

Assoc Prof J Hughes

Convenor, Aboriginal and Torres Strait Islander Health Working Group

C/- Menzies School of Health Research, Darwin

3<sup>rd</sup> November 2020

Dear Jaqui,

**Re: ANZDATA Advisory Committee Endorsement of recent work conducted by the Aboriginal and Torres Strait Islander Working Group.**

In response to your request, we write to confirm the ANZDATA Advisory Committee's **support** of the work put forward by you as the Convenor of the Aboriginal and Torres Strait Islander Health Working Group which incorporates input from patient data contributors, Indigenous patient reference groups and the work associated with Catching some Air.

The efforts of the Working Group have been a key factor in informing the direction of ANZDATA around collection and analysis of data around dialysis and kidney transplantation among Aboriginal and Torres Strait Islander Australians.

These include

- Revised policies and processes for data requests governing access to data, specifically as it relates to Aboriginal and Torres Strait Islander people's data.
- Partnering with patient groups and subsequent groundwork in establishing a patient reference group to assist data requestors to seek expert input from Aboriginal and Torres Strait Islander patient data contributors for data requests seeking to develop data involving Aboriginal and Torres Strait Islander peoples data.
- Specific terms of reference for the Aboriginal and Torres Strait Islander Health Working Group to support work that needs to be conducted in improving health outcomes

The net effect of these changes we anticipate will be to respect the recommendations made by the Catching some Air project around Indigenous data governance, incorporate the "patient voice" in how data is used, and in the longer term build awareness and capacity in utilising ANZDATA data in this area.

We acknowledge, this letter may be circulated to the wider community, Aboriginal and Torres Strait Islander Health Working Group, New Zealand Working Group and all relevant parties.

Kind regards,



Professor Stephen McDonald

ANZDATA Executive Officer



Professor Alan Cass

Chair of ANZDATA Advisory Committee