

# BMJ Open Generating evidence to inform responsive and effective actions for Aboriginal and Torres Strait Islander adolescent health and well-being: a mix method protocol for evidence integration 'the Roadmap Project'

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## ABSTRACT

**Background** Australia does not have a national strategy for Aboriginal and Torres Strait Islander adolescent health and as a result, policy and programming actions are fragmented and may not be responsive to needs. Efforts to date have also rarely engaged Aboriginal and Torres Strait Islander people in co-designing solutions. The Roadmap Project aims to work in partnership with young people to define priority areas of health and well-being need and establish the corresponding developmentally appropriate, evidence-based actions.

**Methods and analysis** All aspects of this project are governed by a group of Aboriginal and Torres Strait Islander young people. Needs, determinants and corresponding responses will be explored with Aboriginal and Torres Strait Islander adolescents (aged 10–24 years) across Australia through an online qualitative survey, interviews and focus group discussions. Parents, service providers and policy makers (stakeholders) will share their perspectives on needs and support required through interviews. Data generated will be co-analysed with the governance group and integrated with population health data, policy frameworks and evidence of effective programmes (established through reviews) to define responsive and effective actions for Aboriginal and Torres Strait Islander adolescent health and well-being.

**Ethics and dissemination** Ethical approval for this study has been obtained from the Aboriginal Health Council of South Australia (Ref: 04-21-956), the Aboriginal Health and Medical Research Council of New South Wales (Ref: 1918/22), the Western Australian Aboriginal Health Ethics Committee (Ref: HREC1147), the Northern Territory Health and Menzies School of Health Research (Ref: 2022-4371), ACT Health Human Research Ethics Committee (Ref: 2022.ETH.00133), the St. Vincent's Hospital, Victoria (Ref:

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ All aspects of the work are governed by an Aboriginal and Torres Strait Islander adolescent governance group with diverse national representation to give primacy to adolescent leadership and voice.
- ⇒ Represents a comprehensive effort to define priority needs and corresponding evidence-based responses for Aboriginal and Torres Strait Islander adolescent health and well-being.
- ⇒ Combines multiple data collection methods and data sources to ensure comprehensive reach, scope and perspectives.
- ⇒ The work entails meaningful engagement of a broad range of stakeholders providing a strong foundation for translation of new knowledge to sustainable actions reflecting adolescent priorities.
- ⇒ Data will largely be collected through online channels, which may exclude some adolescent perspectives; however, in-person data collection will be organised for some regional populations to mitigate this.

HREC 129/22), University of Tasmania (Ref: 28020), Far North Queensland Human Research Ethics Committee (Ref: HREC/2023/QCH/89911) and Griffith University (Ref: 2023/135). Prospective adolescent participants will provide their own consent for the online survey (aged 13–24 years) and, interviews or focus group discussions (aged 15–24 years); with parental consent and adolescent assent required for younger adolescents (aged 10–14 years) participating in interviews. Study findings (priority needs and evidence-based responses) will be presented at a series of co-design workshops with adolescents and stakeholders from



relevant sectors. We will also communicate findings through reports, multimedia clips and peer-reviewed publications as directed by the governance group.

## INTRODUCTION

Adolescence is now recognised as a critical developmental stage. Characterised by profound physiological, social and neurocognitive transitions, it represents a key opportunity to transform health and well-being trajectories across the life course.<sup>1</sup> Adolescents (aged 10–24 years) now also constitute the largest population cohort in history. As a result, there is growing interest to reform policy and to invest in this population group, particularly considering the ‘triple dividend’ generated.<sup>2</sup> However, understanding what adolescents view as priorities for action remains largely undefined. Global efforts to document these are now underway in several countries.<sup>3</sup>

In addition to understanding priority needs, there is a pressing need to ensure that corresponding actions are both responsive and effective. Responsive action requires solutions to be age-based, context-specific and matched to adolescent-identified priorities. Earlier work has demonstrated an excess in mortality among Aboriginal and Torres Strait Islander adolescents, of which 80% remains preventable and avoidable under the current health system.<sup>4</sup> This is strongly suggestive that current actions, where they do exist, may be inadequate and/or poorly aligned to adolescent needs. One of the main reasons for this is the absence of a national strategy for Aboriginal and Torres Strait Islander adolescent health. Consequently, policy and programming actions are fragmented and reactive. Efforts to date have been largely siloed around health issues including sexually transmitted infections,<sup>5</sup> social and emotional well-being,<sup>6</sup> youth suicide,<sup>7</sup> rheumatic heart disease<sup>8</sup> and risk behaviours including substance misuse.<sup>9</sup> In relative isolation, these foci appear incomplete, as indicated by ongoing rates of potentially avoidable mortality.

Delivering effective actions will require that gaps in the evidence base are addressed. Earlier work highlighted the explicit need for more programme and intervention evaluations to build an evidence-based foundation that informs responsive actions.<sup>10</sup> A re-examination of the most suitable platforms for response is also required. Most policies and strategies focus on actions through the health system, but this may be too narrow a focus to address key needs including the high rates of psychological distress among Indigenous adolescents.<sup>4</sup> Action to address broader sociocultural determinants of health—including racism, discrimination, marginalisation, cultural and other forms of identity—have remained absent in broader policy frameworks,<sup>11</sup> most notably for adolescent health. Without a comprehensive approach, efforts are likely to be mismatched with needs, poorly co-ordinated and insufficiently resourced.<sup>12</sup>

Positioning adolescent leadership at the core of health and well-being research is central to generating

responsive and effective evidence that can be appropriately translated into action. Young people bring their own unique perspectives, experiences, skills and knowledge. Leveraging these through adolescent leadership is likely to foreground novel responses that are more aligned to needs, and more likely to contribute to responsive action, better policy making and improved health and well-being outcomes.

In this context, there is a need for a roadmap—guidance for actions that are responsive to the needs and evidence-based. The roadmap will establish what needs to be addressed, and how so, to improve Aboriginal and Torres Strait Islander adolescent health.<sup>13</sup>

## METHODS AND ANALYSIS

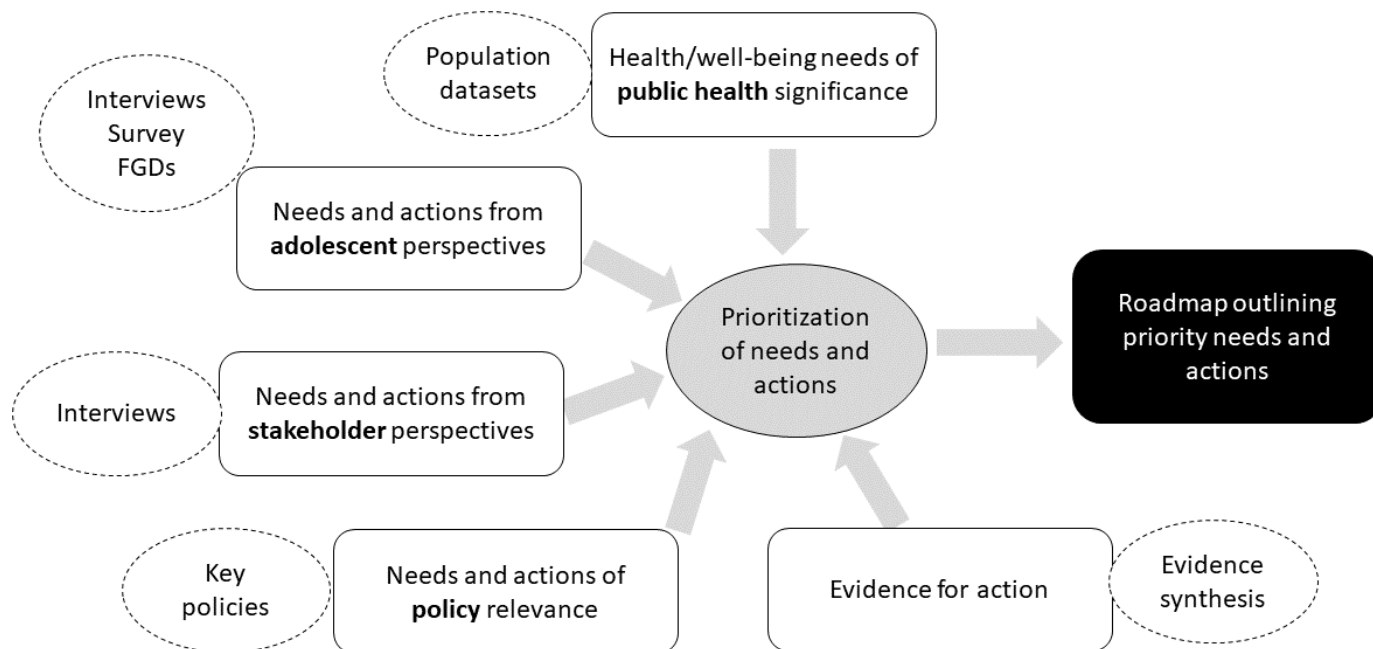
### Study design and setting

The aim of the study is to gather evidence needed to inform the first comprehensive national roadmap for Aboriginal and Torres Strait Islander adolescent health and well-being. The specific objectives are to: (i) define priority health and well-being needs for Aboriginal and Torres Strait Islander adolescents and (ii) to identify evidence-based actions required to address priority needs and knowledge gaps. To achieve this, primary data will be collected from adolescents and stakeholders across the country; this will be complemented with data from national population surveys and syntheses of relevant literature and policies.

Figure 1 represents the conceptual model of inputs that will be used to define priority needs and actions and the process of priority setting that will result in the set of recommendations incorporated into the roadmap.

### Adolescent governance group

The study is governed by a group of Aboriginal and Torres Strait Islander adolescents aged 16–24 years. A total of 18 governance members, 2 representatives living across each state and territory, including the Torres Strait, will play a pivotal role by continuously providing direction on study processes including recruitment strategies and materials, data collection tool development and approaches, analysis and generation of outputs. They will also shape study findings to define health priorities and evidence-based action and co-lead dissemination and translation activities. The group is supported by a diverse network of elders, community leaders and cultural knowledge keepers. Details around the establishment of this group have been detailed previously.<sup>14</sup> In brief, an expression of interest was developed by young Aboriginal researchers in the team and broadly disseminated through established networks and social media channels; applicants were asked to detail their expertise and motivation for joining the group (by email, video message or phone); we sought to identify young people with a capacity to act in a governance role. Two Aboriginal researchers reviewed all applicants and then interviewed short-listed applicants to invite a group of young people who are diverse with



**Figure 1** Conceptual model of inputs and priority definition process for the roadmap. FGD, focus group discussion.

respect to Indigeneity, gender and sexual orientation, geography, educational participation and lived experience (including chronic illness). Governance group members have met in person and more regularly over video-conference, are reimbursed for their time and have access to an annual capacity development scholarship to build their own skills.

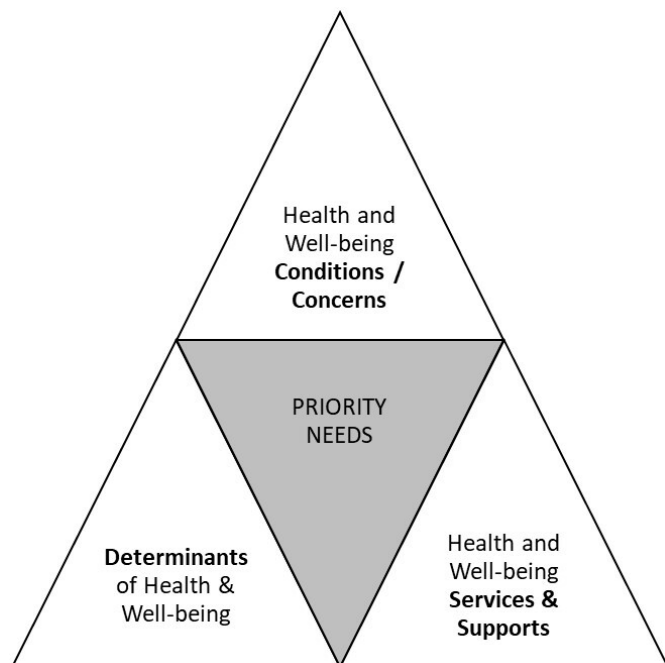
### Primary data collection

#### Types of participants

Two main perspectives will be captured through qualitative inquiry—those of adolescents and those of stakeholders who have an interest in the health and well-being of Aboriginal and Torres Strait Islander adolescents. Adolescent participants (aged 10–24 years) comprise individuals who identify as Aboriginal and/or Torres Strait Islander. Stakeholders include individuals from Indigenous peak bodies, health services and organisations representative of the youth, education and social sectors (such as housing, employment, youth justice, child safety and protection) that impact adolescent health and well-being; parents, community members and policy makers are also considered important stakeholders. Additionally, global First Nations experts and content experts will also be invited to take part in the study. First Nations experts will comprise First Nations researchers and adolescents (aged 15–24 years) from selected high-income countries (Australia, Aotearoa/New Zealand, Canada, the USA, Greenland, Norway and Sweden). Content experts include individuals from established networks such as the Lancet Commission on Adolescent Health (Professor Peter Azzopardi is a commissioner)<sup>15</sup> and the International Association for Adolescent Health.

### Recruitment strategies

A combination of snowball and purposive sampling techniques will be employed to recruit participants to capture diversity in geographical and social backgrounds in three main ways. First, members of the governance group will reach out to their peer and professional networks to identify prospective adolescent and stakeholder participants. Research team members will advertise opportunities to take part in the study via their diverse professional networks. Second, a rapid service mapping exercise is being conducted to identify organisations providing health or well-being support services to Aboriginal and Torres Strait Islander adolescents. This initial database of key stakeholder service organisations will be expanded on to include organisations identified through adolescent and stakeholder interviews or focus group discussions (FGDs). Key stakeholders at these organisations will be approached to promote the study to their adolescent service users and will also be invited to take part in interviews themselves. Recruitment advertisements will also be used on social and traditional media and distributed through email networks. The Roadmap Project website (<https://roadmap.org.au>) will host study information and recruitment materials including links through which potential participants can register their interest in joining the study. Context-specific strategies, such as attending community and youth events, will also be used to create awareness about the study, connect with stakeholder organisations and to recruit interested participants. Finally, community champions identified by governance members, the research team and/or key stakeholders, will be approached to promote the study. Community champions will include individuals such as national and social media personalities and young leaders and elders.



**Figure 2** Overall guiding framework to define priority needs and associated evidence-based actions.

Key stakeholders involved in policy formulation will be identified through key policy documents as well as from interviews with service providers.

#### Recruitment materials

Materials such as flyers, social media tiles, website content, study information sheets, promotional videos and presentations, either co-designed with governance group members or reviewed by them, will be used to create awareness about the study among potential adolescent participants and key stakeholders.

#### Data collection

Three main elements of priority areas of health and well-being needs will be explored as illustrated in [figure 2](#). First, the most important health and well-being conditions or issues faced by adolescents (encompassing physical, mental, emotional, social, spiritual and/or cultural well-being) will be determined. Second, factors that shape health and well-being at various levels of influence will be explored using dimensions of the social ecological<sup>16 17</sup> and Aboriginal and Torres Strait Islander social emotional well-being framework<sup>18</sup> as starting points to more comprehensively incorporate determinants beyond individual behaviours and risk factors. Factors specifically affecting access to and use of services and supports will be examined within this as well.

Data collection will largely take place virtually via video-conference (eg, Microsoft Teams). Regional and remote populations will be prioritised for in-person data collection where feasible. Data collection commenced in May 2022 and is expected to be completed in January 2025.

#### Adolescent perspectives

Adolescent views on the meaning of good health and well-being, priority concerns, determinants and gaps in services and other support structures will be obtained through the following three methods.

#### Online survey

A maximum of 2500 interested Aboriginal and Torres Strait Islanders aged 13–24 years across Australia are being invited to complete a short, anonymous online survey. Hosted on Research Electronic Data Capture (REDCap), a web-based application for survey design and management,<sup>19</sup> the survey consists of five open-ended questions; participants respond using a few keywords and short phrases to questions about key health issues, determinants and desired supports. The survey collects minimal demographic information (age, gender, place of residence) to enable responses to be analysed by these key indicators. A copy of the survey is provided as online supplemental material file 1.

Data will be concurrently analysed to examine ‘conceptual depth’<sup>20</sup> and diversity. The survey will be terminated when no new information is being elicited—this will be determined in conjunction with the governance group.

Adolescents completing the survey can also submit their interest in participating in FGDs or interviews to explore their responses in more detail. The survey was piloted in South Australia in July 2022.

#### Focus group discussions

Adolescents aged 15–24 years will be invited to participate in online FGDs to delve deeper into priority areas for their health and well-being. About four FGDs will be conducted in each of the states and territories in the country including the Torres Strait; FGDs will be conducted separately with adolescents aged 15–18 years and 19–24 years and, where desired, separately between young women, men and non-binary adolescents.

Participatory brainstorming activities will be conducted using virtual whiteboards on collaborative online platforms (eg, Miro) to facilitate online group discussions. Available features such as sticky notes, drawing tools and emojis will first be used to stimulate individual reflection which will then be followed by group discussion. Additionally, FGD participants will use an online platform (eg, Mentimeter) to rank top three priority areas identified. A copy of the FGD guide that is used as a general guide for discussions provided as online supplemental material file 2.

#### Individual interviews

Individual interviews are being used to better understand the meaning attached to health and well-being among younger adolescents aged 10–14 years as well as their main health and well-being concerns. Factors that support and hinder their health and well-being and the services they rely on will also be explored during interviews. Activities suited to eliciting younger adolescent perspectives, such

as draw and write techniques,<sup>21–23</sup> which shift focus away from adults and create young person-centred enabling environments, will be employed. As with FGDs, virtual whiteboards and associated features allow the adolescents to externalise their responses to interviewer questions, which can then be explored through discussion.

Interviews will also be offered to older adolescents (aged 15–24 years) who wish to share their views through this medium. We will aim to conduct between 8 and 10 interviews per state/territory. The interview guide that is used as a general guide for interviews has been included as online supplemental material file 3.

### Stakeholder perspectives

Individual interviews will be conducted with key stakeholders to explore their views on priority health needs and factors influencing Aboriginal and Torres Strait Islander adolescent health and well-being. Determinants of access to care and support service access as well as service and support gaps will also be explored through interviews. When speaking with service providers, additional information about the programmes and services specifically aimed at maintaining adolescent well-being will be discussed to understand what works well and identify areas with gaps. Where appropriate, institutional mechanisms that support adolescent involvement in design, delivery and monitoring of programmes will be visited. The interview guide that is used as a general guide for interviews has been included as online supplemental material file 4.

### Evidence synthesis

To comprehensively incorporate Aboriginal and Torres Strait Islander adolescent perspectives on health and well-being priorities, a scoping review of qualitative studies including Aboriginal and/or Torres Strait Islander adolescents aged 10–24 years will be conducted. Methodological details will be included in a separately published protocol. Briefly, relevant databases (such as PubMed, CINAHL, Embase, Scopus) will be systematically searched. Studies will be eligible for inclusion if they report adolescent perspectives on their health and well-being. Peer-reviewed and grey literature published in English in the 5 years prior to the search date will be included. Mixed-methods studies with a qualitative component will be eligible for inclusion if they include views of adolescents. The framework developed by WHO's Global Action for Measurement of Adolescent (GAMA) health advisory group will be used to abstract and map out priority needs.<sup>24</sup> We will use the following domains from the framework: health outcomes and conditions, health and well-being determinants and systems performance and interventions.

### Priorities of public health importance and policy relevance

Priorities identified through primary data collection and discussed with the project adolescent governance group will be used as a guide to extract relevant indicators (health outcomes and determinants) from available population

health data sources. These will be mapped onto the adapted GAMA reporting framework and descriptive analyses and data visualisation conducted; results will be disaggregated by jurisdiction, age (10–14 years, 15–19 years and 20–24 years), gender and remoteness.

Key policy documents at state and federal levels will be examined, and targets related to Aboriginal and Torres Strait Islander adolescent health mapped out. These will be compared with priority areas described by policy makers during stakeholder interviews. An abstraction tool will be used to extract targets and outcomes explicitly aimed at improving Aboriginal and Torres Strait Islander adolescent health and well-being.

### Qualitative inquiry data analysis

#### Online survey data

Responses from the online survey will be descriptively analysed to identify priority health conditions, determinants and support/service improvements listed by respondents. Responses provided as short phrases or sentences will be coded to enable combined analysis with interviews and FGD data.

Word clouds will also be generated from survey responses to visualise potential priority areas; the size of words will correspond to the frequency with which they are mentioned.<sup>25</sup> Where possible, descriptive maps will be generated to qualitatively depict priority areas by state and subnational jurisdictions where appropriate. Priorities will also be graphed to explore variation by key critical socio-economic factors such as gender, age-group and location remoteness.

#### Interview and focus group data

As part of validation strategies to establish credibility,<sup>26</sup> build trust and ensure appropriateness of analyses, summaries of FGD transcripts and interviews will be shared with participants for feedback on how well they represent participant experiences and views.

Textual data generated through qualitative inquiry will be co-analysed with governance group members primarily using thematic analysis.<sup>27 28</sup> Capacity building Knowledge Exchange sessions have been specifically organised to ensure that all interested governance members have the skills to co-analyse the data generated. These interactive sessions are designed to build on the existing skills, knowledge and experience of governance group and to ensure that development and interpretation of the findings privilege the voices and perspectives of Aboriginal and Torres Strait Islander adolescents.

As part of the analysis process, a subset of transcripts will be coded to develop an initial draft of the codebook, which will iteratively be expanded as the coding process continues. A combination of deductive and inductive coding approaches will be employed. The principles of reflexive coding will be followed to be mindful of the intersection between the data and the analyst as codes and themes are generated.<sup>27</sup> Visual data generated through brainstorming activities integrated into FGDs

and interviews with younger adolescents will be reviewed alongside transcripts to extract additional data contributed by participants that complements what is shared verbally.

Ranking of health and well-being concerns will be compared across FGDs to determine priority areas from adolescent perspectives. Ranked priority areas will be examined by age group, gender and state.

### The Roadmap—recommendations for action

A core document integrating priority health and well-being conditions and associated determinants from adolescent and stakeholder perspectives will be created. Evidence-based responses to these priority areas identified through qualitative inquiry and reviews will be presented alongside. Health and well-being concerns prioritised by adolescents will be compared with health issues that are associated with notable burden of morbidity and mortality that are typically considered to be of public health priority. Additionally, health issues that are prioritised on policy agendas and receive funding will also be compared with adolescent priorities to determine overlap with those considered to be important by adolescents.

This initial document will be presented to the governance group and refined based on their feedback during a co-design workshop. A series of consultation workshops will be held with adolescents and stakeholders to present integrated findings to discuss and finalise priority areas and to explore responses. The consultation workshops will be co-facilitated with the governance group.

A subsequent consultation workshop will be organised with key implementing partners to present priority areas and actions agreed on by adolescents and stakeholders. Discussions, co-facilitated with the governance group, will lead to the finalisation of recommended actions. Additional audience-specific outputs (such as videos for adolescents, resources for service providers, policy briefs for policy makers) will be identified through discussion with the governance group as well as stakeholders and produced.

### Patient and public involvement

The governance group described earlier are at the centre of the Roadmap Project. One of their roles is to ensure that study objectives, activities and outcomes are aligned with the needs and preferences of Aboriginal and Torres Strait Islander adolescents. The governance group was established at the commencement of the project and members are involved in all stages of the research from defining aims to dissemination activities.

## ETHICS AND DISSEMINATION

Ethical approvals have been sought in each state and territory for this national study. Approvals have been obtained from the following human research ethics committees: the Aboriginal Health Council of South Australia (Ref: 04-21-956), the Aboriginal Health and Medical Research

Council of New South Wales (Ref: 1918/22), the Western Australian Aboriginal Health Ethics Committee (Ref: HREC1147), the Northern Territory Health and Menzies School of Health Research (Ref: 2022-4371), ACT Health Human Research Ethics Committee (Ref: 2022.ETH.00133), the St. Vincent's Hospital, Victoria (Ref: HREC 129/22), University of Tasmania (Ref: 28020), Far North Queensland Human Research Ethics Committee (Ref: HREC/2023/QCH/89911) and Griffith University (Ref: 2023/135).

## Ethical considerations

### Consent process

Written consent will be obtained from adolescent and stakeholder participants. Adolescents wishing to take part in the online survey (aged 13–24 years) and FGDs (aged 15–24 years) will provide their own consent after they have had a chance to review information about the study. This consent process for minors has been approved by all nine research ethics committees. Research indicates that young adolescents are developmentally capable of making informed decisions about involvement in low-risk research.<sup>29</sup> Adolescents will be encouraged to discuss the study with parents or caregivers beforehand. Prospective survey participants will provide electronic consent via the REDCap platform. The Participant Information Sheet, made available prior to data collection, highlights study purpose, processes, risks and benefits of participation, data management in addition to emphasising the voluntary nature of participation. For younger adolescents (aged 10–14 years) wishing to take part in an interview, consent will be obtained from parents or primary caregivers. Adolescents will be involved in explanations about the study and given an opportunity to ask questions and provide their assent. Older adolescents (aged 15–24 years) interested in interviews will provide their own consent. Consent will also be sought from stakeholders wishing to take part in interviews.

### Risks and risk management

There is a risk that adolescent participants' negative experiences relating to health/well-being or service use may be recalled. All participants, including those in the online survey, are provided with a list of counselling services to contact if they require support. Participants may also disclose information that could be potentially embarrassing if shared in a group setting. FGDs and interviews will be facilitated by experienced researchers who will set ground rules to create a safe environment operating with mutual respect. A distress protocol will be followed if any participant shows signs of being upset; a break will be offered and if the participant is unable to resume, the interviewer will offer to contact a support professional. With participant consent, a research team member will follow-up with the participant the next day to check on their well-being and to arrange further support if needed.

### Aboriginal and Torres Strait Islander people

The principles in the National Health and Medical Research Council guidelines on ethical conduct in

research and Australian Institute of Aboriginal and Torres Strait Islander Studies code of ethics have been followed in the design and conduct of this study.<sup>30 31</sup> The co-creation of a Roadmap for Aboriginal and Torres Strait Islander adolescent health will be of benefit to young people and their communities as it will help focus policy and action that is effective and efficient. The majority of the investigator and research team identify as Aboriginal and or Torres Strait Islander thus maintaining Aboriginal control of the research. The governance group members comprise Aboriginal and/or Torres Strait Islander adolescents from all Australian jurisdictions representing diverse social, cultural and geographical backgrounds. The study also adheres to the nine principles for conducting Aboriginal research outlined in the South Australian Aboriginal Health Research Accord.<sup>30</sup> Governance group members receive sitting fees as part of the principle of reciprocity. To enhance Aboriginal and Torres Strait Islander adolescent skills and knowledge, a central focus of the study is empowerment and capacity building of the governance group. As well as providing a platform for Aboriginal and Torres Strait Islander adolescents to influence their health and well-being through research, the study will offer opportunities for adolescent members for mentoring, training through scholarships. Governance members will also be named as investigators and invited to coauthor peer-reviewed publications and other outputs.

### Dissemination plan

A variety of audience-specific outputs and dissemination mediums will be used to share the Roadmap recommendations with adolescents and key stakeholders. Outputs will be directed by the governance group and may include social media tiles and snippets, infographics, policy briefs, targeted reports, peer-review publications as well as short videos.

Potential implementation partners representative of the health, education and social sectors will be identified through stakeholder engagement and co-design workshops organised to finalise Roadmap recommendations of priority needs and associated evidence-based responses.

The establishment of a permanent adolescent governance group is also being explored as a next step to ensure a sustainable platform for continued adolescent involvement and leadership in Aboriginal and Torres Strait Islander and well-being.

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**Contributors** The idea was initially conceptualised by PA, SW, OP, KC, TB, AB and RR. All authors subsequently participated in developing and co-designing the project with the Roadmap governance group members. JK drafted the manuscript, building on her leadership (with SW, IS, DMcD and PA) in developing the protocol, study tools and other materials for ethical review. All authors reviewed and approved of the final version. Authors who identify as Aboriginal and/or Torres Strait Islander people: IS, DMcD, BA, FA, SC, MG, TH, CK, JL, MM, HMcC, LR, HR, DR, JT, OP, KC, TB, JC, AB, SW. Authors who are non-Indigenous allies: JK, SE, RR, PA. PA is the guarantor.

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