

NIKTT Secretariat

June Communiqué

Thursday, 27 June 2024

Subject: NIKTT Update

Dear Community, Colleagues, and Partners,

The National Indigenous Kidney Transplantation Taskforce (NIKTT) Secretariat hopes this update finds you well. We are excited to re-engage with the transplantation and kidney health community more actively after a period of downtime and transition.

The NIKTT initially presented its recommendations to the Commonwealth's Jurisdictional Organ Tissue Steering Committee and then completed its original funded activities in early 2023. These included the enhanced data collection project, the cultural bias report, and the Equity and Access Projects. Findings from these activities were detailed in our <u>Final Report</u> and in a <u>Medical Journal of Australia</u> Supplement.

The NIKTT Secretariat (Jaqui Hughes, Stephen McDonald, Kelli Owen, Matilda D'Antoine, and Katie Cundale) met with Assistant Ministers McCarthy and Kearney in March 2023 to present the Taskforce's recommendations on how to improve access to kidney transplantations for Aboriginal and Torres Strait Islander people in Australia.

As a result of this meeting, as well as advocacy to State and Territory Health and Indigenous Affairs Ministers, the Secretariat began working with the First Nations Health Division of the Department of Health and Aged Care to secure funding to continue the work of the NIKTT and aid implementation of the recommendations.

Funding for a 'bridging year' was secured in early 2024 to continue Secretariat functions until a more sustainable process of funding is determined. The Secretariat continues to work with the Department to explore avenues for funding. The work we are undertaking during this bridging year is <a href="https://decaptor.org/decaptor

We are eager to re-engage our kidney Community and everyone who supports, empowers, and works with Aboriginal and Torres Strait Islander people with kidney disease and transplantation. The successes achieved over the past three years would not have been possible without the incredible network of patients, families, clinicians, carers, advocates, researchers, and professionals with whom we work.

We thank you all for your collaboration and commitment, and appreciate your patience as we begin to revitalise this movement towards transplantation equity.

As we plan for the next few years of this work, we would like to hear from you and your Community or team about what you are doing. We are eager to coordinate the work happening around the country and share successes, lessons, best practices, new ideas, or general news.



We would also like to ensure Kelli is in touch with your Community, unit, or region in her efforts to establish and support Indigenous Reference Groups (IRGs) and collect feedback on plans for the future -- please email Kelli with any updates or questions around this: kelli@anzdata.org.au.

We are committed to consistent communication and updates moving forward. To facilitate this, please let us know:

- How you would like to be engaged (e.g. regular updates, meetings, collaborations)
- If you would like to be updated on Secretariat work each month, please sign up to our Communiqué newsletter <u>here</u>.
- If you would like to get in touch with the Secretariat to discuss this work or related business, please email niktt@anzdata.org.au.
- Please email <u>kelli@anzdata.org.au</u> or <u>katie@anzdata.org.au</u> if you would like to share your work, project, or news with us and the network.

We are always available through the Secretariat email for any queries, input, or collaboration opportunities. You can email <a href="mailto:niktt@anzdata.org.au">niktt@anzdata.org.au</a> or <a href="mailto:katie@anzdata.org.au">katie@anzdata.org.au</a>.

Thank you for your ongoing support. We look forward to reconnecting.

Regards,

The NIKTT Secretariat

## **Summary of Completed Activities:**

- 1. The NIKTT completed its original funding agreement activities, submitting a comprehensive final report with recommendations to the Department of Health and Aged Care in 2023.
  - Final Report: https://www.niktt.com.au/finalreport
- 2. The findings and recommendations from the original Taskforce were published in a supplement to the Medical Journal of Australia, providing an evidence-based roadmap for achieving equity.
  - MJA Supplement: https://www.niktt.com.au/supplement
- 3. The NIKTT submitted written input to the public consultation on the Department of Health's draft National Strategy for Organ Donation, Retrieval and Transplantation and attended a number of workshops with the committee organising the development of the Strategy. The Secretariat continues to work with the Joint Organ and Tissue Steering Committee to progress development and implementation of the Strategy.
  - NIKTT input into draft National Strategy for Organ Donation, Retrieval and Transplantation



## Summary of Current Activities:

- 1. Supporting and establishing Indigenous Reference Groups at transplant units
- 2. Creating a data dashboard to track equity metrics
- 3. Hosting a second national Gathering (tentatively in Adelaide, February 2025)
- 4. Developing a plan for a national network of Aboriginal and Torres Strait Islander people affected by kidney disease