

Doing “deadly” community-based research during COVID-19: the Which Way? study

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An Indigenous-led study aims to empower and support Aboriginal and Torres Strait Islander women to be smoke-free



Nothing about us without us

Aboriginal and Torres Strait Islander people have long advocated for a voice on issues that involve them. Aboriginal Community Controlled Health Services are recognised as playing a critical role in mitigating and addressing social and structural determinants of health.¹ The *Close the Gap campaign report 2022* made recommendations to governments to improve health outcomes, including structural reform, innovation driven by cultural intellect and cultural safety, and empowering communities.² Real change requires our voice, our rights to sovereignty, self-determination and agency to transform health systems and beyond, including acknowledging, addressing and mitigating coloniality and systemic racism.

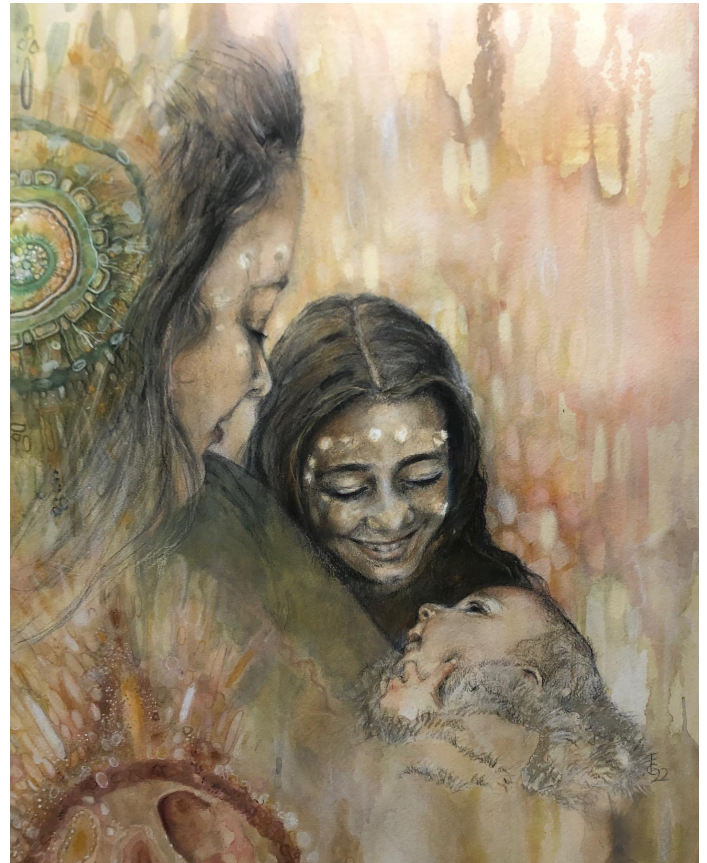


Research has held a poor reputation among Indigenous peoples, commonly being undertaken “on us” and not “with us”.³ However, Indigenous peoples have led meaningful and high quality research since the beginning of time, which is evidenced by our continued existence in spite of colonisation, and across academic disciplines and fields of expertise. Researchers and institutions are beginning to recognise that Aboriginal and Torres Strait Islander peoples and communities are the knowledge holders and have the right to lead research and policy reform.

It was through an acknowledgement of Aboriginal and Torres Strait Islander wisdom and leadership that the Which Way? study was born. “Deadly” is word commonly used by Aboriginal and Torres Strait Islander people to mean “good”;⁴ hence this editorial, written by two Aboriginal women, describes deadly research practice in our study. Before we describe the study, we must first offer our social and cultural positioning.

Our social and cultural positioning

Dr Michelle Kennedy is a Wiradjuri woman raised on unceded Worimi lands, social worker, mother of four, daughter, aunty, sister cousin, and National Health and Medical Research Council Early Career Research Fellow at the University of Newcastle.



Kith and kin: Felicity Cocuzzoli (Wiradjuri), 2021

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This information is critical to our approach to research. Who we are, where we come from, our cultural and community knowledge systems, inform the ways in which we see the world and how we approach research practice. The Which Way? study sought to address the national priority of smoking during pregnancy from an Indigenous standpoint, through a national survey of Aboriginal and Torres Strait Islander women of reproductive age. This research, conducted in partnership and co-ownership with Aboriginal communities in New South Wales found that 90% of Aboriginal and Torres Strait Islander women have tried to quit smoking and that quitting suddenly was associated with staying smoke-free.⁵ We also found that Aboriginal and Torres Strait Islander women are interested in a range of cessation support options.⁶ The supplement accompanying this issue of the *MJA* presents these findings,

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reporting the variances resulting from age, location and use of Aboriginal Health Services.

Our partnership approach: people vote with their feet

The Which Way? study upholds the rights for Aboriginal communities to be in control of the research. Community control “goes beyond either involvement or consultation and requires an acknowledgment that Aboriginal people have the right to make decisions about research affecting them”.⁷

The study was informed by Michelle Kennedy’s PhD research with Aboriginal and Torres Strait Islander women in New South Wales, South Australia and Queensland.⁸ We found that women were motivated to quit smoking and interested in non-pharmacological approaches to be smoke-free. Through knowledge translation activities conducted over 12 months at Aboriginal community events, tobacco control conferences, tobacco workplace forums, and the Indigenous Smoking in Pregnancy Round Table facilitated by the Australian Government Department of Health, Aboriginal Health Services began expressing interest in the study.

Partnership on this study meant that Koori ways of knowing, being and doing were at the forefront. Aboriginal Health Services are bombarded with research inquiries. However, this research came from within and was developed from the ground up, in partnership with communities.

We spent eight months before the COVID-19 lockdowns actively building respectful, reciprocal partnerships, seeking community-based approvals, and applying for human research ethics approvals. We sought to understand which smoking cessation approaches were of interest to Aboriginal and Torres Strait Islander women, initially proposed using yarning circles. However, the COVID-19 outbreak meant face-to-face engagement was not possible and community partners did not feel online yarning circles were feasible or acceptable for this study, or at this time. It was important to us to continue momentum and partners felt an online survey, informed by previous studies and community knowledges would be safe, meaningful and acceptable.

Best practice survey development: who holds the measuring stick holds the power

The Which Way? study, reported in the supplement accompanying this issue of the *MJA*, privileges community-led questions moving beyond quantifying risk factors. The legacy of deficit reporting has restricted our insight into how we can prioritise policy and practice reform. Walter and Anderson argue that “the social positioning of non-Indigenous ‘owners’ of data flows into their interpretation without conscious intent, but with substantive and often predictable outcomes”.⁹

Our research re-frames the research questions. We want to better understand how policymakers and health services can better meet the needs of Aboriginal and Torres Strait Islander women, not how our women can fit the health services that exist. Transformational change is required to appropriately meet the needs of Aboriginal and Torres Strait Islander women, including,

but not limited to, addressing smoking during pregnancy. We acknowledge that pregnancy is only a short but dynamic time our lives, and we should centre our focus on fostering smoke-free norms, including cessation supports among women of reproductive age.

This work is positioned with acknowledgement of the ongoing nature and impacts of colonisation in our country. Coloniality continues to affect our families and community through the dispossession of our lands and erosion of power, social structures and community resources, and embedding racism within the landscape; this directly and indirectly impacts nicotine and tobacco use among Aboriginal and Torres Strait Islander peoples. As Aboriginal women, researching ways to empower and support Aboriginal and Torres Strait Islander women to be smoke-free, we are inherently connected to this work and its outcomes. This work, the survey tool and the outcomes reported embody our sovereignty, self-determination and agency in tobacco control, supporting our communities and future generations to be tobacco-free.

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- 1 Pearson O, Schwartzkopff K, Dawson A, et al. Aboriginal community controlled health organisations address health equity through action on the social determinants of health of Aboriginal and Torres Strait Islander peoples in Australia. *BMC Public Health* 2020; 20: 1859.
- 2 Lowitja Institute. Close the Gap campaign report 2022 – Transforming power: voices for generational change. Lowitja Institute, 2022. <https://www.lowitja.org.au/page/services/resources/Cultural-and-social-determinants/culture-for-health-and-wellbeing/close-the-gap-campaign-report-2022---transforming-power-voices-for-generational-change> (viewed Jan 2022).
- 3 Smith LT. Decolonizing methodologies: research and Indigenous peoples. London: Zed Books, 1999.
- 4 Maddox R, Thurber KA, Calma T, et al. Deadly news: the downward trend continues in Aboriginal and Torres Strait Islander smoking 2004–2019. *Aust N Z J Public Health* 2020; 44: 449–450.
- 5 Kennedy M, Barrett E, Heris C, et al. Smoking and quitting characteristics of Aboriginal and Torres Strait Islander women of reproductive age: findings from the Which Way? study. *Med J Aust* 2022; 217: S6–S18.
- 6 Kennedy M, Heris C, Barrett E, et al. Smoking cessation support strategies of interest to Aboriginal and Torres Strait Islander women of reproductive age: findings from the Which Way? study. *Med J Aust* 2022; 217: S19–S26.
- 7 Aboriginal Health and Medical Research Council of NSW. AH&MRC ethical guidelines: key principles (2020) v2.0. <https://www.ahmrc.org.au/publication/ahmrc-guidelines-for-research-into-aboriginal-health-2020/> (viewed Jan 2022).
- 8 Bovill M. What ngidhi yinaaru nhal yayi (this woman told me) about smoking during pregnancy. *Med J Aust* 2020; 212: 358–359. <https://www.mja.com.au/journal/2020/212/8/what-ngidhi-yinaaru-nhal-yayi-woman-told-me-about-smoking-during-pregnancy>
- 9 Walter M, Andersen C. Indigenous statistics: a quantitative research methodology. New York: Routledge, 2013. ■