

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 (ACST) on 20th November 2024.

Members Present:

Nicholas Gray (NG) Chair
 Sradha Kotwal (SK) Deputy Chair
 Stephen McDonald (SPM)
 Kylie Hurst (KH)
 Georgina Irish (GI)
 Revathy Manickavasagar (RM)
 Bill Mulley (BM)
 Shilpa Jesudason (SJ)
 Hugh McCarthy (HM)

Rachael Morton (RM)
 Samantha Bateman (SB)
 Jenny Chen (JC)
 Matthew Roberts (MR)
 Tina Sun (TS)
 Solomon Meneham (SM)
 Helen Eddington (HE)
 Josephine Chow (JCh)
 Roxanne Perry (RP) KHA proxy
 Michael Garrett (MG)

Guest:

Eric AU (EA)
 Kate Richards (KR)

Apologies:

Breonna Robson (BR)
 Rathika Krishnasamy (RK)
 Philip Clayton (PC)
 Terry Jennings (TJ)
 Mel Wyld

Absent:

Jacqueline Soraru (JS)
 Amali Mallawaarachchi (AM)

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 TS spoke to the Maori welcome and opening karakia	
1.3	Welcome, present and apologies A quorum was met, and NG WELCOMED committee members, and PRESENTED the new WG convenors appointed to 2025: Katherine Richards as the Aotearoa NZ WG convenor and Melanie Wyld as the Living Kidney WG convenor. Apologies and absences were NOTED .	
1.4	AAC Committee membership and ToR: ToR updates were DISCUSSED , including suggestions 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.	
2.	Business Arising from Previous Meeting	
2.1	Minutes of the previous meeting <ul style="list-style-type: none"> - Minutes of the AAC meeting held on 1st September 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 NZ National Renal Strategy Group. Update: Ongoing discussions to be updated next year – Pending . 240901/13 ANZDATA to follow up with the dietitians to better understand the SGA proposal. Update: PC has responded to the dietitians – Completed . 240901/15 Members/ANZDATA to gather all suggestions and further discuss the feasibility of these strategies and the next steps. Update: Keep on the agenda as a standing item – In progress .	
2.3	Change Request Form (CR) Serum Creatinine	
	Members NOTED: <ul style="list-style-type: none"> - The Transplant WG has proposed two changes to the serum creatinine data collection: <ol style="list-style-type: none"> 1. Collect serum creatinine at the time of graft rejection 2. Increase the frequency of serum creatinine collection to annually after year 1 post-transplant Members DISCUSSED: <ul style="list-style-type: none"> - Whether to collect the peak creatinine or the creatinine at the time of diagnosis for the rejection. - For the annual creatinine after year 1, whether to collect it on the anniversary date or just the most recent creatinine in that calendar year. Members AGREED:	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.

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	<ul style="list-style-type: none"> - That creatinine at the time of rejection diagnosis would be most appropriate. - That a calendar year approach might be easier for sites collecting an annual creatinine. - Support of both proposed changes for Tx serum creatinine data collection. 	
3.	Report from Executive	
3.1	Organisation, operational and ongoing Developments	
	<p>Members NOTED the Executive updates from GI, highlighting:</p> <ul style="list-style-type: none"> - A new data systems administrator has been appointed and is starting soon - The 2024 survey period is opening on 2nd December. - The Annual Report progress is going well. The Incident Report has just been finalised and will be released today. - The ANZDATA Capacity Survey will be repeated at the end of this year and is currently being refined by some members of the Working Groups. - The head of units have completed the survey data collection, which is currently being analysed and will be ready for circulation shortly. - A training proposal for involving people with ANZDATA is progressing - There are ongoing discussions between ANZDATA and KHA about their funding relationship going forward, with a positive intent on both sides. - ANZDATA is collaborating with AIHW on data linkage opportunities. - There is an upcoming Datathon event in March 2025 organised by SAHMRI and supported by ANZDATA to allow people to play with artificial ANZDATA and ICU data. 	Nil
4.	Working Groups	
4.1	WG Updates	
	<p><u>COVID Working Group:</u></p> <p>Members NOTED updates from SK, highlighting:</p> <ul style="list-style-type: none"> - The WG has taken advantage of the COVID data as much as possible. - The WG has a publication in process and a couple of other projects underway. - The WG agreed to close out the COVID WG, summarise the work in a special report, and not continue it as an ongoing group. <p><u>Aboriginal and Torres Strait Islander Health Working Group:</u></p> <p>Members NOTED the updates from SB, highlighting:</p> <ul style="list-style-type: none"> - The copyright license for the consumer infographic has expired, so they plan to review the content and graphics. - The WG will try to get time at the upcoming NIKTT gathering in February 2025 to seek consumer input on updating the infographic. 	Nil
4.2	WG Membership & ToR:	
	<p>Members NOTED updates in the Aotearoa NZ WG ToR:</p> <ul style="list-style-type: none"> - There were a few small changes made to the ToR, primarily related to changes in the reporting structure and terminology due to the New Zealand health reforms and restructuring. <p>Members AGREED to endorse the updated Aotearoa NZ WG ToR.</p>	Nil
5.	KHA Update	
	<p>Members NOTED updates from RP, highlighting:</p> <ul style="list-style-type: none"> - KHA was awarded NGO of the Year for 2024. - KHA is launching a new aspiration and focus on early detection, prevention, and treatment of chronic kidney disease, as well as helping more people get transplants. This is being launched at a parliamentary event tomorrow. - KHA has received funding for a First Nations Kidney Health program pilot over the next 3 years. They are in the process of hiring a program manager for this. <p>KHA's Kidney Health for Life Randomised Control trial has been completed, and the data analysis shows promising results on patients' ability to self-manage their kidney disease.</p>	Nil
6.	Other Matters	
6.1	<u>Return to Country request</u>	
	<p>Members NOTED:</p> <ul style="list-style-type: none"> - Request received from Paul Lawton asking ANZDATA to collect 3 additional questions at 10 selected hospital sites: <ol style="list-style-type: none"> 1. Are you of Aboriginal or Torres Strait Islander origin? 2. What is your community/suburb of original residence? 3. What is your current community/suburb of residence? 	

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	<ul style="list-style-type: none"> - The intent is to better understand if patients are being dislocated from their home communities when receiving dialysis. - There is funding available for the Return to Country project to support the development of a community of practice, which is a core component of the project. Each site may decide whether to allocate a portion of this funding towards the additional data collection required for the project. <p>Members DISCUSSED:</p> <ul style="list-style-type: none"> - Concerns about the additional data burden on staff, potential ethical issues, and whether the data would be representative. - Whether this would be a retrospective or prospective data collection, and if it would become a standard part of ANZDATA going forward. - SB clarified that the request involves collecting data through a point prevalence survey where all patients are asked upon the project's commencement. Moving forward, this question will be incorporated for patients starting kidney replacement therapy. The project's future direction will depend on the observed benefits and outcomes. <p>Members AGREED:</p> <ul style="list-style-type: none"> - Provided feedback suggesting a pilot approach first to evaluate its feasibility and resource implications to address a significant additional data collection burden from nurses, ethical issues, and concerns about patient privacy and consent, especially for smaller communities. 	241120/02- ANZDATA to provide feedback on Return to Country request and ask for a complete request form for proposed data collection.
6.2	ANZSN ASM feedback (ANZDATA session and/or ANZDATA posters/presentations)	
	- Not discussed	
7.	Next Meeting – 5th March 2025	
8.	Closing karakia NG thanked the committee for their contributions over the year, acknowledged the support of the ANZDATA team, and wished everyone a restful holiday season.	
9.	Meeting Closed at 1:06 PM	

Action items from the meeting:

Ref No	Item	Responsibility	Status
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.	ANZDATA	
241120/02	ANZDATA to provide feedback on Return to Country request and ask for a complete request form for proposed data collection.	ANZDATA	