



ANZDATA Aboriginal and Torres Strait Islander Health Working Group: 2020 Summary

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In 2020 the working group continued with membership of A/Prof Jaqui Hughes (convenor), Adjunct A/Prof Donisha Duff (deputy convenor) and Dr Mark Tiong. We hosted working group meetings in February, May, August and November, to review our work, and inform feedback to the ANZDATA Advisory Committee meetings. A/Prof Hughes attended all 2020 Advisory Committee meetings.

ANZDATA is a data custodian for a tremendous amount of data for people in Australia and New Zealand. The major 2020 activity of the ANZDATA Aboriginal and Torres Strait Islander Health Working Group related to operationalising processes for Indigenous Data Governance and Sovereignty of data. ANZDATA processes we focussed on included identifying data access requests specific for Aboriginal and Torres Strait Islander peoples, considering a Working Group Terms of Reference for the ANZDATA Aboriginal and Torres Strait Islander Health Working Group, and recognising the importance of sovereignty of data - including patients' right to be involved in the development of their own data. ANZDATA formally responded to and endorsed these activities in a letter dated 3rd November 2020 (<https://www.anzdata.org.au/anzdata/about/working-groups/aboriginal-and-torres-strait-islander-health-working-group/>).

In the last 12 months, our working group has been working on improving the time to develop and publish the infographic describing "Treatment of Kidney Failure for Aboriginal and Torres Strait Islander Peoples of Australia". Since June 2019, we produced the corresponding infographic for the 2017, 2018 and 2019 datasets. Dr Tiong will be presenting a paper (<https://www.anzsnasm.com/11025>) at the Australia and New Zealand Society of Nephrology Annual Scientific Meeting describing how this was achieved, and how ANZDATA will sustain this timely distribution of data. This year we have been supporting the accessibility of the infographic; it was included in the list of patient information sheets publicly available from ANZDATA Registry website (<https://www.anzdata.org.au/anzdata/resources/for-patients/infographic-statistics>) and circulated to all contributing Renal Units for distribution and use. Although in progress, Dr Hughes has worked with Northern Territory Aboriginal Interpreter Services to include translation of the 2018 infographic into Top-End Indigenous languages.

Other matters we proposed to ANZDATA, and await advice include:

Opportunity for ANZDATA to support Close the Gap – we see this as an important health-equity issue for Aboriginal and Torres Strait Islander peoples

ANZDATA Executive to consider linkages to leaders in Aboriginal Health Policy, to support and advocate for kidney health of Australians.

Opportunities for 2021

In line with terms of appointments, ANZDATA Aboriginal and Torres Strait Islander Health Working Group will be seeking new members and a new convenor in 2021. ANZDATA thanks retiring members- Adjunct Associate Professor Donisha Duff for her role as member (2015- 2020) and Deputy Convenor (2019-2020), and Associate Professor Jaquelyne Hughes for her role as a general member (2010-2020), and convenor (2015-2020).