

# Participatory systems modelling to inform improvements in the social and emotional wellbeing of young Aboriginal and Torres Strait Islander people in Australia



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Aboriginal and Torres Strait Islander peoples have sophisticated knowledge systems that have allowed individuals, families and communities to thrive, in harmony with land, sea and waterways, for tens of thousands of years.<sup>1</sup> They developed complex interrelated social systems that supported all individuals to understand themselves as integrated and valued members of a network of more than 400 communities across what is now called Australia. This changed irrevocably more than 200 years ago, when Britain invaded Australia.

The present commentary proposes that Systems Dynamic Modelling (SDM) has a unique value as a potential method to address the social and emotional wellbeing (SEWB) impacts that continue to be deeply felt by all Aboriginal and Torres Strait Islander peoples today, including as a consequence of discriminatory and racist systems and policies in health, employment, housing, education and justice sectors. We suggest that developing an SDM with an Indigenous community, which to our knowledge has never previously been attempted, will align especially well with the holistic concept of SEWB because SDM: supports the integration of diverse information sources and knowledge types; incorporates social determinants that disproportionately affect Aboriginal and Torres Strait Islander people; focuses on community rather than individual outcomes; and has the flexibility to evolve in response to emerging priorities.

Aboriginal and Torres Strait Islander young people experience high levels of psychological distress.<sup>2</sup> According to the National Aboriginal and Torres Strait Islander Health Survey in Australia, 29.7% of Aboriginal

and Torres Strait Islander people in Australia aged 18–24 years experienced high to very high levels of distress in 2018.<sup>3</sup> A 2019 survey of 1500 Aboriginal and Torres Strait Islander young people aged between 15 and 19 years found that 31.7% reported stress and 29% reported a long-term mental health condition.<sup>4</sup> These issues are further exacerbated by poorly funded<sup>5,6</sup> mental health and social services systems which are not always culturally equipped to support Aboriginal and Torres Strait Islander peoples.

Existing research has not always been successful in capturing the diversity of Aboriginal and Torres Strait Islander communities and their experiences of distress<sup>7</sup> or in acknowledging the on-going impacts of post-colonial oppression and racism. Research driven by the interest of non-Indigenous researchers, rather than the priorities of community, is another form of racism, perpetuating the exploitative history of colonisation<sup>8</sup> and leaving communities to face impacts arising from cross-cultural insensitivity. Also, there have been important concerns about data sovereignty; the fundamental human right for Aboriginal and Torres Strait Islander peoples to own their stories, communicate their lived experience expertise, truth and history. The long history of exclusion and misuse of data has led to an awareness among Aboriginal and Torres Strait Islander people of the potential for further exploitation and misrepresentation by external researchers.<sup>9</sup>

SDM is a potential method to overcome these research challenges while improving the SEWB of young Aboriginal and Torres Strait Islander people in Australia. SDM is a robust quantitative method which combines research, expert and local knowledge and experience, and primary and secondary data to develop an interactive decision support tool (“the model”) that simulates real life dynamic systems.<sup>10</sup> SDM has been used across diverse sectors and was essential during the COVID-19 pandemic to support public health decisions.<sup>11</sup> It has also been applied in the field of mental health<sup>11</sup> to allow decision makers and

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community members to explore and analyse system behaviour over time<sup>10</sup> and identify how diverse programmes or initiatives, social determinants, their different combinations and their implementation costs may affect youth mental health outcomes before implementing them in the real world.<sup>10</sup>

The *Right care, first time, where you live* program aims to support the mental health of young people and prevent suicide, through the development of eight SDMs across eight regions in Australia. Each model is the product of direct community engagement and will belong to the community with which it is co-created. For details on the program's methodology and rigorous site selection process please refer to Freebairn et al.<sup>12</sup> Amongst these SDMs, the program will develop an Indigenous-specific SDM for mental health and SEWB.

SDM is especially suitable for Indigenous communities because it uses aggregate level modelling and data and therefore provides a broader, community-based overview. This is particularly compatible with the concept of SEWB, in which the wellbeing of individuals is inseparable from the wellbeing of families, kinship groups and communities as a whole, and the effects of distress are experienced collectively.<sup>13</sup> The inclusive, community-led methodology used within SDM development is also compatible with Indigenous Standpoint Theory, which centres the social, historical and political perspectives of Aboriginal and Torres Strait Islander people, including their experiences of discrimination and racism. Further, it brings the community together to iteratively create the local SDM model and ensure it is fit for purpose. This supports an Aboriginal Participatory Action Research (APAR) approach, in which Indigenous participants maintain authority over the interpretation of the data and information they share, restoring Indigenous ways of knowing, being and doing,<sup>12,14</sup> and strengthening self-determination within communities. APAR is an interactive, reflective, dialogical method which encourages transparency. Its main elements can be found in Dudgeon et al.<sup>14</sup>

In the proposed Indigenous-specific SDM, modelling of the current support system and descriptions of future programs and initiatives that could improve SEWB, as well as the desired outcomes, will be derived from community members' inputs across multiple workshops. Additionally, it is anticipated that the inclusion of Elders, community members and young people with lived experience at all stages of the process (alongside academics, clinicians and service organisations) will encourage community ownership of the model and ensure its sustainability.<sup>15</sup>

Development of Indigenous-specific SDMs also aligns with the World Health Organisation's (WHO) recent recommendation that Member States strengthen their primary health care systems through 'rights-based participatory approaches' which harness the expertise of people with lived experience.<sup>16</sup> The WHO asserts that

lived experience expertise should be recognised as equal to established forms of evidence and data.<sup>16</sup> Further, an Indigenous-specific SDM is aligned with the principle of self-determination.

The *Right care, first time, where you live* program team, guided by Indigenous researchers and advisers, will adopt additional considerations in developing an Indigenous-specific SDM. First, it will be essential to extend the mainstream understanding of 'mental health' to incorporate the much broader concept of SEWB, with implications for the iterative development process. For a more in-depth explanation on SEWB and its components please refer to Gee et al.<sup>13</sup>

Researchers must also adopt a strengths-based approach<sup>17,18</sup> which means reframing the discourse to emphasise the community's strengths and capacities, rather than its deficits. In other words, instead of focusing on 'risk behaviours', 'problems' and 'gaps', the SDM will acknowledge and showcase the existing strengths within the community and how these can be used to improve the SEWB of young Aboriginal and Torres Strait Islander people.<sup>15,17</sup> These strengths may include local, community-based services, programs or informal supports that build resilience, demonstrating the potential for SDM to amplify the voices and priorities of Indigenous communities.

When developing an Indigenous SDM, it will be essential to use relevant indicators of SEWB within the community. Therefore, the model may consider the community's cultural drivers of SEWB as well as other emerging factors, for example, the environment and climate change-related extreme weather events and how these may impact the community's connection to land and water, cultural obligations to Country, and livelihoods.<sup>19</sup>

The *Right care, first time, where you live* program team looks forward to developing a youth-focused SDM to promote wellbeing and prevent suicide with an Indigenous community in Australia, and to sharing experiences of its implementation and outcomes in due course.

## Contributors

OI TH and JR wrote the initial draft of the paper and PD provided conceptualisation and cultural oversight. All authors contributed to literature review, and reviewed and edited the manuscript.

## Declaration of interests

JR serves as a member of the Research Advisory Committee, Suicide Prevention Australia and is a consultant, paid a daily rate, at Centre of Best Practice in Aboriginal and Torres Strait Islander Suicide Prevention at the University of Western Australia. In addition to working at the Brain and Mind Centre, JO is also the Managing Director of Computer Simulation & Advanced Research Technologies (CSART) and acts as Advisor to the OECD Neuroscience-inspired Policy Initiative and the Brain Capital Alliance. She receives no salary support for these positions. JO received support for travel related to CSART activities aimed at building capacity in systems modelling & simulation. IBH has received funding from the NMHRC for the following projects: Centre for Research Excellence for reducing suicidal thoughts and behaviours in young people presented for health care (2020–2025). APP ID:

APP1171910. Optimising Personalised Care, at scale, for Young People with Emerging Mood Disorders (2018–2022) APP1136259 & Right care, first time: delivering technology-enabled mental health care to young people at scale (2023–2027). APP 2016346. He also serves on the Advisory Board for Janssen Cilag for the purpose of gaining an understanding of the interpretation and clinical evaluation of esketamine for the treatment of TRD and also presents and chairs online webinars and educational events for this organisation. He is a member of Mental Health Reform Advisory Committee (2023–2024) at the Department of Health and Member of the Clinical Advisory Group for the evaluation of the Better Access to Psychiatrists, Psychologists and General Practitioners through the Medicare Benefits Schedule (MBS) initiative (ended 2022). He is a Chief Scientific Advisor to, and a 3.2% equity shareholder in, InnoWell Pty Ltd which aims to transform mental health services through the use of innovative technologies.

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Institutional Review Board Statement: This study has been approved by the Sydney Local Health District Human Research Ethics Committee (Protocol No X21-0151 & 2021/ETH00553) and by the Aboriginal Health & Medical Research Council of NSW (1875/21). The described evaluation study has also been approved by and reflects the inclusion, lived priorities and expertise of our Aboriginal and Torres Strait Islander partners, who are also authors of this paper (J.T., T.H., A.B. and P.D.).

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