

# The National Indigenous Kidney Transplantation Taskforce: changing systems to achieve equitable access to kidney transplantation

Jaquelyne T Hughes<sup>1,2,\*</sup>, Katie Cundale<sup>3,4</sup> , Kelli J Owen<sup>3,5,†</sup>, Stephen P McDonald<sup>4,6</sup>

Aboriginal and Torres Strait Islander people with chronic kidney disease seek good health, good kidney health, and good experiences of health care at all stages of their kidney journeys.<sup>1-3</sup> Kidney replacement therapy is crucial for people with kidney failure, so needs to be accessed regularly, safely and sustainably alongside high quality cultural and clinical support. However, access to kidney transplantation, often the best kidney replacement therapy option, is not equally available to Aboriginal and Torres Strait Islander people in Australia.<sup>4</sup>

Racism — whether direct or indirect, institutional or personal — continues to impact the lives, wellbeing and health outcomes of Aboriginal and Torres Strait Islander people living in Australia.<sup>5</sup> This inherent racism plays out in part through the persistent and prolonged lack of access to transplantation experienced by many Aboriginal and Torres Strait Islander people with kidney disease — as well as through inequities in how people access dialysis, experience the impacts of the social determinants of health, and receive culturally (un)safe care.<sup>6</sup> Aboriginal and Torres Strait Islander people have told us time and again of their interest in the option of transplantation; consultations have also told us about people's desires to have dialysis on Country and to prevent young people from progressing to kidney failure.<sup>2-3,7</sup> Yet despite these express desires for change, there continue to be delays in referring Aboriginal and Torres Strait Islander patients for transplantation assessment, delays throughout the workup process, and continuous, often insurmountable barriers to reaching the waitlist, especially for older people and for those living in rural and remote areas.<sup>8-10</sup>

Up until 2018, distinct clusters of dedicated people worked hard to change the reality of kidney failure for Aboriginal and Torres Strait Islander people, yet little coordinated or national action had occurred within our health system to improve differential access to kidney transplantation or address the racism inherent within kidney services. The formation of the National Indigenous Kidney Transplantation Taskforce (NIKTT) — including a secretariat guided by the leadership of a Torres Strait woman (also a nephrologist) and a Kurna, Narungga and Ngarrindjeri woman (also a kidney transplant recipient) — was a pivotal step in changing Australian transplantation access.

As clinicians, researchers, policy makers, and health experts, we must all be drivers for change in how care is delivered so that it best serves the health gains of Aboriginal and Torres Strait Islander people. Racism, identity, culture, language and beliefs cannot be disregarded in deference to non-Indigenous models

of health and care. Aboriginal and Torres Strait Islander people must be given support to exercise their rights to sovereignty, through leadership, workforce, and community involvement, to enable effective design and delivery of kidney services.

The supplement that accompanies this issue of the *MJA* begins with an overview of the NIKTT, explaining how creating such a dedicated group of people — focused on transplantation — was an essential step in progressing transplantation equity in Australia.<sup>11</sup> Cundale and colleagues then explore which features of pilot initiatives help (and hinder) access to the kidney transplant waitlist, highlighting the need for an increased Aboriginal and Torres Strait Islander kidney health workforce, specific service delivery changes, and context-specific educational resource development.<sup>12</sup> Hughes and colleagues provide commentary on a review of cultural bias initiatives to elucidate what can, and should, be done to ensure kidney services are providing equitable care.<sup>13</sup> Owen and colleagues discuss the intricacies of creating Indigenous reference groups in transplantation units, and showcase what it takes to build an effective change-enabling structure to improve the delivery of culturally safe care.<sup>14</sup> Finally, Hughes and colleagues outline what it will take to maintain change in transplantation equity, summarising the NIKTT recommendations and outlining the key principles for next steps in continuing to improve access to transplantation for Aboriginal and Torres Strait Islander people.<sup>15</sup>

While this work showcases what is possible to change inequity, we acknowledge the need for continued research and dedicated effort throughout all aspects of kidney health services and culturally safe care delivery in general. Much remains to be done to improve critical elements of kidney journeys, such as post-transplant outcomes, donation rates, and live donor pathways. Nevertheless, the NIKTT has established a foundation. The challenge for all of us is to build upon this if we are to succeed in achieving equity in access to kidney transplantation.

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\*Wagadagam tribe, Mabuyag Island

†Kurna, Narungga, and Ngarrindjeri

<sup>1</sup>Rural and Remote Health, Flinders University, Darwin, NT. <sup>2</sup>Royal Darwin Hospital, Darwin, NT. <sup>3</sup>National Indigenous Kidney Transplantation Taskforce (NIKTT), South Australian Health and Medical Research Institute, Adelaide, SA. <sup>4</sup>Adelaide Medical School, University of Adelaide, Adelaide, SA. <sup>5</sup>Central and Northern Adelaide Renal and Transplantation, Royal Adelaide Hospital, Adelaide, SA. <sup>6</sup>Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), South Australian Health and Medical Research Institute, Adelaide, SA. ✉ [katie@anzdata.org.au](mailto:katie@anzdata.org.au) • doi: 10.5694/mja2.52107

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