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. One-third of the Aboriginal and Torres Strait Islander (Indigenous) population in Australia are adolescents, and our earlier work has shown that Indigenous adolescents have distinct health needs largely unmet by existing policies and services. 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. As a result, investments to date have been limited, reactive and fragmented. Efforts have been siloed around health issues including sexually transmitted infections, social and emotional wellbeing, youth suicide, rheumatic heart disease, and risk behaviours including substance misuse. 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. 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.

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, 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, and now is the time to move beyond responses based on good intentions to informed needs driven action and change.

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.

The concept of youth participation is not new, and there has been great variation in how young people have been engaged in research, policy and practice. 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.

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. 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. 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” was identified as a limiting factor to successful partnerships between young people and researchers. Much more must be done to overcome this failing.
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). 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
input from specific content experts globally, identified through our established networks including the Lancet commission on adolescent health and wellbeing.1

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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1 Azopardi P, Blow N, Purcell T, et al. The health of first Nations adolescents as the foundation to health equity. Med J Aust 2020; 212: 202-204. https://www.mja.com.au/journal/2020/212/5/investing-health-aboriginal-and-torres-strait-islander-adolescents-foundation
2 Australian Institute of Health and Welfare. Aboriginal and Torres Strait Islander adolescent health and youth health and wellbeing. Canberra: AIHW, 2018. https://www.aihw.gov.au/getmedia/b4014966-d133-4f16-a6e6-5a59e17b8488/aihw-ihw-202.pdf.aspx?inline=true (viewed Sept 2021).
3 Azopardi PS, Sawyer SM, Carlin JB, et al. Health and wellbeing of Indigenous adolescents in Australia: a systematic synthesis of population data. Lancet 2018; 391: 766-782.
4 Australian Government Department of Education, Skills and Employment. Australia’s Youth Policy Framework. Canberra: DESE, 2021. https://www.dese.gov.au/australias-youth-policy-framework/resources/australias-youth-policy-framework (viewed Sept 2021).
5 Australian Government Department of Education, Skills and Employment. Youth Taskforce interim report. Canberra: DESE, 2020. https://www.dese.gov.au/national-youth-policy-framework/resources/youth-taskforce-interim-report (viewed Sept 2021).
6 Australian Government Department of Health. Fifth National Aboriginal and Torres Strait Islander Blood Borne Virus and Sexually Transmissible Infections Strategy. Canberra: Commonwealth of Australia, 2018. https://www1.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-1/file/ATSI-Fifth-Nat-Strategy-2018-22.pdf (viewed Sept 2021).
7 Haswell M, Blignault I, Fitzpatrick S, Jackson Pulver L. The social and emotional wellbeing of Indigenous youth: reviewing and extending the evidence and examining its implications for policy and practice. Sydney: Muru Marri, UNSW Sydney, 2013. https://researchdirect.westernsydney.edu.au/islandora/object/uws:33498 (viewed Sept 2021).
8 The Elders’ report into preventing Indigenous self-harm and youth suicide. People Culture Environment, 2016. https://apo.org.au/sites/default/files/resource-files/2014-04-apo-nid40060.pdf (viewed Sept 2021).
9 Australian Institute of Health and Welfare. Acute rheumatic fever and rheumatic heart disease in Australia, 2016-2020. Last updated: 13 April 2022. https://www.aihw.gov.au/reports/indigenous-australians/rheumatic-heart-disease-in-australia-2016-2020/summary (viewed April 2022).
10 Australian Government. National Aboriginal and Torres Strait Islander Health Plan 2013–2023. Canberra: Commonwealth of Australia, 2013. https://www.health.gov.au/sites/default/files/documents/2021/02/national-aboriginal-and-torres-strait-islander-health-plan-2013-2023.pdf (viewed Sept 2021).
11 Azopardi P, Hijazi Z, Wulan N, et al. Bringing a wider lens to adolescent mental health: aligning measurement frameworks with multisectoral actions. J Adolesc Health 2021; doi:10.1016/j.jadohealth.2021.03.021 (online ahead of print).
12 Patton GC, Sawyer SM, Santelli JS, et al. Our future: a Lancet commission on adolescent health and wellbeing. Lancet 2016; 387: 2423-2478.
13 Taylor HR, Boudville AI, Anjou MD. The roadmap to close the gap for vision. Med J Aust 2012; 197: 613-615. https://www.mja.com.au/journal/2012/197/1/roadmap-close-gap-vision.
14 de la Barra SL, Redman S, Eades S. Health research policy: a case study of policy change in Aboriginal and Torres Strait Islander health research. Aust New Zealand Health Policy 2009; 6: 2.
15 Leon de la Barra S, Redman S, et al. A decade of NHMRC People Support expenditure in review: is support for Indigenous health research increasing? Med J Aust 2009; 190: 28-31. https://www.mja.com.au/journal/2009/190/1/decade-nhmrc-people-support-expenditure-review-support-indigenous-health.
16 Azopardi PS, Kennedy EC, Patton GC, et al. The quality of health research for young Indigenous Australians: a systematic review. Med J Aust 2013; 199: 57-63. https://www.mja.com.au/journal/2013/199/1/quality-health-research-young-indigenous-australians-systematic-review.
17 Paul CL, Sunson-Fisher R, Stewart J, Anderson AE. Being sorry is not enough: the sorry state of the evidence base for improving the health of Indigenous populations. Am J Prev Med 2010; 38: 566-568.
18 National Commission on Resources for Youth. Youth participation: a concept paper. a report of the National Commission on Resources for Youth to the Department of Health, Education and Welfare. New York: Office of Youth Development, 1975.
19 Wong NT, Zimmerman MA, Parker EA. A typology of youth participation and empowerment for child and adolescent health promotion. Am J Community Psychol 2010; 46: 100-114.
20 Sellars E, Pavarini G, Michelson D, et al. Young people’s advisory groups in health research: scoping review and mapping of practices. Arch Dis Childhood 2021; 106: 698.
21 Das S, Davenberger L, Diesendruck L, et al. An inquiry into involving young people in health research: executive summary. London: Wellcome, 2020. https://wellcome.org/sites/default/files/an-inquiry-into-involving-young-people-in-health-research-executive-summary.pdf (viewed Sept 2021).