

ANZDATA ADVISORY COMMITTEE Members List

Member		Position	Organisation	Term Start
Nicholas	GRAY	Chair	Sunshine Coast Health	2022 (3)
Sradha	KOWTAL	Deputy Chair	The George Institute for Global Health	2022 (3)
Stephen	MCDONALD	Director Strategy & Policy	ANZDATA	N/A
Philip	CLAYTON	Technical Director	ANZDATA	N/A
Georgina	IRISH	Director Projects & Analytics	ANZDATA	N/A
Dana	FORCEY	Epidemiology Fellow	ANZDATA	N/A
Kelly	MARSHALL	Registry General Manager	ANZDATA	N/A
Breonny	ROBSON	Representative	Kidney Health Australia	2018
Rathika	KRISHNASAMY	Representative	ANZSN	2023
Amanda	MCKIE	Representative	RSA	2025
Rachel	MORTON	WG Chair	PROMs	2017 (8)
Matthew	ROBERTS	WG Chair	Haemodialysis	2018 (7)
William	MULLEY	WG Chair	Transplantation	2019 (6)
Jenny	CHEN	WG Chair	Peritoneal Dialysis	2022
Solomon	MENAHM	WG Chair	COVID-19	2022
Kate	RICHARDS	WG Chair	Aotearoa New Zealand	2025
Samantha	BATEMAN	WG Chair	Aboriginal & Torres Strait Islander Health	2023
Hugh	MCCARTHY	WG Chair	Paediatric	2023
Shilpa	JESUDASON	WG Chair	Parenthood	2023
Mel	WYLD	WG Chair	Living Kidney	2025
Jacqueline	SORARU	SIG Chair	Genetics Data- SIG	2022
Josephine	CHOW	General Member	Contributing Unit	2020
Revathy	MANICKAVASAGAR	General Member	Early Career Nephrologist	2023
Michael	GARRETT	General Member	Contributing Unit	2023
Helen	EDDINGTON	General Member	NZ Representative	2023

ANZDATA Advisory Committee MINUTES

Meeting Date:	Wednesday 6 th August 2025
Meeting Location:	Videoconference
Members Present:	Per members list
Guests:	Kevan Polkinghorne, Roxanne Perry, Paolo Cardelli
Apologies:	Matthew Robert, Shilpa Jesudason, Mel Wyld, Jacqueline Soraru, Josephine Chow, William Mulley.
Secretariat:	Jo van Dommele

No.	Agenda Item	Discussion/Decision	Action No.
1	Meeting Opening		
1.1	Welcome and Apologies	NG provided acknowledgement of country KR provided opening karakia The chair welcomed members and guests PC welcomed and congratulated Helen Pilmore as newly appointed Deputy Chair for Advisory Committee <i>There were no decisions or actions for this item.</i>	
1.2	Declarations of Conflict of Interest	No Conflicts declared <i>There were no decisions or actions for this item.</i>	
1.3	Confirmation of Previous Minutes (11 th June 2025)	The minutes of the previous meeting held on 11th June 2025 were confirmed as an accurate record. <i>There were no decisions or actions for this item.</i>	
1.4	Terms of Reference	Accepted <i>There were no decisions or actions for this item.</i>	
1.5	Action List	The action list was discussed. DECISION: Remove Paediatric Infographic from action item list as ongoing, lengthy project. <i>There were no actions for this item.</i>	
2	Change Request		
2.1	Change Request Dashboard	Noted <i>There were no decisions or actions for this item.</i>	
3	Report from Executive		
3.1	Executive Report	PC Provide a comprehensive update, noting; KM was commended for doing exceptional job as new appointed Registry General Manager and supported by JV new Business Support Officer. Dana is doing fantastic work as the EPI Fellow, and ANZSN has agreed to fund the position for another year. The Consumer Advisory Panel is in flux, with the chair Jasmine Mazis resigning. In the future it hopeful to make consumer input a core part of ANZDATA's funding. ANZDATA has received more funding from the OTA, but overall funding is tight and can't take on major new projects without additional support.	

		The data lock process has improved significantly, with earlier data releases and no increase in missing data. ANZDATA is developing a new Quality and Safety Working Group, to be chaired by Nick Gray, to enhance their quality reporting and outlier management. ANZDATA is reviewing all policies and procedures, including updating their data breach policy after a recent minor incident. ANZDATA is supporting new initiatives like data collection on imlifidase use and revisions to kidney allocation systems in Australia and New Zealand. Risks noted ANZDATA rollover funding with no significant increase, SAHMRI Infrastructure charge increase, and NZ WG policies related to data custodianship related to Maori and has the potential to make it difficult to include NZ patients in analyses. <i>There were no decisions or actions for this item.</i>	
3.2	Survey Progress Report	The demographics, comorbidities, modality, and cause of death data in ANZDATA is generally good with low missingness. Positive improvement in genetic testing. Areas with higher missingness include: • Iron studies • Haemodialysis and peritoneal dialysis adequacy testing • Residual kidney function and PET tests in PD • Rejection data • Parenthood Was discussed about potentially defining "core" vs "non-core" data elements, but concerns were raised that this could lead to units not entering the "non-core" data. Noted: the missingness may be more about certain units not reporting certain data points, rather than an overall issue across all units. ACTION: WG chairs to review the missingness data and discuss it within their groups to identify ways to improve data completeness in problem areas. <i>There were no decisions for this item.</i>	250806/01
4	Epidemiology Fellow Update		
4.1	Epidemiology Fellow Update	DF provided an update noting: Teaching at the Trainee weekend, presenting at the ANZSN ASM, attending the Indigenous Datathon in Brisbane. Launched an Advanced Training Research Project Program to support 5 trainees across Australia and NZ doing research using ANZDATA. The committee expressed appreciation for the valuable contributions of the EPI Fellow role and the importance of maintaining this position to support research and training. ACTION: Investigate the work of the EPI Fellow being tracked through a dashboard to track publications, presentations, and trainee project outcomes to report back to ANZSN. <i>There were no decisions for this item.</i>	250806/02

4.2	Head of Unit Special Report – Workforce & Capacity	Head of Unit Special Report tabled. Release plan for report discussed, to be released prior to ANZSN Congress. <i>There were no decisions or actions for this item.</i>	
4.3	Unit Survey 2025 – Peritoneal Dialysis Focus	DF tabled planned Survey with PD focused questions. Survey has a focus on understanding practices to PD catheter insertion, waiting lists, and guidelines for PD peritonitis in Australia and NZ. <i>There were no decisions or actions for this item.</i>	
5	Working groups update		
5.1	Consumer Advisory Panel	PC provide update on CAP. The CAP currently has about 10 active members, with 2 on temporary hiatus. They are looking to add 1-2 more members. Key priorities for the CAP include increasing diversity of membership, promoting and presenting their work externally, and ensuring the language and design of infographics is accessible to consumers. Noted: challenges in creating an effective group given the infrequent meetings and emphasized the importance of stability in guidance. The CAP is working to grow their community interest register and get consumer feedback on what information they want to see represented on social media. <i>There were no decisions or actions for this item.</i>	
5.2	Aboriginal & Torres Strait Islander Health	PL provided an update on behalf of SB convener. The process of developing a new infographic for Aboriginal and Torres Strait Islander patients and families has been progressing very slowly. Given the delay for several years SM noted there is a real risk that no infographic will get developed. <i>There were no decisions or actions for this item.</i>	
5.3	Haemodialysis	KP (proxy) for MR The Group has been focused on the implementation of the new bloodstream infection reporting. They are now working on how to best report this data back to units. Other ongoing projects, include TheraNova, Membrane Classification and Fistula bleeding. <i>There were no decisions or actions for this item.</i>	
5.4	Living Kidney Donation	No update	
5.5	Aotearoa New Zealand	NZ WG is focused on improving the visibility, accessibility, and relationships between ANZDATA and the New Zealand nephrology community. Supporting trainee research projects Building relationships and working on how to best handle ethnicity data in a way that aligns with New Zealand guidelines. <i>There were no decisions or actions for this item.</i>	
5.6	Paediatric	WG represents a small number of patients (~300) Engagement and missing data have been challenging. Planning a "roadshow" to visit each of the 7-8 paediatric units to present the previous year's report and increase engagement. Currently 6 research projects ongoing, including 2 by fellows, and have published a couple papers in the last year.	

		Developing an infographic for patients/families is a new initiative being working on. <i>There were no decisions or actions for this item.</i>	
5.7	Parenthood	No update provided.	
5.8	Transplant	No update provided.	
5.9	Peritoneal Dialysis	The WG is looking for nursing representation from New Zealand. The group has had some recent publications and is now focused on a Sharesource project analysing PD data linked to ANZDATA. The group is looking forward to the implementation of the new PD catheter-related infection variable in January 2026. The new variable is hoped to improve the missing data and real-time reporting for next year. <i>There were no decisions or actions for this item.</i>	
5.10	PROMs	The ANZDATA SWIFT trial, the largest haemodialysis trial in Australia, has completed recruitment of over 2,400 patients across 92 centres. The results of the SWIFT trial are expected to be presented at ASN in 2026 after the 12-month follow-up period. The group is also conducting a Delphi survey to prioritise which PROMs/PREMs should be included in a future ANZDATA PROMS module. This has achieved great consumer engagement. A research assistant, Jess Nikolowski, is developing a research program around consumer engagement in kidney health and chronic disease. Delphi survey, Patient Voices in Focus, will be presented at a New South Wales Health Patient Reported Measures Symposium. The Department of Health has provided a grant to develop a PROMS module for ANZDATA, which the working group is working on in parallel with the Delphi survey. <i>There were no decisions or actions for this item.</i>	
5.11	Special Interest Group Genetics Data Collection	<i>There were no decisions or actions for this item.</i>	
5.12	Safety and Quality Working Group	First meeting to be held 11th September 2025. <i>There were no decisions or actions for this item.</i>	
6	KHA Update		
6.1	Kidney Health Australia Update	Launching a new "Kidney Health for Life" online support portal for consumers with kidney disease next week. This provides education, resources and support across the spectrum of kidney disease. KHA is organizing a national "CKD Detect Early, Act Now, Save Lives" summit in October to bring together stakeholders and develop a roadmap for improving early detection and treatment of CKD in primary care. The new KHA-ANZSN Research Alliance has been formed and will be holding its first meeting in the coming weeks.	

		Annual Red Socks fundraising run is happening in October KHA indicate desire to resume funding, once a clear purpose been outlined thorough collaboration between both groups. ACTION: ANZDATA and Kidney Health Australia to continue their ongoing discussions and meetings to leverage data and findings collaboratively, meeting at ANZSN.	250806/03
7	All Other Business		
7.1	Funding Strategy and Opportunities	Various funding opportunities for ANZDATA were discussed, including exploring pharma, partnerships with private health insurers or dialysis machine providers, and potentially asking renal units to contribute funding. Challenges around securing ongoing government funding were also noted. <i>There were no decisions or actions for this item.</i>	
7.2	ANZSN ANZDATA Session – Polling Questions	Reviewed potential polling questions to include in the ANZSN Congress session, focusing on topics like new quality indicators, data dashboards, and funding. Discussed the need to balance questions that would engage the broader nephrology community versus just "preaching to the converted" ANZDATA supporters. ACTION: Develop a set of poll questions for the ANZSN Congress session, potentially including questions around funding, quality indicators, and dashboards <i>There were no decisions for this item.</i>	250806/04
7.3	ANZDATA 50th Anniversary Plan	Proposed holding a standalone 50th anniversary event for ANZDATA in 2027, potentially including a datathon, workshop, and gala dinner. Discussed logistics around timing, location, and integrating the event with the existing ANZSN meeting schedule. <i>There were no decisions or actions for this item.</i>	
7.4	NIKTT Dashboard Release	Letter of request to display unit level data on NIKTT dashboard tabled for consideration. NIKTT is developing a new interactive dashboard to provide public reporting on access to kidney transplantation, with a focus on stratifying data by Indigenous versus non-Indigenous patients. Discussed the need to carefully manage small sample sizes to avoid identification of individual units. DECISION: Sample size would not be release <5 DECISION: Advisory Committee supported this request ACTION: NG/SK to provide letter of support	250806/05
8	Close of Meeting		
	Next Meeting	Date: Wednesday, 26th November 2025 Location: Videoconference	
		HE closed the meeting with the closing karakia	