


# BMJ Open Bigiswun Kid Project: a longitudinal study of adolescents living with high rates of prenatal alcohol exposure, fetal alcohol spectrum disorder and early life trauma in remote Australian Aboriginal communities

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## ABSTRACT

**Introduction** The Lirilwan Project was the first Australian population-based prevalence study of fetal alcohol spectrum disorder (FASD) using active case ascertainment. Conducted in 2010–2011, the study included 95% of all eligible children aged 7–9 years living in the very remote Aboriginal communities of the Fitzroy Valley, Western Australia. Women from Marninwarntikura Women's Resource Centre, a local Aboriginal-led organisation, are concerned that some participants from the study are struggling in adolescence so partnered with researchers from the University of Sydney to follow up the Lirilwan cohort in 2020–2022 at age 17–19 years.

The overarching aim of the Bigiswun Kid Project is to identify adolescents' needs and build knowledge to inform services to improve the health and well-being of adolescents in remote Aboriginal communities. The specific aims are to: (1) provide a voice to adolescents and their families to understand the health and well-being status of the Lirilwan cohort at 17–19 years. (2) Examine relationships between exposures during pregnancy, birth characteristics, and health and neurodevelopment at 7–9 years, and positive/adverse adolescent outcomes at 17–19 years. This information will identify prenatal and early life factors that predict good health and well-being in adolescence. (3) Determine whether management plans provided in the Lirilwan Project were followed, and identify past and present service gaps, support needs and barriers to service use. (4) Determine if key physical characteristics of FASD change between childhood and adolescence in this Aboriginal population.

**Ethics and dissemination** Approved by the Kimberley Aboriginal Health Planning Forum and relevant ethics committees.

Following implementation of community-wide alcohol restrictions in 2008, women leaders in the Fitzroy Valley of Western Australia (WA) became worried about the

## Strengths and limitations of this study

- The project is conducted in accordance with national guidelines on research with Aboriginal and Torres Strait Islander people.
- The research was initiated, co-designed and led by local Aboriginal people, including consumers, and uses a community-based participatory research approach to respond to community priorities.
- This longitudinal project will use data collected in childhood and adolescence and has access to data from the prenatal period.
- The methodology has carefully been adapted with local Aboriginal community members to account for the local context, including multiple Aboriginal languages, very remote location, historical and current trauma, and social disadvantage.
- The sample size is relatively small, but it is population based and identified by active case ascertainment.

impact of alcohol use in pregnancy on the Aboriginal community, including the potential for fetal alcohol spectrum disorder (FASD). FASD is a complex neurodevelopmental disorder resulting from brain injury caused by prenatal alcohol exposure (PAE). FASD is characterised by severe developmental, learning and behavioural problems, and may also be associated with birth defects and facial anomalies. The term fetal alcohol syndrome (FAS) is applied to children with the sentinel facial features of short palpebral fissure, flat philtrum and thin upper lip that have been linked with PAE in trimester one.<sup>1</sup> Aboriginal women were concerned that FASD would limit children's capacity to pass to the next generation the languages, stories,



dances and traditions vital to preserving Aboriginal culture. They developed the Marulu Strategy to address the diagnosis, management, and prevention of FASD and early life trauma (ELT) and provide support to families living with FASD. Marulu is a Bunuba word that means 'precious, worth nurturing', which is how the community regards its children.<sup>2,3</sup>

In 2009, following an initiative of Aboriginal leaders, the Lililwan Project was initiated to determine the prevalence of alcohol use in pregnancy, FASD and ELT. Lililwan is a Kimberley Kriol word that means 'all the little ones,' or children. The project was a partnership between Nindilingarri Cultural Health Services and Marninwarrtikura Women's Resource Centre (MWRC) in Fitzroy Crossing, the University of Sydney (Discipline of Paediatrics and Child Health) and the George Institute for Global Health.<sup>2,4</sup> Before commencing research, we undertook extensive consultation to seek community consent.<sup>5</sup>

In 2010, all children born in 2002 or 2003 and living in the Fitzroy Valley were invited to participate in the Lililwan Project and 127 of 134 (95%) eligible families gave consent. In stage 1 (interviews with parents/carers), we identified that 55% of children had PAE, usually at high-risk levels<sup>6</sup> and ELT was almost universal. Examples of ELT included overcrowding, poverty, parental drug and alcohol dependence, parental incarceration, witnessing or experiencing violence in the home, and loss of a parent, sibling, or other close relatives. In stage 2, we conducted comprehensive, multidisciplinary neurodevelopmental assessments on 108 of 127 participants. Rates of FASD (19%), including FAS (9%),<sup>7,8</sup> were among the highest recorded internationally.<sup>9,10</sup> FASD was associated with high rates of behavioural, learning and academic problems, attention deficit hyperactivity disorder (ADHD), and problems with mental health, speech, motor skills, hearing and vision. Physical features included microcephaly, facial dysmorphism and other birth defects and growth delay.<sup>8,11-17</sup> An individualised management plan was provided for all children and with consent shared with their health professionals and schools. Many children were referred for ongoing health, allied health and child psychology or psychiatry assessment or treatment. However, there were concerns regarding the capacity of the health and education services to deal with the large numbers of children with chronic, complex and acute medical needs identified in stage 2 of the project.<sup>18,19</sup>

Following the Lililwan Project, the community established the Marulu team to develop a community-led response to support children and families living with FASD and ELT throughout their lifespan; and enhance services for children, adults and families impacted by FASD and ELT. Two National Health and Medical Research Council (NHMRC)-funded projects were introduced by the community to address behaviour and learning at home and school:

1. Triple P, the Positive Parenting Program (Jandu Yani U, meaning 'For all families'), trained 39 'parent coaches' to assist local families to gain the knowledge

and skills required to parent children with emotional and behavioural problems.<sup>20</sup>

2. The Alert Program was trialled in schools to promote impulse control in children and assist them in learning.<sup>21,22</sup>

The community identified many benefits of the Lililwan Project, which is considered an exemplar for community-driven research. Children had access to comprehensive neurodevelopmental and health assessments, diagnosis, treatment and referral. Two assessment tools were validated for use in Aboriginal communities: one for FASD diagnostic assessment<sup>23</sup> and another for assessment of motor skills.<sup>13</sup> The best-fit racial norms for assessment of the sentinel facial features in FASD in Aboriginal children were determined.<sup>24</sup> The characteristic FASD facial phenotype comprises three sentinel features: a small palpebral fissure, a smooth philtrum and a thin upper lip.<sup>1</sup> Microcephaly and small stature are common. Diagnostic criteria for FASD are intended to apply to children, adolescents and adults.<sup>1</sup> However, there are a few longitudinal studies that suggest that although some of the craniofacial features of FASD (short-upturned nose, maxilla hypoplasia) diminish after puberty, microcephaly, thin upper lip and small stature persist in most individuals.<sup>24-26</sup> More research is needed to determine if and how the sentinel FASD facial features change after puberty, particularly in other population groups.<sup>27</sup> No such cross-sectional or longitudinal study has yet been conducted in Australia, and findings from previous studies cannot be generalised to the Australian Aboriginal populations.

Data from the Lililwan Project led to funding for the Marulu team, health professional education and training, development of a FASD and ELT resource for educators, employment of local people, community awareness about FASD (including production of two films)<sup>28,29</sup> and implementation of the Positive Parenting and Alert programmes in Fitzroy Crossing. The new knowledge was presented nationally and internationally, including at the United Nations forum on Indigenous issues in New York in 2012.<sup>30</sup> Data on alcohol harms in children have also helped the community advocate for continued alcohol restrictions in face of repeated challenges to the legislation.<sup>30</sup>

Although the Marulu Strategy and Lililwan Project have raised awareness about FASD, resulted in programmes to reduce alcohol consumption in pregnancy,<sup>31</sup> and provided families with support, more work is needed. Leaders and families report that some of the Lililwan cohort are struggling in adolescence with poor health, well-being and educational attainment; self-harm; alcohol or drug dependence; and contact with the juvenile justice system. These concerns are consistent with findings of Coroner Fogliani's 2017 Inquiry into the deaths of 13 children and young people in the Kimberley<sup>32</sup> and a recent study of adolescents in WA's Banksia Hill Juvenile Detention Centre in which 36% had FASD and 89% had at least one neurodevelopmental impairment.<sup>33</sup>

Concern for adolescents led MWRC to initiate the Bigiswun Kid Project and invite the University of Sydney to partner with them with the overarching aim to improve health and well-being of adolescents in remote Aboriginal communities. Bigiswun Kid means ‘adolescent’ in Kimberley Kriol.

The specific aims are to:

1. Provide a voice to adolescents and their families to understand the health and well-being status of the Lililwan cohort at 17–19 years.
2. Examine relationships between exposures during pregnancy, birth characteristics, and health and neurodevelopment at 7–9 years, and positive/adverse adolescent outcomes at 17–19 years. This information will identify prenatal and early life factors that predict good health and well-being in adolescence.
3. Determine whether management plans provided in the Lililwan Project were followed, and identify past and present service gaps, support needs and barriers to service use.
4. Determine if key physical characteristics of FASD change between childhood and adolescence in an Australian Aboriginal population.

## METHOD

### Historical context

This project is being conducted in the Kimberley region, which is located in the northwestern corner of WA and has been occupied by Aboriginal people for at least 40 000 years.<sup>34</sup> It is culturally and linguistically rich and diverse and about 40% of the population (80% in the Fitzroy Valley) are Indigenous people, from over 30 language groups and hundreds of dialects and clan groups. The Kimberley is vast, but Aboriginal people across the region are interconnected through one of the most sophisticated kinship systems in the world. Through this strong web of relationships, intergenerational knowledge is transferred, and responsibility bestowed on Aboriginal people today to care and nurture country, family and kin.

The impact of historical trauma on Aboriginal people of the Fitzroy Valley is immense. The full onslaught of European colonisation began in the late 1880s.<sup>35 36</sup> The occupation of lands through dispossession and massacres of Aboriginal people by colonists was met with fierce resistance by Aboriginal people.<sup>37</sup> This period of frontier wars is known as the ‘killing times’ by Aboriginal people today.<sup>38</sup> Beyond this period, colonisation continued to impact through discriminatory and assimilatory legislation, policies and practices that resulted in forced removal of Aboriginal children from their families, mass imprisonment, introduction of religion through missions, indentured labour, prohibition of use of Aboriginal languages and cultural practices, and exploitation of the land for oil and minerals.<sup>39 40</sup>

In the mid-1960s, racially discriminating clauses that prohibited Aboriginal people from accessing the age pension and maternity allowance were removed from

Commonwealth legislation.<sup>41</sup> In the Kimberley, these funds were given to pastoralists to pass on to Aboriginal people; however, many pastoralists found ways to keep the money.<sup>39</sup> The ways in which Aboriginal people responded to this period were complex. Although there were many atrocities, Aboriginal people found ways to survive, learning pastoral skills and forging new relationships and ties across language groups, while finding ways to continue to practise their culture and ceremonies.<sup>37</sup> When time was available, mainly during the wet season, Aboriginal people would travel the region, gathering to safeguard and maintain culture so it was not lost.

The referendum of 1967 gave the Commonwealth the power to include Aboriginal people in the census and limited the State’s control over the lives of Aboriginal people.<sup>42</sup> This effectively ended the assimilationist policy era and heralded a new era of civil rights and self-determination.<sup>36</sup> In 1969, introduction of the Pastoral Industry Award (with rights to equal pay) unexpectedly resulted in mass eviction of Aboriginal people from their traditional lands by pastoralists unwilling to pay equal wages. In the Fitzroy Valley, this caused widespread homelessness and unemployment, and many were left to live in atrocious conditions on the fringes of small settlements like Fitzroy Crossing, Halls Creek, Broome and Derby.<sup>36 43</sup>

The late 1960s saw many discriminatory practices against Aboriginal people change, allowing Aboriginal people to buy and use alcohol. The binge-drinking culture of the white stockman spread into Aboriginal communities who used alcohol to deal with awful living conditions, grief, loss of family and intergenerational trauma.<sup>40</sup> Historical events threatened the preservation and ongoing practice of Aboriginal culture and people’s ability to continue their traditional lives on their land. Despite these overwhelming structural forces and limited supports from government, Aboriginal people in the Fitzroy Valley have remained connected and culturally strong. Where practices were lost, people have continued to engage in revitalisation and resurgence efforts. After the 1960s, all the language groups of the Fitzroy Valley worked closely together to grow Fitzroy Crossing into a township and establish their own community-controlled and self-determining organisations.<sup>40</sup> These organisations, many of which still exist today, were the mechanism by which the community could develop their own, culturally grounded, social and economic infrastructure for the Fitzroy Valley. Despite these incredible community efforts, disadvantage persists, entrenched by ongoing structural marginalisation. In 2021, many Aboriginal families across the Kimberley live with the legacy of intergenerational trauma, compounded by ongoing poverty, unemployment, severe overcrowding and inconsistent access to healthcare, education and other services. Aboriginal people’s inherent strengths, resilience and culture are the source of healing and recovery.

## Setting

Fitzroy Crossing is a small Kimberley town, 400 km east of Broome and 300 km west of Halls Creek. Fitzroy Crossing is the service town for the Fitzroy Valley, which is home to five predominant language groups (Bunuba, Gooniyandi, Nyikina, Walmajarri and Wangkatjungka). People live in 45 communities, all classified as very remote.<sup>44</sup> Approximately 3500 people live in the Valley of whom 80% are Aboriginal.<sup>45</sup> Aboriginal-led organisations in the Fitzroy Valley are recognised internationally for their forward-thinking initiatives to reduce harms from alcohol in their community and recognise and address FASD and ELT.<sup>46</sup>

## Patient and public involvement

The research was prioritised and initiated by Aboriginal leaders. The research questions and study protocol were designed following extensive consultation with the wider Fitzroy Valley community, parents and young people, including study participants, as described in detail below. An Expert Advisory Group (EAG) comprising Aboriginal people and consumers was also established to inform the study design and help interpret and disseminate results. During the consent process, adolescents and their parents are asked if they would like to receive a summary of the results. We will also run on-country events to present results to communities. In addition to journal articles, key findings will be presented at conferences and included in a final report for government with clear recommendations of how to improve services for young people.

## Community consultation

The Bigiswun Kid Project (adolescent health and well-being) was prioritised by local Aboriginal women who initiated the project and invited the research team to partner with them. Conduct of research with Aboriginal communities requires both community and individual (participant) consent.<sup>47</sup> In 2018–2019, we conducted extensive consultation with Aboriginal leaders in the Fitzroy Valley and relevant local Aboriginal-led and government organisations, to explain the project's aims, conduct, proposed outcomes, ownership of data and dissemination of results and seek consent for the project.

At least one member of the research team and one member from the Marulu team met representatives from the following organisations to discuss the Project: Nindilingarri Cultural Health Services, Marra Worra Worra, Western Australian Country Health Service (paediatrics, allied health, child and adolescent mental health, and Fitzroy Crossing Hospital), Western Australian Department of Education, National Disability Insurance Agency, Juvenile Justice, Fitzroy Crossing Police, Fitzroy Valley District High School, Kimberley Aboriginal Medical Services, Kimberley Aboriginal Law and Culture Centre. In June 2019, we held a FASD Forum in Broome to inform people about the Lililwan Project and Jandu Yani U Project and discuss the design of the Bigiswun Kid Project. The forum was attended by 160 people from

across the Kimberley, many travelling great distances to attend.

## Parent and youth consultation

During the consultation process, community leaders wanted to ensure the research benefits outweighed the cost to the community and discussed the need for research to provide direct and immediate benefits to participants during the data collection phase. So, we asked 30 parents and 17 adolescents from the Lililwan Project how the Bigiswun Project could provide direct and immediate benefits to adolescents. Parents reported that they wanted community-led supports for adolescents. Some wanted local Aboriginal people, respected by adolescents, to be trained to support them and provide information about topics of concern, such as sexual health, well-being and how to deal with their feelings. Young people wanted more recreational activities and support to access services such as applying for a driver's licence or understanding their post-school education options. We will employ local Aboriginal people who are well respected in the community (one male and one female) as Youth Support Officers to work alongside a social worker to design and implement these supports during the data collection phase.

## The partners

The project is a collaboration between MWRC and clinicians and researchers from the University of Sydney. The roles and expectations of partners are outlined in a Memorandum of Understanding. The Marulu team at MWRC is a group of local Aboriginal people with experience in research, education and community service relating to FASD and ELT. The Marulu team co-designed the project aims, participant information statements, consent forms and interview questions to ensure that they are culturally and linguistically appropriate. The Marulu team includes local Aboriginal people employed as community navigators; provides cultural expertise and training for the research team; advocates for and supports community members; and oversees data collection in the community. The University of Sydney and Elizabeth Elliott have a long and productive relationship with the Fitzroy Valley communities, having worked in partnership with them on the Lililwan and Jandu Yani U projects. The University of Sydney team brings clinical and research expertise. They co-designed the project aims, protocols and research documents with the Marulu team. They reviewed the literature to identify the most appropriate assessment measures, which were then reviewed by the Marulu team for suitability and feasibility. Members of the University of Sydney team will walk alongside the Marulu team throughout the project. They will lead the research activities, including grant applications, ethics applications, development of databases, data entry and data analysis, and provide clinical expertise and advice in how to use the data to improve services. They will also train local community members in research methods to build capacity.

### Expert Advisory Groups

For additional expert and cultural advice pertaining to this project, external experts were invited to join an EAG. The EAG includes people from WA familiar with the region and who have expertise in FASD, ELT, data linkage, education, justice, health and mental health, and for Aboriginal cultural protocols. Some of these members are Aboriginal people living in Fitzroy Valley communities. Members of the EAG provided input into the project design. The EAG will meet bimonthly to provide recommendations on data collection, analysis and interpretation of data, and how best to use these data to respond to the adolescent's needs and improve service delivery.

### Community navigators

Local Aboriginal people who are well respected in the community, fluent in Kimberley Kriol and understand at least one local Aboriginal language will be employed as community navigators to help conduct the interviews with parents and adolescents. They will assist with community engagement, recruitment and consent-seeking; parent and adolescent interviews; translation or interpretation as required; and cultural training for non-Aboriginal research team members. Non-Aboriginal researchers will always work alongside local Aboriginal people to conduct interviews. The community navigators will receive project-specific research training from the research team in interview techniques, data collection, ethics, confidentiality and seeking consent. They will be offered support if they elect to obtain a Australian Technical and Further Education Certificate II in Community Research or a Diploma in Community Welfare Work. Several MWRC staff members have already attained these certificates and/or have worked with Elizabeth Elliott on previous projects.

### Project design

This project includes:

1. Interviews with parent/carers and adolescents about the health, behaviour, education and social outcomes in a population-based cohort (the Lililwan cohort) at 17–19 years of age.
2. Data linkage to identify specific health and education outcomes and contact with police and child protection.
3. Descriptive analyses and regression analyses when appropriate to identify childhood predictors of adolescent outcomes.
4. Examination of the implementation of Lililwan personalised management plans.
5. Facial photography and anthropometry to assess physical changes over time.

Initial community consultation occurred in 2018 and 2019 and will run throughout the project. Data collection commenced in August 2020 and will continue until December 2022.

### Participants

All participants in the Lililwan Project cohort and their primary caregiver will be eligible for the Bigiswun Kid Project. In 2010, all children (born in 2002 or 2003 and living in the Fitzroy Valley) were invited to participate in the Lililwan Project and 127 of 134 (95%) eligible families gave consent.<sup>8</sup> We expect a similar participation rate in this Aboriginal community-initiated project. We have identified key members from each remote community to help us locate participants from the Lililwan Project. So far, we have located 120 of the original 127. Data will be collected throughout 2020–2022.

### Recruitment

The Marulu team has maintained contact with most families who took part in the Lililwan Project. Community navigators will approach families and lead them through participant information and consent forms, either in English, Kimberley Kriol or an Aboriginal language of their choice. Consent will be obtained from the parent/carer and the young person. Participants will choose the location of this meeting (their home, the Marulu office, by the river or any other accessible community space), format of the meeting (in person or by phone), the community navigator and whether they are accompanied by others.

We will also ask parents for consent to contact their child's school for information. If school principals provide consent, they will be asked to identify the most relevant person to extract information for participants who are attending/attended their school. We will follow the NHMRC guidelines for consent for research with Aboriginal people<sup>48</sup> and be informed by our own research in the Fitzroy Valley on obtaining consent.<sup>47 49</sup> Consultation with cultural advisors and community members during the development of the participant information sheet and consent forms for the Lililwan Project and the Jandu Yani U Project suggests that this approach is acceptable to the community.

Community leaders decided parents and adolescents should receive a local supermarket voucher to reimburse them for time spent completing the interviews. Interviews take approximately 90 min and participants will receive an \$A80 voucher, an amount based on that provided in previous projects led by the University of Sydney. To minimise risk of coercion, participants are informed during the consent process that they may choose not to answer questions and can withdraw from the study at any time, and this will not prevent them from receiving the vouchers. The use of vouchers was approved by relevant ethics committees.

## METHODS

### Aim 1

Provide a voice to adolescents and their families to understand the health and well-being status of the Lililwan cohort at age 17–19 years, 10 years after the Lililwan



Project. This will identify what community and health services are needed to promote adolescent health and well-being in the community.

### Parent interview

Together, the research and Marulu teams developed an interview for parents/carers to address key outcomes prioritised by the community. In the Lililwan Project, a 113-item interview took approximately 45 min to administer, was acceptable to parents and produced reliable data.<sup>4 23</sup> We have retained some questions from the Lililwan Project to allow us to examine changes over time and included additional questions to identify adolescent outcomes.

The parent interview is provided as online supplemental files 1–3 and includes the following topics:

*Health outcomes:* new diagnoses, including FASD; prescription medications; injuries, accidents and health service utilisation since participation in the Lililwan Project; lifestyle factors (physical activity, sedentary behaviour, smoking and other substance use in the home, smoking and other substance use by the adolescent); psychosocial and mental health diagnoses; and pregnancy of the adolescent; and with parents we will review implementation of individual management plans from the Lililwan Project, including access to health services. The local paediatrician employed by the WA Country Health Service provided input into the health questions.

*Education outcomes:* highest educational attainment; education aids used; attendance; suspensions; expulsion; alternative education pathway; enrolment in the Yirimalay Wesley Studio School or schools outside the Fitzroy Valley. Two local school principals and two local teachers provided input into the education questions.

*Social outcomes:*

*Disability:* disability diagnoses; allowances received (carer's/disability allowances); engagement with National Disability Insurance Scheme; supports received (eg, disability services); support needs.

*Child protection:* contact with the Department of Child Protection (including placement in family, foster or adoptive care).

*Criminal justice:* contact with the criminal justice system (including local police, temporary detention or incarceration in the Banksia Hill Juvenile Justice facility in Perth).

*Training and employment:* vocational training; alternative education; employment status.

*Behavioural outcomes:* behaviour problems (assessed using the Achenbach System of Empirically Based Assessment) were a major concern of parents and teachers in the Lililwan Project cohort.<sup>17</sup> We will assess behaviour at 17–18 years using the Achenbach Child Behaviour Checklist (CBCL) for parents/carers. The CBCL is considered the gold-standard measure of emotional and behavioural problems in children aged 6–18 years. The measure includes a total problem behaviour score, composite scales (activities, social relations, school and total competence), syndrome scales (anxious/depressed, depressed,

somatic complaints, social problems, thought problems, attention problems, rule-breaking behaviour and aggressive behaviour), Diagnostic and Statistical Manual (DSM)-oriented scales (affective problems, anxiety problems, somatic problems, ADHD, oppositional defiant problems, conduct problems) and critical items (self-harm, suicide attempts). The measure has well-established psychometric properties.<sup>50</sup> Parent interviews will be completed in the first year of data collection before participants turn 19 years.

*Well-being and community participation:* parents/carers will report on proxy indicators of well-being including participation in community activities, for example, engagement in Garnduwa after-school sports programme; participation in football, netball and rodeo teams; employment; tertiary education; involvement in cultural events run by the Kimberley Aboriginal Law and Culture Centre (KALAC); and participation in the cultural Yiriman Project (suicide prevention and resilience-building programme run by KALAC that includes 'back to country' bush trips with cultural elders and traditional activities such as fishing, hunting and dance); the Marra Worra Worra Community Development Program (Work for the Dole and assisted job-seeking); and the Karrayili Adult Education Centre's ranger, land management and Aboriginal tourism re-employment programmes.

*Data linkage:* we will invite parents/carers and adolescents for consent to access data from Western Australian police, education, health and child protection records to supplement the interview data. Extraction of the health and education data is discussed in aim 3. The police and child protection records are centralised for WA so will be accessible from one source. We have consulted with the data custodians to confirm what data are available and gained approval to access these data. Police record data will include any contact with police as either a victim or offender between 0 and 18 years of age. Data from the child protection records will include any contact with child protection from 0 to 18 years, including reasons for initial contact, and the nature and outcomes of the contact.

### Adolescent interview

Participants will complete the online interview in person with a researcher and community navigator present (and parent if desired) using TickiT (<https://tickithealth.com/>). TickiT is an electronic, tablet-based survey platform that uses simple text, icons, and images to engage adolescents across cultures, ethnicity, and demographics, including those with English as a second language.<sup>51 52</sup> It is embedded with multiple standardised assessment tools to enable self-report of health, mental health and well-being by adolescents, and generates scores or risk levels (green/orange/red alerts) to identify adolescents at risk. It requires a year 4 literacy level and has been successfully used with Aboriginal adolescents.<sup>53</sup> We piloted the interview battery and found the online format with pictorial aids makes the interview efficient and user-friendly. Our

**Table 1** Summary of parent and youth interview measures

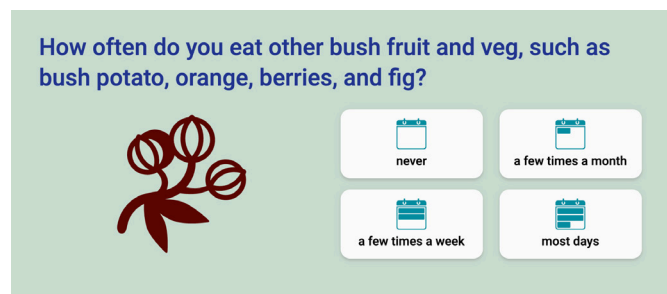
Variables	Measures
<b>Parent interviews</b>	
Adolescent health, education and social outcomes and community participation	Parent interview based on the Lililwan Project parent interview
Child behaviour (total problem behaviour score, syndrome scales and Diagnostic and Statistical Manual-oriented scales)	Child Behaviour Checklist
<b>Adolescent interviews</b>	
Home life, education, eating/diet, daily activities, drug and alcohol use, sexual health and safety	HEEADSSS
Depression, anxiety, suicidality, resilience	Strong Souls Inventory
Post-traumatic stress disorder (PTSD)	PTSD Checklist for the Diagnostic and Statistical Manual–Fifth Edition
Early life trauma	Revised Adverse Childhood Experiences Scale
Parent and peer attachment	Inventory Parent and Peer Attachment Measure Trust and Communication subscale and Peer Attachment subscale
Self-esteem	The Multidimensional Body-Self Relations Questionnaire Appearance Evaluation subscale Self-Description Questionnaire Self-Concept subscale
Experience of racism	The Measure of Indigenous Racism Experiences
Hopefulness and despair	Hunter Opinion and Personal Expectation Scale

HEEADSSS, Home, Education, Eating, Activities, Drugs, Sexuality, Suicidality/Depression and Safety.

pilot included people with FASD, and everyone could complete the full battery in one sitting. [Table 1](#) shows the measures we have incorporated into the TickiT platform and an example question from the TickiT platform is provided in [figure 1](#).

#### Home, Education, Eating, Activities, Drugs, Sexuality, Suicidality/Depression and Safety

The Home, Education, Eating, Activities, Drugs, Sexuality, Suicidality/Depression and Safety (HEEADSSS) interview schedule was developed to obtain psychosocial profiles of adolescents attending health clinics. The original framework included six psychosocial domains pertaining to: home, education, activities, drugs, depression and suicidality, and sexual behaviour. More recent iterations include an extra E for eating and S for safety.<sup>54</sup> The measure is clinically useful for screening adolescents for psychosocial issues and risks<sup>55</sup> and capturing data to help design, modify and obtain funding for youth intervention programmes.<sup>56</sup> The HEEADSSS interview was



**Figure 1** Example question in the TickiT health online youth interview.

adapted into an online self-administered tool using the TickiT software.<sup>52</sup> Compared with the HEEADSSS face-to-face interview, the online version is faster to administer, can be administered by non-medical professionals and elicits a higher disclosure rate for sensitive questions in all domains.<sup>57</sup>

In the present study, we included additional questions about health in the HEEADSSS interview. These include whether participants take any medication, how much help they receive at home with their health, the types of health professionals they have seen in the past 12 months and barriers they have experienced in accessing health services. We removed the HEEADSSS questions about suicide and depression because we will capture this information in the Strong Souls Inventory (SSI).

#### Strong Souls Inventory

The SSI was developed to assess the social and emotional well-being of Australian Aboriginal adolescents. The tool has strong construct validity and internal reliability and is considered culturally and age appropriate by participants. The SSI includes 25 items that assess anxiety, depression, suicide risk and resilience.<sup>58</sup>

#### Post-Traumatic Stress Disorder Checklist for the DSM–Fifth Edition

The Post-Traumatic Stress Disorder Checklist (PCL-5) is a self-report measure to assess symptoms listed in the DSM–Fifth Edition that contribute to a diagnosis of post-traumatic stress disorder (PTSD). A structured clinical interview is the gold standard for diagnosing PTSD, but the PCL-5 can be used to make a provisional diagnosis. The PCL-5 has excellent internal consistency (Cronbach's alpha 0.94), good test–retest reliability (correlation

coefficients 0.82), high construct validity (correlation coefficients 0.74–0.85) and moderate discriminant validity (correlation coefficients 0.31–0.60)<sup>59</sup>

### Revised Adverse Childhood Experiences

Fitzroy Valley community representatives chose the Revised Adverse Childhood Experiences (ACE) over other measures of ELT because they felt it best captured the childhood adversities experienced by their community without being too invasive or burdensome for the adolescents. However, the representatives decided not to ask about sexual abuse in the Bigiswun Kid Project. The ACE Scale assesses 10 negative childhood experiences including five personal experiences (physical and emotional neglect and verbal, physical and sexual abuse) and five negative experiences relating to other people in childhood (mental illness, incarceration, substance abuse, criminal behaviour and violent acts towards the mother).<sup>60 61</sup> The scale can predict poor health and mental health outcomes in adulthood.<sup>62 63</sup> However, the scale was not developed through a systematic process and some important adverse experiences were omitted. The Revised ACE Scale builds on the original measure and includes additional four items (peer victimisation, peer isolation/rejection, exposure to community violence and low socioeconomic status). These additional items, which were identified through a representative national survey of almost 2000 adolescents aged 10–17 years, increase the scale's capacity to predict mental and physical health problems<sup>64</sup>

Some of the ACE items contain multibarrelled questions, which can create confusion. We have therefore separated these items to form individual questions but will combine the responses as they are presented in the original ACE when reporting total scores. The ACE uses dichotomous responses; however, we felt some items were better asked with multiple-response options (eg, never, sometimes, often, frequently) as the and so have offered multiple responses for these questions. These can be converted into dichotomous responses for scoring. Finally, we included the following preamble to prepare participants for the sensitive nature of the questionnaire: 'The next few questions are sensitive but important so that we can better understand how to support kids in the Valley. Like all the questions, these will be kept confidential so that no one sees your answers.' The psychometric properties of the ACE are not known, which is a limitation of this measure.

### Inventory Parent and Peer Attachment Measure Trust and Communication subscale and Peer Attachment subscale

The Inventory Parent and Peer Attachment Measure (IPPA)<sup>65</sup> is one of the most widely used and evaluated psychometric measures of adolescent attachment to parents and peers.<sup>65–67</sup> The inventory comprises two scales, Parent Attachment (28 items) and Peer Attachment (25 items). The Parent and Peer Attachments Scales both include three subscales: Trust, Communication and

Alienation. The measure has good to excellent internal consistency across subscales (Cronbach's alpha 0.72–0.91), good to excellent test–retest reliability (correlation coefficients 0.93 Parent Attachment, 0.86 Peer Attachment), and acceptable convergent validity with a range of other measures (correlation coefficients 0.46–0.78 Parent Attachment, 0.28–0.57 Peer Attachment).<sup>65</sup> The IPPA has been revised twice, once by Gullone and Robinson<sup>68</sup> and once by Cook *et al.*,<sup>69</sup> and the nature of these revisions is discussed below. The large-scale Longitudinal Study of Australian Children used eight items from Gullone and Robinson's version for Peer Attachment and eight items from Cook *et al.*'s version for Parent Attachment. We chose to use the same 16 items that were used in the Longitudinal Study of Australian Children in the Bigiswun Kid Project to ensure our survey was a manageable length and to allow for potential comparison of data between studies.

### Peer Attachment

Gullone and Robinson<sup>68</sup> simplified the wording of the original IPPA and assessed the psychometric properties of the revised IPPA (IPPA-R). The IPPA-R was sensitive to gender and age differences. Internal consistency coefficients ranged from 0.79 to 0.81 for Parent Attachment and 0.68–0.88 for Peer Attachment when conducted with adolescents. Convergent validity was comparable with the original IPPA and ranged from 0.49 to 0.73 for Parent Attachment and 0.24–0.50 for Peer Attachment. The Longitudinal Study of Australian Children used 8 of the original 25 items from the IPPA-R on Peer Attachment, 4 from the Communication subscale and 4 from the Trust subscale. These eight items will be used in the present project.

### Parent Attachment Scale

Cook *et al.*<sup>69</sup> revised the original IPPA by simplifying the wording and changing the scoring so that responses provided continuous rather than dichotomous measures of secure versus insecure attachment. The revised measure, called the People in My Life (PIML), has similar psychometric properties to the IPPA with excellent internal consistency for Parent Attachment (0.88) and Peer Attachment (0.90) and acceptable discriminant validity.<sup>70</sup> The Parent Attachment Scale of the PIML consisted of 10 items to assess Trust, 5 items to assess Communication and 5 items for Alienation. Eight of the original 25 items from the PIML were used in the Longitudinal Study of Australian Children to measure adolescents' perceptions of their parent's Trust and Communication.<sup>71</sup> These eight items have excellent internal consistency (0.88)<sup>72</sup> and will be used in the present project.

### The Multidimensional Body-Self Relations Questionnaire Appearance Evaluation subscale

The Multidimensional Body-Self Relations Questionnaire (MBSRQ) is a self-report measure of a person's attitudes toward their physical appearance, designed for use with people aged 15 years and over. The MBSRQ is a 69-item

inventory that includes 10 subscales. We will use the Appearance Evaluation subscale, which measures 'Feelings of physical attractiveness or unattractiveness; satisfaction or dissatisfaction with one's looks. High scorers feel mostly positive and satisfied with their appearance; low scorers are generally unhappy with their physical appearance'—page 4.<sup>73</sup> The Appearance Evaluation subscale has good internal consistency (Cronbach's alpha 0.88); good to excellent test–retest reliability (correlation coefficients 0.81 male, 0.91 female)<sup>73</sup>; and good convergent validity with other measures.<sup>74 75</sup>

#### Self-Description Questionnaire Self-Concept subscale

The Self-Description Questionnaire (SDQ-II) is a valid and reliable measure of self-concept<sup>76–78</sup> comprising 102 items and 9 subscales. We will use the 10-item General Self-Concept subscale in the present project. This subscale is based on a self-esteem scale developed by Rosenberg<sup>79</sup> and modified by Bachman.<sup>80</sup> The negatively worded items were omitted based on recommendations from a previous report that they did not load well in a confirmatory factor analysis in Aboriginal Australian populations.<sup>81</sup>

#### The Measure of Indigenous Racism Experiences

The Measure of Indigenous Racism Experiences (MIRE) was developed to assess self-reported racism among Aboriginal and Torres Strait Islander Australians. The measure has good content and construct validity<sup>82</sup> and includes 31 items presented as six multi-item questions. The MIRE measures interpersonal racism; racism responses and reactions; internalised racism; recognition of systemic racism; and race, consciousness, salience of indigeneity within social groups; and salience of indigeneity among strangers.

#### School Connectedness Scale

The School Connectedness Scale was developed for the US National Longitudinal Study of Adolescent Health<sup>83</sup> and used in the Australian Young Minds Matter Survey.<sup>84</sup> The measure was designed to assess how well students felt they belonged, felt safe and were respected at school. The measure has acceptable reliability (0.82–0.88) and concurrent validity (0.44–0.55) across a range of sociocultural groups.<sup>85</sup> Previous studies found school connectedness is a negative predictor of risk-taking behaviours and mental health problems.<sup>83 84</sup>

#### Hunter Opinion and Personal Expectation Scale

The Hunter Opinion and Personal Expectation Scale is a 20-item scale that provides an overall measure of hopefulness (global personal hopefulness, GPH) and has two subscales, hopefulness and despair. Internal consistency in various populations (adolescents, medical students, psychiatric hospital staff) ranged from 0.87 to 0.92. The GPH total score has good test–retest reliability (0.71) and correlates well with the General Health Questionnaire and Beck Depression Inventory.<sup>86</sup> From each subscale (hopefulness and despair), one item has been shown to correlate highly with other items on the subscale and with

measures of anxiety and depression.<sup>87</sup> These two items will be used in the Bigiswun Kid Project.

#### Aim 2

Conduct exploratory analyses of selected relationships between exposures during pregnancy, birth characteristics, and health and neurodevelopment at 7–9 years, and positive/adverse adolescent outcomes at 17–19 years. This information will identify prenatal and early life factors that predict good health and well-being in adolescence and opportunities to intervene to alter life trajectory.

Data from the Lililwan Project cohort include a detailed maternal and pregnancy history (including alcohol and drug use, health and mental health, substance use); exposures (prenatal alcohol exposure, ELT, overcrowding, injury, hospitalisation) and outcomes at 7–9 years (FASD diagnosis, growth, head circumference, hearing, vision, IQ, academic achievement, cognition, executive function, ADHD, behaviour, executive function, motor skills/function, speech and language, medical diagnoses); and personalised management plan.<sup>8</sup>

We will use logistic regression in this exploratory analysis of predictors of adverse outcomes (eg, school suspension, substance use, justice involvement) or favourable outcomes (eg, school completion, positive peer and family relationships, resilience) in adolescence at age 17–19 years from three stages in life: (1) prenatal (eg, PAE); (2) infancy (eg, low birth weight, hospitalisation); and (3) at 7–9 years of age (eg, FASD diagnosis, ELT) (see the Statistical methods section).

#### Aim 3

Determine whether management plans provided in the Lililwan Project were followed, and identify past and present service gaps and support needs and barriers to service use. This information will be used to inform future service planning.

#### Review with parents

We will review individual management plans, recommendations and referrals provided by the Lililwan Project team for each child and confirm with parents/carers that treatment/referral was accessed. We will invite parents to identify gaps in services and barriers to access. This will inform future models of care.

#### Review of health records

There is a central record system used by the Department of Health and six additional databases that may include the same or additional health data. All seven databases will be reviewed. We have developed an Excel spreadsheet that lists each recommendation and referral made in the management plan for each participant. Referrals were made to a: psychologist, paediatrician, physiotherapist, speech pathologist, occupational therapist, behaviour specialist, optometrist, ear nose and throat specialist, and Hearing Australia. Other recommendations were for the child to receive treatment for a specific condition, for example, scabies, tinea corporis, asthma. The spreadsheet

lists the services each child was referred to and the reason and date of referral. For some referrals, it includes a time frame (eg, follow-up in 18 months). The person extracting the data will document implementation of the management plan, for example, whether the referral is noted or included in the child's file, whether the recommendation was enacted, the outcome of the referral (eg, treatment provided) and whether it was achieved within the recommended time frame.

#### Any serious diagnosis or health problem

We will review the participants' medical records for any serious diagnoses or health problems that have arisen since the Lililwan Project.

#### Service usage

We will extract information about health, allied and mental health service use. This information will be used to determine whether access to early interventions and/or mental health services influenced adolescent outcomes.

#### Medicare Benefit Schedule/Pharmaceutical Benefit Scheme

Although most participants in the Lililwan Project still reside in the Fitzroy Valley, some have moved away permanently and others have spent months to a few years out of the Valley (eg, for the wet season, boarding school, kinship care or extended visits with family). We will request participant consent to access individual Medicare Benefit Schedule/Pharmaceutical Benefit Scheme data to capture types of services and medications the youth received when they lived away from the Kimberley. This information will be used to determine whether Lililwan Project management plans were followed during time away and identify the range of services children received that might have influenced their developmental trajectory.

#### Education records

We will access the participant's primary and high school records to collect information on attendance, suspension, expulsion, National Assessment Program–Literacy and Numeracy scores, classroom support/assistance, and if the school was aware the child had FASD or another disability. We have confirmation from the WA Department of Education that these data are available centrally for government schools. The Association of Independent Schools of WA confirmed that although the same data are collected in a similar format, not all this information is centralised for Independent Schools. So, some data will be extracted individually from each school. Following consultation with schools, we have agreed to provide a research assistant to visit the schools to help extract and code these data.

#### Aim 4

Determine if key physical characteristics of FASD including facial features change between childhood (age 7–9 years) and adolescence (age 17–19 years) in an Australian Aboriginal population.

As part of the Bigiswun Kid Project, weight, height and head circumference will be measured and changes in the percentile ranking for growth and head circumference assessed in all participants. Digital two-dimensional (2D) facial photographs will be taken. Ranks for lip and philtrum and Z scores for palpebral fissure length (PFL) will be compared with those derived from photographs taken of 106 children in the Lililwan Project. Comparison of features at 7–9 years of age and 17–19 years of age will indicate if and how key FASD facial features change from childhood to adolescence in this Aboriginal population. Identification of changes to the facial features of FASD over time will inform future diagnostic evaluations of adolescent and adult Aboriginals and improve the likelihood that they will be connected to interventions, services and supports. Of the 108 children assessed for the physical characteristics of FASD in the Lililwan Project, 16 had microcephaly, 20 had growth deficiency, 15 had short PFL, 21 had a smooth philtrum and 36 had a thin upper lip (rank 4 or 5) on clinical examination by a paediatrician.<sup>88</sup>

To document growth, height and weight will be measured, and body mass index calculated and charted against WHO growth references for adolescents.<sup>89</sup> Microcephaly is defined as a head circumference <3rd percentile (2 SD below the mean) and growth deficiency is defined as height and/or weight <10th percentile for age and gender.

Using a Digital single-lens reflex camera, a set of frontal, 45° and lateral facial photographs will be taken of each youth, and analysed by a blinded assessor for the three sentinel features of FAS using the FAS Facial Photographic Analysis Software.<sup>90</sup> For an internal measure of scale, an adhesive 20 mm paper sticker will be placed on the adolescent's forehead between their eyebrows for the photograph.

#### SAMPLE SIZE AND POWER CALCULATION

We anticipate a similar participation rate to the Lililwan Project (95% of all eligible children). Knowing the maximum sample size, we have calculated the power needed for priority analyses. Priority outcome variables will include those identified as important by the community (eg, suicidal risk, self-harm, teenage pregnancy, contact with the justice system) and those that are modifiable (eg, alcohol use, obesity). There is no consensus on power calculations for multivariable models, but to allow a robust estimation of the coefficients, the standard used is 10 or more events per variable. With a known sample size of about 102 adolescents (95% of 108 children who took part in stage 2 of the Lililwan Project), we expect that many variables of interest will have  $\geq 10$  or more events (eg, exposure to high-risk drinking during pregnancy and several birth, health, educational and behavioural outcomes). Therefore, we expect the sample recruited will be more than adequate for planned multivariable analysis models to investigate the role of  $\leq 10$  variables on

each outcome. The statistical analysis was developed in consultation with a biostatistician.

## STATISTICAL METHODS

Data will be analysed using IBM SPSS Statistics for Windows Version 27 (IBM Corp).

### Aim 1

Frequencies (including %) and/or continuous data will be reported for adolescent measures (CBCL, SSI, PCL-5, SDQ Self-Concept subscale, MBSRQ, MIRE and IPPA) and responses from the parent interview and HEEADSS. Measures obtained at both childhood (Lililwan cohort at 7–9 years) and adolescence (the Bigiswun Kid cohort at 17–19 years) will be compared for the total cohort. Measures will also be reported in adolescents who had ever received a FASD diagnosis.

### Aim 2

For this exploratory investigation of predictors of adverse outcomes in adolescence, multivariable logistic regression analyses will be used for each outcome, adjusting for gestational age and prenatal exposures other than alcohol as potential confounders. Independent variables of interest will be entered in the models. These may include prenatal data (history of PAE); postnatal data (maternal education, maternal mental health history, ELT, child's hospital admissions, child's medical diagnoses) and data obtained at age 7–9 years (FASD diagnosis, neurodevelopmental impairment, behaviour issues, medical diagnoses, hearing, vision). For each outcome, bivariate relationships with each of the independent variables will be determined using bivariate logistic regression. Then, those independent variables which have a bivariate relationship to the outcome (dependent) variable at  $p < 0.20$ , and which are not correlated, will be included as predictors in the multivariable logistic regression analysis for that outcome. Outcome variables of interest (dependent variables) at 17–19 years include educational attainment (completed year 10 or higher), employment status, resilience (SSI), contact with the justice system (one or more conviction), health (chronic health problems), behaviour (CBCL), risk of mental illness or suicide (SSI for depression, anxiety, suicide ideation or PTSD), teenage pregnancy and drug and alcohol use (self-reported use, more than several times a week). For the multivariable logistic regression models, Bonferroni adjustment will be applied.

### Aim 3

Descriptive data on access to and receipt of assessments or treatments recommended in the Lililwan personalised management plans will be summarised. The proportion of recommendations followed/not followed, including by type of recommendation and referral service, will be recorded, as will reported difficulties in accessing those recommendations.

### Aim 4

The University of Washington (UW) FAS facial Photographic Analysis Software,<sup>90</sup> which was used to analyse photographs of the cohort taken at 7–9 years of age,<sup>88</sup> will be used at 17–19 years of age. The software enables measurement of PFL and lip circularity on 2D photographs and uses formulae generated from published growth charts to calculate PFL and inner canthal distance Z scores, upper lip circularity and 'ABC scores' for each feature, which are used to generate an overall facial severity score.<sup>90</sup> The Scandinavian PFL normative values<sup>92</sup> and UW lip–philtrum guide 2 for upper lip circularity and philtrum assessment will be used<sup>90</sup> as they were found to be the best fit for use with the Lililwan cohort. Differences in the raw values (for PFL and inner canthal distance (in millimetres) and lip circularity) and in ranks for lip and philtrum, ABC scores for each feature and resulting 4-Digit Diagnostic Code Rank will be examined within subjects (using paired sample t-tests and McNemar's tests).

## ETHICS AND DISSEMINATION

We have approval from the following Human Ethics Research Committees: (1) Kimberley Aboriginal Health Planning Forum Research Subcommittee; (2) Western Australian Aboriginal Health Ethics Committee and (3) Western Australian Country Health Services Human Ethics Committee.

Dissemination of the project findings will occur at multiple levels. Participants who indicate on the consent form that they wish to receive a summary of the project findings will be contacted in the way they choose (eg, mail, email, in person). The research team will host feedback meetings at the end of the project to disseminate and discuss the overall group findings with partners, community members, local Aboriginal-led and government organisations. These meetings will increase knowledge, skills and capacity of community members, health professionals and teachers, to predict and identify difficulties in adolescence. A project report containing de-identified group data will be written and disseminated to all relevant services and government agencies. Results will be described in scientific presentations and publications which will include Aboriginal speakers and authors.

## POSSIBLE CHALLENGES

Below are potential challenges that may arise during data collection and strategies we have developed to address these.

*Weather:* the Fitzroy Valley has a tropical climate that includes severe flooding during the wet season (December–March) that prohibits access to remote communities. Data collection will, therefore, occur between April and November of each year.

*Remote location:* all communities of the Fitzroy Valley are classified as very remote<sup>93</sup> and are spread over a 400 km



diameter. Some families are transient and live between two or three communities. The interviews will be conducted over several years to ensure there is sufficient travel time to reach all participants living in each remote community.

*Sorry business*: the high mortality of Australian Aboriginal people means that losing family members is common. The five language groups observe cultural protocols for responding to the loss of a family member, known as 'sorry business', during which participants cannot be contacted. The community navigators in the Marulu team will know who is in sorry business and plan data collection accordingly.

## DISCUSSION

This project will be conducted in accordance with NHMRC guidelines for improving Aboriginal health through research<sup>94</sup> and for ethical conduct in research with Aboriginal and Torres Strait Islander people<sup>95–96</sup> and will address NHMRC Indigenous Research Excellence Criteria.<sup>97</sup> Specifically, community engagement is at the core of this project. Adolescent health and well-being were prioritised by the Aboriginal community as an important issue for the very remote Fitzroy Valley, where rates of FASD, ELT, suicide and chronic health disorders in childhood are higher than the general population. A comprehensive consultation was conducted before the project commenced to obtain community consent for the research and consultation will continue throughout. Aboriginal people will lead the project and will be involved in every phase of the research including developing the protocol, seeking consent, and data collection, analysis, and dissemination. Assessment tools have been selected only if they are appropriate for use in the cultural context. Importantly, the study will fill knowledge gaps. Few data are available on Aboriginal adolescents living in remote settings that have been impacted by historical trauma and current disadvantage. Few studies are population based, include the voice of adolescents or include longitudinal data.

The research will therefore provide novel, current data about adolescent health, mental health and well-being and the resilience, aspirations, and community contributions of adolescents. The data will address questions raised by the community, specifically about gaps in services and supports, and help inform solutions. It will also identify modifiable, prenatal and early childhood predictors of adolescent outcomes, and use these to inform future interventions to promote a favourable trajectory into adulthood. Data will underpin advocacy for funding for services, professional training and facilities for adolescents. As part of the project, we will build community capacity through employing, training, and supporting local Aboriginal people to conduct the adolescent and parent interviews and provide ongoing support to adolescents.

Regarding FASD, this study will provide novel data on changes over time in the characteristic physical features

including microcephaly, the three sentinel facial features and growth. Longitudinal studies conducted with predominantly Caucasian participants suggest that some physical characteristics change with age, particularly after puberty, making the diagnosis of FASD difficult.<sup>24 26</sup>

We will measure height, weight and head circumference and take and analyse 2D digital photos of participants at 17–19 years and compare assessments with those conducted at 7–9 years. This will determine whether the physical characteristics that contribute to a FASD diagnosis in children remain relevant in adolescents. This information will inform assessment of Aboriginal adolescents and adults for FASD. If we find that craniofacial features diminish after puberty, the diagnostic criteria may need to be reviewed for Aboriginal adolescents and adults.

This is an ambitious study given the complexity of the community (eg, multiple languages, very remote location, historical and current trauma, social disadvantage, transport and climate). One limitation is the small sample size (n=127). However, the sample is population based so provides a good representation of the issues of adolescents in the Fitzroy Valley. Although findings will be relevant to similar communities, particularly within the Kimberley, they may not be generalisable to less remote or urban settings. The study also includes comprehensive information from a range of sources (parents, adolescents, government records). Wherever possible, we have included measures that have been validated and the norm for use in Aboriginal and Torres Strait Islander communities. However, validation, normative values and psychometric properties were not available for all assessment tools used in our population, for example, the PTSD screener and the ACE Scale, which is a study limitation. The logistical regression analysis used in aim 2 is exploratory and hypothesis generating, further research will be needed to confirm these findings.

The Fitzroy Valley community reports many benefits from previous collaborative research projects. Consistent with NHMRC guidelines for Indigenous Research Excellence,<sup>95</sup> we also expect to achieve capacity-building, sustainability and transferability in the Bigiswun Kid Project, which will:

- ▶ Identify adolescents in need of support and connect them with local services (eg, health, mental health, disability, education/employment).
- ▶ Collect data on the prevalence of positive and adverse adolescent health and mental health and well-being outcomes.
- ▶ Identify childhood predictors of outcomes that will inform therapies and supports.
- ▶ Identify gaps in services and facilities to enable advocacy to government for service planning, additional funding, and resources to help narrow the 'gap' between health outcomes and lifespan between Indigenous and non-Indigenous Australians.
- ▶ Inform local services about the educational, vocational, recreational, residential, and supervisory needs

of adolescents and the gaps in support for adolescents with disability and involvement with the justice system.

- ▶ Increase knowledge, skills and capacity of community members, health professionals and teachers, for identification and management of poor adolescent health and well-being.
- ▶ Likely be generalisable to other remote Aboriginal communities and other disadvantaged Indigenous communities internationally.
- ▶ Improve services to help improve the health and well-being of adolescents in disadvantaged, remote communities, enabling kids to succeed at school and beyond and make a meaningful contribution to their communities.

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