

ANZDATA ADVISORY COMMITTEE MEETING: Videoconference



Meeting of the ANZDATA Advisory Committee (AAC) of the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) held by videoconference at **12:00-1:00 PM (ACDT) on 5th March 2025.**

Members Present:

Nicholas Gray (NG) Chair
Sradha Kotwal (SK) Deputy Chair
Stephen McDonald (SPM)
Kylie Hurst (KH)
Georgina Irish (GI)
Revathy Manickavasagar (RM)
Shilpa Jesudason (SJ)
Hugh McCarthy (HM)
Rachael Morton (RM)
Kate Richards (KR)

Mel Wyld (MW)
Samantha Bateman (SB)
Jenny Chen (JC)
Matthew Roberts (MR)
Josephine Chow (JCh)
Michael Garrett (MG)
Helen Eddington (HE)
Breonna Robson (BR)
Dana Forcey (DF)

Apologies:

Bill Mulley
Terry Jennings
Jacqueline Soraru
Phil Clayton

Absent:

Rathika Krishnasamy

Minute Taker:

Thais Turibio (TT)

Minutes:

Item	Matter	Action
1.	Acknowledgment, welcome, present and apologies	
1.1	Acknowledgment of Country NG (Chair) acknowledged the traditional custodians of the lands and their culture and heritage.	
1.2	Māori Welcome HE spoke to the Maori welcome and opening karakia	
1.3	Welcome, present and apologies A quorum was met, and NG WELCOMED committee members. Apologies and absences were NOTED .	
1.4	AAC Committee membership and ToR: ToR updates for alternating annual long meetings between virtual and in-person, as well as adding two consumer representatives to attend the longer meetings once a year were ACCEPTED .	
2.	Business Arising from Previous Meeting	
2.1	Minutes of the previous meeting - Minutes of the AAC meeting held on 20th November 2024 circulated prior to the meeting. - Members ACCEPTED minutes as an accurate record of the event with no redactions for website publishing.	
2.2	Outstanding Action Items	
240901/01	SPM to report back on the outcomes of discussions with the National Renal Strategy Group.	Pending
241120/01	ANZDATA to finalize the details to implement the changes and follow up with the TX WG to ensure the final definitions are clear.	Complete
241120/02	ANZDATA to provide feedback on Return to Country request and ask for a complete request form for proposed data collection.	Complete
2.3	New Variable Change Request	
KH PROVIDED an update on the status of currently active variable change requests: - The PD infection variable is being expanded to include tunnel infections, based on feedback from the PD working group. - The transplant serum creatinine variable is now in development, with specifications approved. However, there is still some discussion around the implementation, specifically around using annual census date vs anniversary date for the data collection. - The request to add community of origin and a specific question on Indigenous status is still pending feedback from Paul Lawton and waiting on details on how this would be implemented across pilot return to country sites.		
3.	Report from Executive	
3.1	Organisation, operational and ongoing Developments	
GI PROVIDED an update on the Executive Report: Eric Au has finished his role as the ANZSN-ANZDATA epidemiology fellow, and Dana Forcey (DF) has started in this position.		Nil

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	- DF has been focused on the ANZDATA training projects, with an EOI currently open to support five trainee projects and has also been working on the head of unit capacity report, which will be presented by NG at the upcoming DNT meeting. - There is also a nursing unit manager capacity survey open currently, which will inform dialysis chair numbers going forward. - ANZDATA is looking to formalize and solidify the governance structure for the broader ANZDATA registries group. - KH ANNOUNCED that she will be finishing up in her position as General Manager at the end of the current funding agreement, after 14 years of service. ANZDATA will be undertaking a review of the role and advertising for a replacement.	
4.	Working Groups	
4.1	WG Updates	
	Members NOTED updates from: <u>PROMs Working Group by RM:</u> - Granted funding to develop PROMs modules for the Registry, involving a Delphi process to identify which PROMs should be included. - The goal is to allow patients to securely log in and complete the PROMs online, which will be integrated with the website redevelopment. - There are plans for a pilot implementation in 5-6 units. <u>Aboriginal and Torres Strait Islander Health Working Group by SB:</u> - The First Nations infographic has reached the end of its copyright agreement. - EOI to form a consumer working group to provide input on the infographic content and design was announced at the NIKTT Gathering. <u>PD Working Group by JC:</u> - A plan to submit a new variable proposal to expand the PD infection variable to include tunnel infections is underway. - The definition and timing of "pre-PD peritonitis" are in discussion, as there are inconsistencies in how this is captured. - WG is following up with units on missing data for adequacy tests and PET tests to determine if it is due to not reporting or not performing the tests. <u>HD Working Group by MR:</u> - They plan to invite the data statisticians and ANZSN QISC chair to their next meeting to discuss the access-related bacteraemia data that started collection this year. Action item: Coordinate the meeting with the data statisticians and QISC chair. <u>Parenthood Working Group by SJ:</u> - A paper on labour and delivery outcomes for Australian transplanted women has been published in JAMA. - Currently working on additional analyses around home dialysis and pregnancy. - A collaboration with the French registry to leverage their linkage with perinatal data is being explored as a potential project. <u>Paediatric Working Group by HMC:</u> - There is a need for an annual infographic summary designed specifically for patients and families. WG seeks the ANZDATA team's support in collaborating to develop a clear and meaningful infographic that effectively communicates key information.	250305/01- ANZDATA to support Paed WG in the development of an infographic for patients and families.
5.	KHA Update	
	Members NOTED updates from BR: - KHA launched a project around ending dialysis by 2050 in late 2021, now developing a strategy with 10 pillars to work towards this goal, covering areas like early detection, equity in transplants, and increasing living donors. - KHA has hired a new Program Manager for First Nations Kidney Health, who is engaging with communities, especially in the Pilbara, Central Australia, and Northern Territory, for a pilot program around early detection of kidney disease. - For World Kidney Day, KHA's focus will be on advocacy, including media releases, an advocacy webinar for patient advocates, and trying to generate awareness around the need for people to get checked for kidney disease. - In this year Q3, KHA plans to hold a national summit on early detection of kidney disease, aiming to develop a consensus paper and roadmap to inform KHA's strategy and advocacy work.	250305/02- KH to update the KHA representation in the ToR to "CEO or delegate" or "general manager clinical research or delegate.

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	- KHA is also launching a patient self-management program in July alongside healthcare teams, initially targeting those just starting dialysis and those newly diagnosed by their GP. - KHA is looking to better communicate ANZDATA's data and findings through their media and community work. - SB SUGGESTED exploring opportunities to link the new First Nations Kidney Health work back to the previous KSB Yarning sites and community engagement.	250305/03- KHA to coordinate with ANZDATA team on ways to leverage data and findings in KHA's advocacy and community outreach efforts.
6.	Other Matters - Nil	
7.	Next Meeting – 28th May 2025	
8.	Closing karakia	
9.	Meeting Closed at 12:48 PM	

Action items from the meeting:

Ref No	Item	Responsibility	Status
250305/01	ANZDATA to support Paed WG in the development of an infographic for patients and families.	ANZDATA	
250305/02	KH to update the KHA representation in the ToR to "CEO or delegate" or "general manager clinical research or delegate".	KH	
250305/03	KHA to coordinate with ANZDATA team on ways to leverage data and findings in KHA's advocacy and community outreach efforts.	KHA/ANZDATA	
