BMJ Open 'Next Generation Youth Well-being Study:' understanding the health and social well-being trajectories of Australian Aboriginal adolescents aged 10-24 years: study protocol

Lina Gubhaju,¹ Emily Banks,² James Ward,^{3,4} Catherine D'Este,⁵ Rebecca Ivers,⁶ Robert Roseby,⁷ Peter Azzopardi,^{3,8} Anna Williamson,⁹ Catherine Chamberlain,⁹ 10 Bette Liu,¹¹ Cherj Hotu,¹² Jacqueline Boyle,⁷ Bridgette McNamara,¹ Sandra J Eades, on behalf of the 'Next Generation' investigator team

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For numbered affiliations see end of article.

Correspondence to

Dr Lina Gubhaju; lina.gubhaju@unimelb.edu.au

ABSTRACT

Introduction Australian Aboriginal and/or Torres Strait Islander (hereafter referred to as 'Aboriginal') adolescents (10-24 years) experience multiple challenges to their health and well-being. However, limited evidence is available on factors influencing their health trajectories. Given the needs of this group, the young age profile of the Aboriginal population and the long-term implications of issues during adolescence, reliable longitudinal data are needed.

Methods and analysis The 'Next Generation: Youth Wellbeing Study' is a mixed-methods cohort study aiming to recruit 2250 Aboriginal adolescents aged 10-24 years from rural, remote and urban communities in Central Australia, Western Australia and New South Wales. The study assesses overall health and well-being and consists of two phases. During phase 1, we qualitatively explored the meaning of health and well-being for adolescents and accessibility of health services. During phase 2. participants are being recruited into a longitudinal cohort. Recruitment is occurring mainly through community networks and connections. At baseline, participants complete a comprehensive survey and undertake an extensive age relevant clinical assessment. Survey and clinical data will be linked to various databases including those relating to health services; medication; immunisation; hospitalisations and emergency department presentations; death registrations; education; child protection and corrective services. Participants will receive follow-up surveys approximately 2 years after their baseline visit. The 'Next Generation' study will fill important evidence gaps by providing longitudinal data on the health and social well-being of Aboriginal adolescents supplemented with narratives from participants to provide context.

Ethics and dissemination Ethics approvals have been sought and granted. Along with peer-reviewed publications and policy briefs, research findings will be disseminated via reports, booklets and other formats that will be most useful and informative to the participants and community organisations.

Strengths and limitations of this study

- ► This is a large Aboriginal-led prospective cohort study of Aboriginal adolescents aged 10-24 years of age from rural, remote and urban areas, supported by foundational qualitative work.
- Collection of a wide range of health and social well-being information through a survey, age-specific clinical assessments and linkage to administrative data sources will allow a holistic examination of the health and well-being of Aboriginal adolescents.
- ► This ongoing cohort with follow-up will examine trajectories and data linkage to routinely collected health and social data.
- We have established strong community partnerships and relationships with Aboriginal adolescents.
- A limitation of this study is that the survey is being conducted only in English, which may exclude some participants in remote regions who speak primarily Aboriginal languages and English as a second or third language.

INTRODUCTION

Adolescents (defined as individuals between the age of 10 and 24 years) encounter multiple health and social challenges. Changes during this life phase can have a long-lasting impact on future health and well-being. Despite this, adolescents have been largely neglected in terms of their specific health and well-being needs and in robust evidence to underpin effective support. Investing in the adolescent life phase will not only benefit the current generation but will also have a positive impact on their future adult lives and on the next generation of children.

Health during adolescence is influenced by health during infancy and early childhood



and the specific biological and social-role changes that accompany puberty, as well as family, community and environmental contextual factors. We have used Bronfenbrenner's Bioecological Model of Human Development as a conceptual base, which will be adapted to the specific adolescent and youth context. The model emphasises the importance of both the immediate and broader environment, as well as the individual's own attributes, in contributing to the development of physical and mental health.

Increased activity in brain regions associated with reward, pleasure and other emotional responses is thought to be linked to the tendency for adolescents to be more affected by exciting or stressful situations when making decisions, especially in the presence of peers.³ This is associated with the willingness to try stimulating experiences which is an important mediator of risky behaviour, and increases between 10 and 15 years of age.^{3–5} Some of the key health behaviours associated with adolescence include initiation of tobacco, alcohol and use of other drugs, sexual debut and patterns of sexual risk and protective actions, driver licensing and driving, participation in sports/physical activity and adoption of long-term dietary patterns. Therefore, there is enormous potential for prevention of health risk behaviours and promotion of positive health behaviours among adolescents.

Recent data have shown that there is an urgent need to prioritise the health and well-being of Aboriginal adolescents.⁶⁷ Data from 2008 to 2012 from the National Mortality Dataset showed that all-cause mortality for Indigenous adolescents is more than twice that of non-Aboriginal adolescents, with 60% of deaths in this age group due to intentional self-harm and road traffic injury. Eighty per cent of all deaths among Indigenous adolescents are potentially avoidable⁶; a strong reason to focus attention on prevention and creating a health system that meets the needs of young Aboriginal people. Encouragingly, tobacco smoking rates have declined among Aboriginal people; the proportion of young people aged 15–24 who smoked daily fell from 45% in 2002 to 31% in 2014–2015;⁸ however, there is yet more work to be done to reduce the smoking rates even further.

Mental health disorders and substance use disorders are the most common non-communicable diseases among Aboriginal adolescents. In 2014–2015, 67% of Aboriginal adolescents aged 15–24 years reported low to moderate levels of psychological distress in the past month and 33% experienced high to very high levels of psychological distress. A recent review by Young and colleagues identified that negative cohesion with families and the presence of adverse events appeared to be the most reliable predictors of negative mental health outcomes among Aboriginal children and adolescents, whereas positive family and peer relationships and high self-esteem and optimism were associated with positive mental health outcomes. Further understanding the links between the social determinants of health, mental health, risk and

protective behaviours and injury will allow development of targeted preventive programmes.

In 2016, 65% of Aboriginal people aged 20–24 had Year 12 or equivalent attainment and 37% of 15–24-year-old people were employed. However, 'Not being able to get a job' was the most common stressor among young Aboriginal people. Of concern, is the over-representation of Aboriginal adolescents in the juvenile justice system; in 2016–2017, 50% of the adolescents aged 10–17 in the juvenile justice system were Aboriginal; with the proportion higher in detention (59% of the young people aged 10–17 years 10). Similarly, given high rates of road deaths in young Aboriginal people, and evidence of significant barriers to driver licensing and implications for employment, 11 12 identification of factors associated with positive social trajectories will enable implementation of support services to improve outcomes for Aboriginal adolescents.

Encouragingly, between 2010 and 2016, the proportion of Aboriginal 15–24-year-old adolescents who had a health check increased from 6% to 22%. Although 83% of Aboriginal adolescents reported having access to a doctor in their local area in 2012–2013, approximately 11% reported 'not going to the doctor when needed'.

Why is an Aboriginal adolescent cohort study needed?

Although there is cross-sectional data about the health and well-being of Aboriginal adolescents, there is a general lack of longitudinal studies examining causality and healthy trajectories. Prospective longitudinal studies can identify and relate exposure to risk and protective factors to causation of health and illness; further define the impact of the timing of these exposures and sequence of events (pathways); avoid problems with recall bias and understand which factors are unique to individuals within a population. The majority of the existing Aboriginal longitudinal studies have focused on the early childhood years (Aboriginal Birth Cohort¹³; Study of Environment on Aboriginal Resilience and Child Health (SEARCH) 14 and Longitudinal study of Indigenous Children)¹⁵ or on specific health conditions (Antecedents of Renal Disease Among Aboriginal Children)¹⁶; hence, there is a need for an adolescent-specific cohort which will provide more comprehensive information for this age group.

Further information on specific health conditions, health risk factors and healthcare utilisation is also required for this age group. It is well known that Aboriginal adults have a high burden from diabetes, cardiovascular disease and chronic kidney disease; however, further evidence is required on the onset and progression of major causes of morbidity and mortality during the adolescent life phase. There is also limited data available on the assessment of risk and protective factors for cardiovascular disease and type 2 diabetes among Aboriginal adolescents aged 15–34 years. Turthermore, as smoking is a major risk factor for a number of chronic conditions, identifying the factors associated with smoking and non-smoking behaviour and ways of reducing smoking uptake among Aboriginal adolescents

will be essential in curbing the overall smoking rate among Aboriginal people. Given the underutilisation of health services among this age group, further elucidation of the ways health services can be made more accessible and 'youth friendly' is likely to increase service utilisation.

Study aims

The aims of this study are as follows.

- 1. Explore the views of Aboriginal adolescents, their parents/caregivers and youth healthcare providers on the importance of health and well-being, what it means to be healthy and access to health services.
- 2. Quantify among Aboriginal adolescents, patterns of physical and mental health risk and protective behaviours and major physical and mental health conditions and disability.
- 3. Describe the social and environmental context in which Aboriginal adolescents are growing up including community, school, family and individual-level factors.
- 4. Identify factors relating to resilience, risk behaviours, physical and mental health outcomes at baseline and follow-up and quantify changes over time.
- 5. Establish meaningful partnerships with communities to better understand factors relating to positive adolescent and youth health development and support the communities to take action to improve it.

METHODS AND ANALYSIS Study design

The 'Next Generation' Study uses a two-phase mixed-methods study design. The first phase is composed of a qualitative study which explores perspectives on health and well-being from adolescents, their parents/carers and healthcare providers. Second phase is a prospective longitudinal cohort study of Aboriginal adolescents residing in Central Australia, Western Australia and New South Wales.

Patient and public involvement

Although participants were not directly involved in the design of the study, public involvement in the study was through the partnerships that were established with the Central Australian Aboriginal Congress (Central Australia), Derbarl Yerrigan Health Service (Western Australia), South West Aboriginal Medical Service (Western Australia), Mingaletta Aboriginal and Torres Strait Island Corporation (New South Wales). These partnerships and relationships were essential for successful recruitment of participants. As described in more detail below, peer recruiters/data collectors were employed to support the research staff. Results will be disseminated to the participants and study partners through newsletters and presentations in the community.

Phase 1 (qualitative study)

Semistructured focus groups and interviews were conducted with adolescents, their parents/carers and

healthcare providers. The study was promoted through local Aboriginal radio, word of mouth and at local community events. A form of snowball sampling was used via community and family networks. Engagement and promotion of the study was conducted at public and private primary and secondary schools, Aboriginal organisations, youth services and affiliated stakeholders. Separate focus groups were conducted with the following age groups: 10–13 years, 14–17 years and 18–24 years. The trigger questions used are shown in table 1.

Phase 1 data analyses

Qualitative data from the three sites were analysed separately to identify community-specific themes and priorities. Emerging themes from the three sites were compared to identify similarities and differences between communities. The themes that emerged from the focus groups were compared with the themes that emerged from the parents/primary carers and health-care professionals in order to determine the similarities and differences in attitudes to health, well-being and access to health services between the three groups. A summary of findings was disseminated to the local community for review and feedback. The findings from phase 1 were also used to inform the development of phase 2 of the study.

Phase 2 (prospective longitudinal cohort study)

Phase 2 involves the establishment a cohort of Aboriginal adolescents aged 10–24 years to be followed-up longitudinally to examine trajectories in health and well-being over time.

Participant recruitment and retainment strategy

Recruitment commenced on April 2018 and will continue until June 2020. Adolescents are being recruited using several different strategies led by Aboriginal researchers in each site.

Community networks

Adolescents are being recruited from the community through personal contacts and networks, youth centres, sporting clubs and youth health services. Aboriginal researchers are leading the participant contact and survey procedures in each local community.

Public/private schools

In order to work more closely with schools and also recruit participants through schools, we are in the process of seeking the relevant approvals from the States and Territories Departments of Education and from the Catholic and Independent schools.

Peer recruitment

Of note, 2–4 young people in each site are employed as peer recruiters to recruit peers within their networks. Peer researchers will be important for cohort retention.

Table 1 Trigger questions used for focus groups and interviews with young people, parents/carers and healthcare providers

Young people

1. How important is health to you?

- 2. What does it mean in your experience to be a healthy young person?
- 3. How much control do you think you have over your health?
- 4. What are the major factors that have a positive influence your health?
- 5. What are the major factors that have a negative influence on your health?
- 6. What are the most important things that could be done in your communities and families to improve the health and well-being of young people?
- 7. What was important in making a transition from going to get healthcare with your parents versus going to get healthcare alone?
- 8. What would make a healthcare service easier for young people to
- 9. What makes healthcare services difficult for young people to use?
- 10. Have you any experience with attending healthcare services as a young person?
- 11. What kind of health services are you currently using (AMS and/or mainstream)?
- 12. How comfortable are you going to these health services?
- 13. What do you like about these health services (for AMS and mainstream separately if they go to both)?
- 14. What do you not like about these health services (for AMS and mainstream separately if they go to both)?
- 15. What things do you think would make services (AMS/mainstream) better or more comfortable for you?

Parent/carer

- 1. What does it mean in your experience for a young person to be healthy?
- 2. How much control do you think young people have over the own health?
- 3. What are the major factors that have a positive influence on the health of young people?
- 4. What are the major factors that have a negative influence on the health of young people?
- 5. What kind of health services is available to young people?
- 6. What are the main health services young people are using?
- What do you like about these health services?
- 8. What do you not like about these health services?
- easier for young people to use?

Healthcare providers

- 1. Do you think young people have specific health needs that are different from adults?
- 2. Have you received any training in providing healthcare for adolescents?
- 3. Do you know of or use any frameworks or practice guidelines for the care of adolescents?
- 4. In general do you think your service provides accessible or appropriate healthcare for young people?
- 5. What factors do you think are important in providing accessible and appropriate healthcare for young people?
- 6. What do you think are the major barriers to young people accessing healthcare?
- 9. What would make a healthcare service 7. What do you consider are the sorts of health issues are important in providing healthcare to young people?
 - 8. What are the values and attributes that are important for a healthcare provider to have when interacting in a clinical setting with young people?

AMS, Aboriginal Medical Service.

Social media

A study Facebook page has been set up and managed by researchers in each site. Regular posts targeted to adolescents in the age group are set up to provide more information about the study and details about any upcoming events. Social media will also be an important tool to keep current study participants informed of study outcomes and engaged to ensure high retention.

Other strategies to ensure high retention of the cohort include regular contact through phone and email to keep participants informed of the study. We will also endeavour to hold events such as cultural activities and sports days.

Consent

Young people under 16 years of age require signed consent from their parents/carers as well as their own consent. Young people aged 16 years and over can consent for themselves. Once informed consent is received, participants are asked to come in for a baseline appointment to complete the surveys and health assessments.

Data collection: youth surveys

All surveys have been designed on REDCap (Research Electronic Data Capture) and designed to be self-completed electronically on tablets. REDCap features an audio option whereby participants are able to have the question and response options read aloud to them. The

Table 2 Next Generation youth survey domains and constructs		
Domain	Constructs	Age group
Cultural/community/family engagement	a. Identityb. Practicesc. Knowledged. Family connectione. Community connection	10–15 16–24 Parent/carer
2. Social determinants of health	 a. Education b. Employment c. Financial stressors/security d. Driver license e. Housing f. Racism/discrimination g. Interaction with police/justice 	10–15 (education only) 16–24 Parent/carer
3. Physical health and injury	a. Adolescent health conditionsb. Injuriesc. Sleepd. Physical activity/sedentary behavioure. Diet	10–15 (questions on health conditions to be completed by parent/carer) 16–24 Parent/carer
4. Mental health	a. Psychological distressb. Self-harmc. Resilienced. Bullyinge. Support systems/access to health services	10–15 16–24 Parent/carer
5. Sexual and reproductive health	 a. Puberty b. Sexual identity c. Sexual activity d. Sexually transmitted infections/diseases e. Contraception f. Pregnancy g. Parenting h. Access to health services 	10–15 (only asked about puberty) 16–24
6. Tobacco, alcohol and drugs	a. Initiationb. Frequencyc. Amount consumedd. Attitudes	10–15 (only tobacco and alcohol) 16–24

surveys were designed to cover six major domains: (1) social determinants of health; (2) Aboriginal cultural engagement/family and community connections; (3) physical health and injury; (4) social and emotional wellbeing; (5) tobacco, alcohol and drugs and (6) sexual and reproductive health. Table 2 shows the constructs captured for each domain. Survey questions have been identified by investigators and sourced, where possible, from existing studies: WA Aboriginal Child Health Survey, SEARCH and the Longitudinal Study of Indigenous Children. Where appropriate and possible, scales that had been previously validated among Aboriginal people were included. To measure social and emotional well-being, the Strengths and Difficulties Questionnaire and the Kessler-6 scale were used. 21 22

Separate surveys were designed according to age: one for younger adolescents aged 10–15 years of age and another one for older adolescents 16–24 years of age. Questions about sexual activity and illegal drugs are not included in the questionnaire for 10–15-year-old participants.

Data collection: parent/carer surveys

Parents/carers of the participants are also asked to complete a survey. The purpose of the parent/carer survey is to capture the social and demographic profile of families, as well as about stressful life events that may impact the health of adolescents. Parents/carers are also asked about medical history and physical health conditions of the 10–15-year-old participants.

Responding to potential adverse responses

Survey content was carefully selected to avoid emotional distress among participants; however, in case of adverse emotional responses, all participants will be provided with the contact details of the social and emotional well-being support centres in their local area. Aboriginal researchers have also been trained to look out for any adverse physical or emotional response to the study survey. In the event of severe responses, participants are advised to stop the survey at any time. Researchers refer them to appropriate mental health services if requested/required.

Data collection: clinical measures

Baseline clinical measures are being undertaken by Aboriginal researchers. To gain competency in measuring each of the assessments and to ensure consistency in measurements across all sites, a training workshop was conducted with all data collectors from all three sites prior to the start of data collection in February 2018.

Anthropometry measurements

Measurements include weight, height, waist and hip circumference. Body Mass Index is calculated as weight (in kilograms) divided by the square of height (in metres). Weight is measured in kilograms using a digital floor scale on a firm surface or board (SECA). Height is measured in centimetres using a stadiometer (SECA) placed on a firm surface or board.

Cardiometabolic risk markers

Measurements include systolic and diastolic blood pressure, resting heart rate (pulse), point-of-care blood lipids and glycated haemoglobin A1c (HbA_{1c}). Blood pressure is measured using an automated blood pressure monitor (Omron HEM-907) on the participant's non-dominant arm. Participants are given 5 min to relax before the first measurement is taken. The second and third measurements are taken with at least 2–3 min in between each measurement. The average of the second and third measurements will be used for analysis. Pulse is also measured three times using the same blood pressure monitor described above.

Point-of-care blood tests are being used to measure levels of blood lipids (low-density lipoprotein cholesterol, high-density lipoprotein cholesterol [HDL-C], total cholesterol and total cholesterol/HDL-C ratio) using the Cobas b 101 instrument (Roche). HbA_{1c} levels is also being measured using the Cobas b 101 instrument.

Kidney function

Kidney function is being assessed by measuring albuminuria (defined as urinary albumin-to-creatinine ratio ≥3.0 mg/mmol) in keeping with current Kidney Disease/Improving Global Outcomes recommendations. ²³ A clean catch urine specimen is obtained from participants in urine collection jars and analysed immediately using the Clinitek Status+Analyzer. Urine samples are discarded immediately and not stored.

Reporting of clinical measurements

Aboriginal researchers were provided with age-specific (and if available, Aboriginal-specific) reference ranges for each measurement. Based on the reference ranges, researchers provide participants with a summary/feed-back report of all the results. Participants are being advised to follow-up any abnormal clinical results with their primary caregivers or will be provided a referral/contact details of their local Aboriginal health service provider. For any indicators of severe abnormalities that require urgent attention (eg, extremely high blood pressure), participants are advised to visit the nearest medical

service immediately. For young participants under the age of 16 years, researchers ensure that their parents/carers were made aware of their results from the clinical assessments if they were not present during the assessment.

Pilot testing

The survey was pilot tested among a sample of Aboriginal adolescents in each age group in each site to determine (1) the time taken to complete the survey, (2) appropriateness and comprehension of the survey questions and (3) any adverse reactions to the survey questions. Further refinement on wording of questions and the order of the questions were made following the pilot test phase.

Data linkage

Consent is being obtained from adolescents and their parents/carers to link the youth survey data to the following databases: Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), Australian Immunisation Register,National Assessment Program-Literacy and Numeracy, Education data, Births/Deaths registry, perinatal records, hospitalisations, emergency department presentations, Child Protections data and Juvenile Justice data. Retrospective (from date of birth) and prospective (15 years from date of consent) MBS and PBS data will be requested.

Data management and statistical methods

All survey data and data collected from the clinical assessments are being recorded and stored in REDCap hosted by the University of Melbourne server. Data from adolescents are linked to their parent/carers using a unique family code number. Once data collection is finalised, deidentified data will be exported for analyses.

Descriptive statistics and baseline data analyses

For each of the key baseline measures, prevalence with 95% CIs (for categorical variables) or mean with SDs (for continuous variables) will be calculated. These will be presented for each of the three sites by age group (10-14, 15-19 and 20-24) and by sex, adjusted for age (based on national census age estimates), where appropriate. Overall age-adjusted sex-specific estimates with 95% CIs will be obtained for all sites combined. It is important to note that the study is designed primarily to provide relevant data for communities; it is not designed to be representative of the general population, since this is neither necessary nor desirable for this type of study. However, measures from the cohort and individual sites will be compared with nationwide age-specific data from the National Aboriginal and Torres Strait Islander Health Survey (n=~2500 aged 10-24). Using Bronfenbrenner's Bioecological Model of Human Development, individual-level, family-level and community-level factors associated with each of the baseline measures will be identified using linear or logistic regression models adjusted for age and sex. Analyses will be undertaken using random effects models to account for correlation of measures within families.

Longitudinal data analyses

Changes over time will be assessed using data from baseline and follow-up surveys and from linked data such as changes in medication use, hospitalisations and primary care service use. The number and percentage of individuals with different trajectories of interest for categorical variables (eg, the distribution of those who develop conditions or behaviours, improve or remain the same), and the mean changes over time for continuous measures will be reported, with 95% CI for each site and age group separately. Incidence (and 95% CIs) of some outcomes, such as births, hospitalisation/emergency department presentations for injuries and other conditions and health services use, will be estimated from linkage of participant data to relevant data sets.

Identification of factors relating to resilience and risk behaviours and physical and mental health outcomes at baseline and changes over time will be undertaken by combining data from all three sites. Separate analyses will be undertaken for each outcome and will involve different subgroups of the sample as relevant. Where appropriate, survival analyses, including Cox proportional hazards modelling will be used to quantify the relationship of baseline variables to time to outcome, particularly those measures ascertained through data linkage. Longitudinal analysis will be undertaken using random effects to adjust for repeated observations within individuals. To account for missing data, the characteristics of individuals with missing data will be assessed. Primary complete-case analyses will be supplemented with sensitivity analyses using multiple imputation.

Sample size and statistical power

The study aims to recruit 2,250 Aboriginal adolescents (750 participants from each study site). Within each site, there will be approximately 250 individuals in each age group (10–14 years; 15–19 years; 20–24 years) at baseline for outcomes obtained from participants and through data linkage. Assuming 20% loss to follow-up there will be about 200 participants in each age group at follow-up in 2 years' time. For sex-specific estimates there will be between 300 and 375 individuals.

For Aims 1 to 3, these numbers of participants will allow estimation with 95% CI within $\pm 3\%$ –5% for low prevalence estimates (5%–15%), 5%–6.5% for moderate prevalence estimates (20%–35%), 3%–3.5% for high prevalence estimates (46%–60%) and 0.12–0.14 SDs for means for the smallest subgroups (age groups with sites) to $\pm 1.5\%$ –2.5% for low prevalence estimates, 2.5%–3% for moderate prevalence estimates, 3%–3.5% for high prevalence estimates and 0.06–0.07 SDs for means for the large subgroups (sex specific for all sites). There will be similar precision for estimation of changes over time.

For cross-sectional and longitudinal analyses (Aim 4), the study will have at least 80% power, with a 5% significance level, to detect between group differences of 3%–7% for binary outcomes with low prevalence, 6%–8% for outcomes with moderate prevalence and

7%–9% for outcomes with higher prevalence; 0.13–0.17 SDs for continuous outcomes and hazard ratios of 1.6–2 for time to event analyses. These estimates are based on analyses of the entire group; detectable differences for subgroups will be larger (\sim 1%–2% more for binary outcomes, \sim 0.03–0.04 SDs for continuous outcomes and hazard ratios of 0.2–0.23 for time to event analyses).

ETHICS AND DISSEMINATION

Additional requests for data linkage to a range of other routinely collected data will be submitted once recruitment is complete and the cohort has been established.

Research findings will be disseminated via reports, booklets and other formats that will be most useful and informative to the participants and community organisations. Findings will also be written as policy briefs, presented at relevant conferences and published in peer-reviewed journals.

A major strength of this study is the wide range of data that will be available about participants to create a holistic picture. The main comprehensive survey covering six major domains will be linked to the clinical biomarkers for cardiometabolic and renal function. The addition of linked health and social data from administrative data sources will expand the range of health outcomes recorded within the cohort.

Another important strength is the community partnerships that have been established to successfully undertake the work. Fostering meaningful engagement with community organisations is a time-consuming process especially given the breadth of communities that we are aiming to engage through this study. However, these partnerships are important for the success of the study and for the findings to be successfully translated into services and programmes in the community in which the adolescents reside. In all study sites, it has been a priority that Aboriginal researchers are leading the work at all stages from community engagement, recruitment, data collection and analyses and interpretation of findings. We have involved Aboriginal peer researchers/recruiters wherever possible in order to foster positive relationships with adolescents. Throughout the study, we will also link with key policy makers and ensure that our findings are translated into policies to support Aboriginal adolescents.

Aboriginal adolescents continue to experience preventable health and well-being issues and greater levels of ill health compared with non-Aboriginal adolescents. Due to the gaps in current evidence on the health and social well-being of Aboriginal adolescents, there is a need for a longitudinal study that examines health trajectories over time. This study will provide critically important longitudinal evidence to inform life-course approaches to improve the experiences and outcomes for future generations of adolescents. It will also provide evidence to lay the foundations for enhanced physical and mental health in adulthood. This will inform evidence-based resources for improving the well-being of adolescents and potentially

generate learnings for other Indigenous population groups worldwide.

Author affiliations

¹Melbourne School of Population and Global Health, University of Melbourne, Melbourne, Victoria, Australia

²ANU College of Medicine, Biology and Environment, Australian National University, Canberra, Australian Capital Territory, Australia

³Infection and Immunity, South Australia Health and Medical Research Centre, Adelaide, South Australia, Australia

⁴Flinders University Faculty of Medicine Nursing and Health Sciences, Adelaide, South Australia, Australia

⁵National Centre for Epidemiology and Population Health (NCEPH), ANU College of Medicine, Biology and Environment, The Australian National University, Callaghan, Western Australia. Australia

⁶Public Health and Community Medicine, University of New South Wales, Sydney, Australia

Monash Children's Hospital, Monash Health, Clayton, Victoria, Australia
 Burnet Institute, Melbourne, Victoria, Australia

⁹The Sax Institute, Haymarket, New South Wales, Australia

¹⁰ Judith Lumley Centre, School of Nursing and Midwifery, La Trobe University, Melbourne, Victoria, Australia

¹¹School of Public Health and Community Medicine, University of New South Wales, Sydney, New South Wales, Australia

¹²Baker Heart and Diabetes Institute, Melbourne, Victoria, Australia

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Contributors LG led the writing of this paper. SJE, EB and JW had overall responsibility for the conception of this study with scientific input from the chief investigators (BL, CD, RI, AW and RR). CD contributed expertise in the development of the statistical analysis plan for the study. LG, PA, CC, CH, JB and BM contributed expertise to the design of the survey tool and clinical assessments described. All authors contributed to the design of the study, the writing of this paper and approved the final draft.

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REFERENCES

- Sawyer SM, Afifi RA, Bearinger LH, et al. Adolescence: a foundation for future health. Lancet 2012;379:1630–40.
- Bronfenbrenner U, Morris P. The bioecological model of human development. In: Damon W, Lerner RM, eds. Handbook of child psychology. New York: John Wiley & Sons, 2006:793–828.
- Galvan A, Hare TA, Parra CE, et al. Earlier development of the accumbens relative to orbitofrontal cortex might underlie risk-taking behavior in adolescents. J Neurosci 2006;26:6885–92.
- Martin CA, Kelly TH, Rayens MK, et al. Sensation seeking, puberty, and nicotine, alcohol, and marijuana use in adolescence. J Am Acad Child Adolesc Psychiatry 2002;41:1495–502.
- Steinberg L. A social neuroscience perspective on adolescent risktaking. Dev Rev 2008;28:78–106.
- Azzopardi PS, Sawyer SM, Carlin JB, et al. Health and wellbeing of Indigenous adolescents in Australia: a systematic synthesis of population data. Lancet 2018;391:766–82.
- 7. Welfare AloHa. Aboriginal and Torres Strait Islander adolescent and youth health and wellbeing 2018: in brief. Canberra: AlHW, 2018.
- AlHW. Aboriginal and Torres Strait Islander adolescent and youth health and wellbeing 2018. Canberra: Australian Institute of Health and Welfare, 2018.
- Young C, Tong A, Nixon J, et al. Perspectives on childhood resilience among the Aboriginal community: an interview study. Aust N Z J Public Health 2017;41:405–10.
- Welfare AloHa. Youth Justice in Australia 2016–17. Canberra: Australian Institute of Health and Welfare, 2018.
- Clapham K, Hunter K, Cullen P, et al. Addressing the barriers to driver licensing for Aboriginal people in New South Wales and South Australia. Aust N Z J Public Health 2017;41:280–6.
- Ivers RQ, Hunter K, Clapham K, et al. Driver licensing: descriptive epidemiology of a social determinant of Aboriginal and Torres Strait Islander health. Aust N Z J Public Health 2016;40:377–82.
- Sayers SM, Mackerras D, Singh G, et al. An Australian Aboriginal birth cohort: a unique resource for a life course study of an Indigenous population. A study protocol. BMC Int Health Hum Rights 2003;3:1):1.
- Study of Environment on Aboriginal Resilience and Child Health Investigators. The Study of Environment on Aboriginal Resilience and Child Health (SEARCH): study protocol. *BMC Public Health* 2010;10:287.
- Thurber KA, Banks E, Banwell C. LSIC Team. Cohort Profile: Footprints in Time, the Australian Longitudinal Study of Indigenous Children. Int J Epidemiol 2015;44:789–800.
- Haysom L, Williams R, Hodson E, et al. Risk of CKD in Australian indigenous and nonindigenous children: a population-based cohort study. Am J Kidney Dis 2009;53:229–37.
- Azzopardi P, Brown AD, Zimmet P, et al. Type 2 diabetes in young Indigenous Australians in rural and remote areas: diagnosis, screening, management and prevention. Med J Aust 2012;197:32–6.
- Azzopardi PS, Kennedy EC, Patton GC, et al. The quality of health research for young Indigenous Australians: systematic review. Med J Aust 2013;199:57–63.
- Maple-Brown LJ, Sinha AK, Davis EA. Type 2 diabetes in indigenous Australian children and adolescents. J Paediatr Child Health 2010;46:487–90.
- Stone M, Baker A, Maple Brown L. Diabetes in young people in the Top End of the Northern Territory. J Paediatr Child Health 2013;49:976–9.
- McNamara BJ, Banks E, Gubhaju L, et al. Measuring psychological distress in older Aboriginal and Torres Strait Islanders Australians: a comparison of the K-10 and K-5. Aust N Z J Public Health 2014;38:567–73.
- Williamson A, McElduff P, Dadds M, et al. The construct validity
 of the strengths and difficulties questionnaire for aboriginal
 children living in urban New South Wales, Australia. Aust Psychol
 2014;49:163–70.
- KDIGO. 2012 Clinical practice guideline for the evaluation and management of chronic kidney disease: KDIGO, 2013.