

# The need for a roadmap to guide actions for Aboriginal and Torres Strait Islander adolescent health: youth governance as an essential foundation

The current lack of a national strategy for Indigenous adolescent health in Australia is a glaring gap

Adolescence (10–24 years of age) is now recognised as a key developmental window for the health of individuals, their communities and the next generation.<sup>1</sup> One-third of the Aboriginal and Torres Strait Islander (Indigenous) population in Australia are adolescents,<sup>2</sup> and our earlier work has shown that Indigenous adolescents have distinct health needs largely unmet by existing policies and services.<sup>3</sup> Fundamentally, adolescence is a dynamic developmental phase characterised by transitions in the social and cultural determinants of health — key targets for addressing health inequities experienced by Indigenous Australians. For these reasons, adolescent health is a core focus for health policy and action, not only for Indigenous peoples but all populations.

While there has been work to establish a policy framework for Australia's young people, there is no national strategy for Indigenous adolescent health.<sup>4,5</sup> As a result, investments to date have been limited, reactive and fragmented. Efforts have been siloed around health issues including sexually transmitted infections,<sup>6</sup> social and emotional wellbeing,<sup>7</sup> youth suicide,<sup>8</sup> rheumatic heart disease,<sup>9</sup> and risk behaviours including substance misuse.<sup>10</sup> However, these foci are inadequate given the persistent high rates of potentially avoidable mortality; unintentional injury (a key driver of adolescent mortality) is a notable gap.<sup>3</sup> Additional policy gaps relate to the health needs of Indigenous 10–14-year-olds, including the excess burden of sexually transmitted infection, injury, substance use, and poor mental health (including self-harm and suicide). Young adolescents typically cannot access youth services independently and have needs beyond those currently provided for in paediatric services. Further, many existing efforts focus on diseases and risks amenable through the health system, too narrow a focus to address needs largely driven by complex social and structural determinants. More than one-third of Indigenous adolescents report high rates of psychological distress, a symptom of systemic racism and discrimination, intergenerational trauma, and associated socio-economic deprivation. While responsive health services play a critical role, broader investments in health promotion and prevention are also required.<sup>11–13</sup>

In this context, there is a need for a comprehensive roadmap which outlines the strategic direction for Indigenous adolescent health into the future, establishing key needs and priorities and evidence-based actions that will produce tangible improvements

in health and social outcomes. There is a history of roadmaps that have demonstrated success in Indigenous health,<sup>14–16</sup> and a roadmap for Indigenous adolescent health in Australia would help guide a comprehensive, multisectoral and coordinated approach. Our earlier work has shown that the evidence base for Indigenous adolescent health is improving,<sup>17</sup> and now is the time to move beyond responses based on good intentions to informed needs driven action and change.<sup>18</sup>

## Youth governance as an essential foundation

We strongly believe a roadmap for Indigenous adolescent health can only be effective if young people are meaningfully engaged at all stages. Young people have a fundamental right to participate in issues that affect them and bring their own unique perspectives, experiences and skills which are essential to building a more equitable and sustainable future.<sup>1,12,13</sup>

The concept of youth participation is not new,<sup>13,19</sup> and there has been great variation in how young people have been engaged in research, policy and practice.<sup>20</sup> At one extreme, young people may be engaged as ad hoc advisors, having limited power as decision makers, while at the other, they may be empowered to embody a governance role, holding equal power and agency within decision making. This is less common, but imperative if we are to meaningfully engage young people, harness the potential of their energy and skills, and ensure sustainability through their ongoing engagement.<sup>1,13</sup>

While good examples of youth leadership exist (the United Nations Global Indigenous Youth Caucus being one), youth engagement in health research has been limited to date.<sup>21</sup> In 2020, an inquiry into involving young people in health research found limited engagement of adolescents in health research overall, with youth typically engaged to assist with specific research activities (such as recruiting participants) yet rarely to design or implement solutions.<sup>22</sup> Identified barriers to the meaningful involvement of young people included inadequate funding support and lack of evidence and clear guidelines. Additionally, the culture of research teams where “technical knowledge is prioritised over local, contextual knowledge and power dynamics”<sup>22</sup> was identified as a limiting factor to successful partnerships between young people and researchers. Much more must be done to overcome this failing.

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## The power of a third: a national roadmap for Aboriginal and Torres Strait Islander adolescent health

Our group, comprising a national governance group of Indigenous young people and experienced researchers in Indigenous and adolescent health, is working in partnership to develop Australia's first roadmap for Aboriginal and Torres Strait Islander adolescent health. Funded by the National Health and Medical Research Council, research activities focus around two key themes: defining priority needs for Indigenous adolescents (aged 10–24 years); and defining evidence-based actions to meet these needs.

Several key principles have guided our approach. First, the project is governed by a national group of Indigenous adolescents (Box).<sup>13</sup> Membership of the group is intentionally diverse with respect to Indigeneity, gender (including LGBTQ+ and gender diverse young people), geography, educational participation, and lived experience (including chronic illness). Regarding age, we have sought to engage adolescents aged 16–24 years in the governance process (reflecting the age of consent to participate and capacity to provide in depth contributions).

Governance group members make decisions (with technical support from the research team) on all aspects of the research including project design and implementation, recruitment of participants, research methodologies and the dissemination and translation of findings. Across the 5-year life of the project, the group will have opportunities to engage directly in all research activities of interest to them, while being supported by the research team to build their skills and capacity in research, advocacy and leadership. Importantly, all members of the group are remunerated for their time, knowledge and input, equal to that of other advisory members and stakeholders.

Because of travel restrictions imposed during the coronavirus disease 2019 pandemic, a notable change to our plans has been the need to engage

the governance group online. This has associated challenges, particularly regarding the development and maintenance of trusting relationships, and the bias of engaging only young people with access to specific technologies. However, the move to digital engagement brings advantages with respect to cost and young people's time (and the need to not travel). Our first meeting (September 2021) over three evenings was highly successful in building relationships (between the governance group and members of the research team) and providing opportunities for the group to advise on the overall project design.

Second, we have committed to capacity exchange. Through the governance process, members will have opportunities to engage with a broad range of research constructs and methods. Additionally, members will have access to a scholarship fund for their own self-identified capacity development needs and interests. We will work with young people in partner communities to build their capacity for effective advocacy and action, while also seeking to develop the capability and capacity of researchers and stakeholders (adult partners) to work effectively with young people. We will engage with a range of key stakeholders nationally, including representatives from youth advocacy groups and organisations, health services, the Aboriginal Community Controlled Health Organisation sector, and policymakers. This will bring a focus to redressing traditional power dynamics and ensure that engagement goes beyond tokenism.

Third, we seek to prioritise evidence, extending beyond that available in the peer-reviewed literature. Through our planned consultations with young people across the nation, we will generate contemporary evidence on needs that inform the investments required to strengthen and support Indigenous adolescent health and wellbeing. We will engage with Indigenous expertise globally (including youth advocates and researchers), drawing on our established network of Indigenous adolescent health experts across Aotearoa New Zealand, Canada, the United States (including Hawaii), and the Circumpolar region. We will also seek

### Establishing the youth governance group

- Acknowledging the diversity of Indigenous young people, the recruitment process was broad in scope. An expression of interest was developed by younger members of the research team (to ensure language was engaging and comprehensible) and circulated through the extensive professional and community networks of the investigator team, including social media posts. We asked applicants basic demographic questions, and about their previous study and work experience, their engagement with Indigenous communities, and why they wanted to be involved in the governance group. Applicants could provide their application in written, video or verbal format. This application process was designed to identify applicants who were motivated, but also to help identify members with diverse experience.
- From the expressions of interest, potential members were shortlisted by two Indigenous researchers, both with experience in adolescent health and community engagement. Shortlisted candidates were offered a phone or video interview. These two team members then reviewed those interviewed to invite members with different community, educational, professional and life experience.
- Membership of the governance group at the time of this publication stands at 16 representing every state and territory. Recruitment is ongoing for two representatives from the Torres Strait. Acknowledging and respecting leadership structures within Indigenous communities, consultations are also underway with Elders who will join as cultural guides and mentors of the group. Since formation, the group has met multiple times virtually over videoconference; during these meetings we have invested effort and time to build rapport and to create a safe place for all to contribute as they would like to. We plan to meet four times per year across the life of the project and in person when possible to do so. Governance group members are financially reimbursed for their time. They additionally have access to a professional development fund. Members recruited for this governance group will remain engaged for the duration of this project if they wish, regardless of their age.
- In order to learn, and improve, how to best engage young people in a governance role, we will evaluate our approach. We will use a developmental evaluation approach which is well suited to the evaluation of emerging programs or initiatives. The evaluation framework will explore constructs (roles, power, gender), processes (who, what, how, when and where), what is working (or not working), and impacts (positive/negative) on young people, the researchers and the research project, and will look at how youth engagement and governance could be improved. We will also explore innovations and adaptations required to strengthen and enhance the engagement process.

input from specific content experts globally, identified through our established networks including the *Lancet* commission on adolescent health and wellbeing.<sup>12</sup>

Fourth, we will bring a focus to the translation of the roadmap to effective policy and action. Dissemination products will be co-designed with the governance group but are likely to include academic papers, reports, policy briefs, website posts, and social media messaging/infographics. Building on and fostering the networks and expertise of the governance group and research team, we will identify, engage and strengthen relationships with key national and jurisdictional stakeholders and partners (including health, education and social services as well as community/youth ambassadors), building the platform for the sustainable translation and implementation of the roadmap's resources, findings, recommendations and actions. Indeed, our conversations to date are already helping to bridge the chasm that often exists between service providers and Indigenous youth, facilitating opportunities for strengthened services and responses in the immediate term.

Finally, we seek to evaluate our approach to youth governance not only to improve our own processes, but also to inform meaningful approaches to future youth engagement. This project will result in a deep understanding of how to move from simple engagement and participation to real governance and agency. The strong emphasis on self-determination and capacity development is central to ensuring a network of upskilled and engaged young people, which is essential to implementation of the roadmap but will also support young people to realise their full potential.

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