever had have seizures (fits)? Did this child ever have any fits?	<input type="checkbox"/> Yes If yes, go to next Q <input type="checkbox"/> No <input type="checkbox"/> Unknown If no or unknown, go to Q 66
65	Does (CHILD) have an ongoing seizure disorder? Does this child have an ongoing problem with fits?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
66	Is (CHILD)'s development behind other children their age? Is this child behind other children in their age group?	<input type="checkbox"/> Yes If yes, go to next Q <input type="checkbox"/> No <input type="checkbox"/> Unknown If no or unknown, go to Q 68
67	If yes, in what areas is (CHILD) delayed? (please tick all that apply) In what ways is this child behind? (tick all the ones that apply to this child) Are there any other ways you think this child might be behind other children the same age? (Clarify if child doesn't like doing it, or if they have difficulty)	<input type="checkbox"/> Gross motor (big muscles) – running, jumping, throwing <input type="checkbox"/> Fine motor (small muscles) – drawing, using a pencil, etc <input type="checkbox"/> Speech and language - speaking and understanding language <input type="checkbox"/> Literacy – writing or reading <input type="checkbox"/> Personal/social – making friends <input type="checkbox"/> Cognitive - thinking and learning <input type="checkbox"/> Vision / seeing <input type="checkbox"/> Hearing / hearing <input type="checkbox"/> Other (please specify):

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Has the child received therapy or help		
List of referrals needed from the question above		
68	<p>Has (CHILD) been diagnosed with a Fetal Alcohol Spectrum Disorder (FASD)? <i>Has anyone told you that this child has FASD?</i></p>	<input type="checkbox"/> Yes If yes, go to next Q <input type="checkbox"/> No <input type="checkbox"/> Unknown If no or unknown, go to Q 73
69	<p>If yes, what is the diagnosis? <i>What did they tell you this child has?</i></p>	<input type="checkbox"/> FAS <input type="checkbox"/> Partial FAS <input type="checkbox"/> Alcohol Related Birth Defects <input type="checkbox"/> Alcohol Related Neurodevelopmental Disorder <input type="checkbox"/> Unknown <input type="checkbox"/> Other (specify):
70	<p>Who made the diagnosis? <i>Who told you this child has FASD?</i></p>	<input type="checkbox"/> Hospital doctor <input type="checkbox"/> Children's doctor <input type="checkbox"/> Clinic nurse <input type="checkbox"/> Clinic doctor <input type="checkbox"/> Unknown <input type="checkbox"/> Other (specify):
71	<p>Don't ask this question – we will get from records. Who else was involved in making the diagnosis?</p>	Select all that apply <input type="checkbox"/> Children's doctor <input type="checkbox"/> Hospital doctor <input type="checkbox"/> Clinic nurse <input type="checkbox"/> Clinic doctor <input type="checkbox"/> Occupational Therapist <input type="checkbox"/> Physiotherapy <input type="checkbox"/> Psychologist <input type="checkbox"/> Social worker <input type="checkbox"/> Aboriginal Health Worker <input type="checkbox"/> Speech Therapy <input type="checkbox"/> Unknown <input type="checkbox"/> Other (specify):
72	<p>Don't ask this question – we will get from records. What information was used to make the diagnosis (diagnostic criteria)? Specify all from health record.</p>	Assessment by: <input type="checkbox"/> Paediatrician <input type="checkbox"/> Occupational Therapist <input type="checkbox"/> Psychologist <input type="checkbox"/> Psychiatrist <input type="checkbox"/> Speech Therapist <input type="checkbox"/> Physiotherapist <input type="checkbox"/> Other (specify):
73	<p>Is (CHILD) registered with the Disability Services Commission or another disability organisation? <i>If the child has a disability, are they registered with Disability Services?</i></p>	<input type="checkbox"/> Yes: which organisation? <hr/> <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Other (specify):
74	<p>Does the family receive Carer or Disability Allowance for (CHILD)? (Carer Allowance is a Centrelink benefit for caring for children with a disability or medical condition) <i>Do you get disability pay for looking after this child?</i></p>	<input type="checkbox"/> Yes (specify): <input type="checkbox"/> No <input type="checkbox"/> Unknown
75	<p>Do any of your other biological children have a Fetal Alcohol Spectrum Disorder? If so, specify age, gender & diagnosis. <i>Do any of your other birth children have FASD?</i> <i>If they do, can you tell us their age, gender and the diagnosis?</i></p>	<input type="checkbox"/> Yes (specify age, gender and diagnosis of child / children): FAS / FASD / ARND / ARBD <hr/> <input type="checkbox"/> Suspected but not diagnosed (specify age and gender of child / children): <hr/> <input type="checkbox"/> No <input type="checkbox"/> Don't know

PART 6 – ABOUT YOU AND THE FAMILY – BIRTH MOTHER’S DETAILS

76	What level of school education did you reach? What was your last year in school?	<input type="checkbox"/> Primary <input type="checkbox"/> Year 10 <input type="checkbox"/> Year 11 <input type="checkbox"/> Year 12 <input type="checkbox"/> TAFE <input type="checkbox"/> Unknown <input type="checkbox"/> Other (specify):
77	Post-school study Have you done any other study after school?	<input type="checkbox"/> Short courses / certificates <input type="checkbox"/> TAFE <input type="checkbox"/> Undergraduate degree <input type="checkbox"/> Postgraduate degree / diploma <input type="checkbox"/> No
78	Are there any medical conditions which run in your family or the birth father's family? Is there any medical condition that runs in your family or the father's family?	<input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Yes (specify):
79	Do you have any medical problems? Do you have any medical problem like diabetes or other sickness you see the doctor or nurse for? If you do, what is the problem?	<input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Yes (specify):
80	Do you have any mental health issues? Do you have any mental health problems like depression or something like that you see the doctor or nurse for? If you do, what sort of problem?	<input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Yes (specify):
81	Do you have any learning problems? Do you have any problems learning or memorising things?	<input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Yes (specify):
82	Do you currently smoke, drink alcohol or use any drugs? Do you currently: drink alcohol? smoke cigarettes? use any drugs?	Drink alcohol <input type="checkbox"/> Yes <input type="checkbox"/> No Smoke cigarettes <input type="checkbox"/> Yes <input type="checkbox"/> No Other drugs <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No <input type="checkbox"/> Don't know
83	Have you ever had an alcohol related hospital admission? Have you ever had to be admitted to hospital because of alcohol?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
84	Have you ever had an alcohol related injury while intoxicated? Have you ever been injured while drunk?	<input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Yes (specify):
85	Have you ever had an alcohol related disease? e.g. liver Have you ever had a disease that the doctor said is because of alcohol - like a liver problem or any other problem inside your body?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
86	Have you ever been diagnosed with alcohol dependency requiring treatment? Have you ever been told by a health worker that you are addicted to alcohol?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
87	Do you have a Fetal Alcohol Spectrum Disorder? Did anyone ever say you had a FASD?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown <input type="checkbox"/> Suspected but not diagnosed / maybe
88	If yes, what is the diagnosis? If yes, did they say what sort of FASD?	<input type="checkbox"/> Fetal Alcohol Syndrome <input type="checkbox"/> Partial FAS <input type="checkbox"/> ARND <input type="checkbox"/> Alcohol Related Birth Defects <input type="checkbox"/> Other <input type="checkbox"/> Unknown

PART 7 – AT HOME / BRINGING UP THE CHILD

The next questions are about things in your home that might have affected this child's growing up

89	How many people (adults and children) usually live with (CHILD)? How many people (adults and children) usually live in the same house as this child?	Number:
90	Which adult/s usually lives with (CHILD)? (select all that apply) Which adults usually live in the same house as this child? (Tick all those that apply)	<input type="checkbox"/> Birth mother <input type="checkbox"/> Birth father <input type="checkbox"/> Foster carers <input type="checkbox"/> Adoptive family <input type="checkbox"/> Other (specify)
91	Unemployment of household members Do any of those adults have jobs? (tick if any of them do)	<input type="checkbox"/> Full time <input type="checkbox"/> Part time <input type="checkbox"/> CDEP <input type="checkbox"/> Volunteer <input type="checkbox"/> No-one works <input type="checkbox"/> Unknown
92	Family separation (parents splitting up) Are this child's father and mother separated from each other?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
93	Who has been the adult most involved in growing up this (CHILD)? (please identify relationship to CHILD) Who has been the main person growing up this child?	<input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Aunt <input type="checkbox"/> Uncle <input type="checkbox"/> Brother <input type="checkbox"/> Sister <input type="checkbox"/> Grandmother <input type="checkbox"/> Grandfather <input type="checkbox"/> Other relative (specify): _____ <input type="checkbox"/> Other person not a relative (specify relationship to child): _____ <input type="checkbox"/> Don't know
94	How many homes has (CHILD) lived in since he/she was born? How many places has this child lived in since they were born?	Number:
95	How important have cultural and traditional activities been in (CHILD'S) life? How important have cultural and traditional activities like hunting, fishing and camping out been in this child's life?	<input type="checkbox"/> Very important <input type="checkbox"/> Pretty important <input type="checkbox"/> Not important <input type="checkbox"/> Don't know
96	Is this a good community or neighbourhood for children where they can feel safe? Is this a good community for children where they feel safe?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
97	Are there good places for children to play in this community? Are there good, safe places for children to go in this community?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
These next few questions are about things that could have made the child worry or feel sad while they were growing up. We know these questions might be hard for you. Is it OK to keep going? This is nearly the end of the interview.		
98	Household worries about money Are there times when adults in this child's house worry about not having enough money?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
99	Not enough food Are there times when adults in this child's house worry about not having enough food?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
100	Overcrowding of home Do you think there are too many people living in this child's house?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
101	Domestic violence Do adults or parents fight a lot at home?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
102	Household member going to jail Has any family member close to this child been put in prison?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
103	Patterns of alcohol and drug taking by adults in the house We want to ask about alcohol and drug taking by adults in the house	
	Alcohol or other drug addiction Is there anyone in the house who has to use alcohol or other drugs every day	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
	Has there been a problem with people bringing grog or drugs in the house so the child felt unsafe or lost sleep all the time?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
104	Mental health problems Is there anyone in the home who may have mental health problems like paranoid or depression or are mental health clients that need counselling?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
105	Unexpected death of a household member Has any family member passed away that have made this child worry or feel sad?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown

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106	Has Department for Child Protection been involved with (CHILD)? Have DCP or welfare been involved with this child?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
107	If yes, is the involvement current or past? If yes, are DCP involved now or was it before?	<input type="checkbox"/> Now	<input type="checkbox"/> Before	<input type="checkbox"/> Unknown
108	Has (CHILD) been placed in foster care at any time? Has welfare at any time taken this child away from you to live somewhere else?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
109	If yes, in how many foster homes has this child lived? How many different families has welfare put this child with?	Number:		

PART 8 – THE LAST FEW QUESTIONS

110	Where do you go for advice or information about looking after (CHILD)? If you are worried about growing up your children, where do you go for advice or information?	<input type="checkbox"/> Media (eg. TV, magazine) <input type="checkbox"/> Nowhere or self <input type="checkbox"/> Partner or family member <input type="checkbox"/> Friends or neighbours <input type="checkbox"/> Women's resource centre <input type="checkbox"/> Karrayili <input type="checkbox"/> Nindilingarri <input type="checkbox"/> Centrelink <input type="checkbox"/> Health clinic or hospital <input type="checkbox"/> School <input type="checkbox"/> No-one <input type="checkbox"/> Don't know <input type="checkbox"/> Other (specify):
111	Are there any other things you would like to tell me about (CHILD)? Are there any other things you would like to tell me about this child?	

Thank you so much for being part of this interview. We know some questions have been hard and it has taken a long time. Thank you for giving such personal information.

Nindilingarri, Marninwarntikura and other organisations will work hard to make sure this project helps all children in the Fitzroy Valley.

CONFIDENTIALITY

Remember, the information you give us is confidential between you and the Liliwan Project workers. What you say will be put only on this form without giving it to anyone else outside.

Every person doing these interviews had to sign a confidentiality form saying we are not allowed to tell anyone about what you have told us.

Names on this form will be taken off and replaced with a number so nobody will know whose form it is. Your name or the child's name will not be used, only the number (ID number).

LAST QUESTION

112	Were there any problems with this interview? How do you think we could do it better?	
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COMMENTS FROM INTERVIEWER on anything that may be relevant to the accuracy or nature of the data collected from this interview?

Interviewer to fill in at the end of questionnaire:

How reliable was the source of information about antenatal alcohol exposure?

- Very reliable – source was the birth mother who recalls her level of consumption well
- Very reliable – source is not the birth mother, who directly observed the mother drinking during pregnancy and recalls the level of consumption well
- Somewhat reliable – source is the birth mother who does not recall her consumption well
- Somewhat reliable – source is not the birth mother and is somewhat sure of the mother's consumption during pregnancy
- Alcohol use in pregnancy confirmed from medical records
- Not reliable – No reliable history or medical record information available