

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 1:00-6:00 PM (ACST) on 1st September 2024.

Members Present:

Nicholas Gray (NG) Chair
 Sradha Kotwal (SK) Deputy Chair
 Stephen McDonald (SPM)
 Philip Clayton (PC)
 Kylie Hurst (KH)
 Georgina Irish (GI)
 Breonny Robson (BR)

Rachael Morton (RM)
 Samantha Bateman (SB)
 Jenny Chen (JC)
 Matthew Roberts (MR)
 Josephine Chow (JCh)
 Helen Eddington (HE)
 Fiona Donnelly (FD) RSA proxy for TJ

Guest:

Eric AU (EA)

Apologies:

Revathy Manickavasagar (RV)
 Rathika Krishnasamy (RK)
 Michael Garrett (MG)
 Tina Sun (TS)
 Bill Mulley (BM)
 Shilpa Jesudason (SJ)

Absent:

Terry Jennings (TJ)
 Jacqueline Soraru (JS)
 Amali Mallawaarachchi (AM)
 Solomon Meneham (SM)
 Hugh McCarthy (HM)

Minute Taker:

Thais Turibio (TT)

Minutes

Item	Matter	Action
1.	<p>Acknowledgment of Country and Māori Welcome NG (Chair) acknowledged the traditional custodians of the lands and their culture and heritage, and Helen (NZ Rep) spoke the Māori welcome and opening Karakia. Welcome, present and apologies. A quorum was met, and NG WELCOMED committee members, NOTING apologies and absences.</p>	
2.	<p>Business Arising from Previous Meeting</p>	
2.1	<p>Minutes of the previous meeting</p> <ul style="list-style-type: none"> Minutes of the AAC meeting held on 29th May 2024 circulated prior to the meeting. Members ACCEPTED minutes as an accurate record of the event with no redactions for website publishing. 	
2.2	<p>Outstanding Action Items</p> <ul style="list-style-type: none"> No outstanding action items from the previous meeting 	
3.	<p>Report from Executive</p>	
3.1	<p><u>Organisation, operational and ongoing Developments:</u> Members NOTED the Executive update from SPM, highlighting:</p> <ul style="list-style-type: none"> Core structure of the Registry remains unchanged noting a slightly expanding group of the activities and management. There is a formalised consumer advisory group with terms of reference, which oversees many of the project-specific consumer interests. KH is back after a period of leave with Kelly Marshall filling in as acting GM very capably during her absence. A new Epi Fellow has been recruited for 2025 to continue from the current Epi Fellow, Eric Au's period ending. Registry core funding is unchanged with an ongoing three-year contract set to expire on June 30, 2025. Discussions are underway, potentially expanding ANZDATA's activities. Data collection and reporting have steadily improved, with the annual survey results now available earlier. The National Framework for Clinical Quality Registries (CQRs) was recently released. This framework aims to establish an accreditation system and possibly a separate governance structure that differs from research ethics and approval for registries to operate. 	<p>240901/01- SPM to report back on the outcomes of discussions with the National Renal Strategy Group.</p>
4.	<p>Working Groups Update</p>	
4.1	<p><u>Transplant (written report): tabled as read</u></p> <p><u>Aotearoa New Zealand (written report): tabled as read</u></p>	

Item	Matter	Action
	<p><u>Parenthood (written report): tabled as read</u></p> <p><u>Haemodialysis:</u> Members NOTED:</p> <ul style="list-style-type: none"> - The HD working group has been meeting regularly, with no changes in membership. - The WG's recent discussion is around the dialysis capacity report and the BSI data collection with positive reviews in the last WG meeting. - The hemodiafiltration (HDF) project is progressing slowly. - The self-care initiative is not progressing as expected, raising concerns about getting meaningful uptake. - WG members have tried to standardise the way dialysis membranes are classified but have faced challenges in getting the required data from companies. - The goal is to create a useful table categorising different types of dialysis membranes, as the current approach is no longer included in reports, and track trends related to "medium cutoff membranes" <p><u>Peritoneal Dialysis:</u> Members NOTED:</p> <ul style="list-style-type: none"> - The PD working group has been trying to increase representation from New Zealand but has faced difficulty in attracting members. - Gender representation is balanced with four male and five female members, including two nurse practitioners - The group is currently seeking new Advanced Trainee members with EOI being accepted. - The group has published one paper related to Indigenous health and has a few other papers in progress. - JC raised concerns about possible under-reporting of peritonitis, noting a risk of similar issues with access-related infections. JC highlighted the low number of hybrid dialysis patients reported in Australia and New Zealand - SPM updated that the ShareSource project has been slow and hopes for an end round by the end of the year. <p><u>Aboriginal and Torres Strait Islander Health:</u> Members NOTED:</p> <ul style="list-style-type: none"> - The Aboriginal and Torres Strait Islander working group has been trying to increase membership and representation, with over 50% of the group being Aboriginal & Torres Strait Islander for the first time. - Challenges in achieving meeting quorum persist due to Aboriginal and Torres Strait Islander clinicians' inability to attend, stemming from a lack of protected time and technology access. - There are three EoI on the way, hoping to engage them in the WG. - The 2024 projects have been relatively quiet, with no data requests but two presentations and one poster from last year's data request. - SB emphasised the importance of ensuring consistent use of terminology in the report, preferring "Aboriginal and/or Torres Strait Islander" over "Indigenous" or "ATSIH". - The WG will explore more strategies to better support and enable participation, such as contacting unit managers to request release time and providing out-of-session support. <p><u>Paediatric:</u> - No updates or written report provided</p> <p><u>Living Kidney Donor:</u> Members NOTED:</p> <ul style="list-style-type: none"> - The living kidney donor working group chair position is currently vacant, and a call for expressions of interest has been circulated. <p><u>PROMS:</u> Members NOTED:</p> <ul style="list-style-type: none"> - The SWIFT trial is going well, having recently recruited 2,000 patients, which is a significant milestone. - The SWIFT trial is engaging dialysis units across Australia, including some that have not previously participated in randomised trials. The trial is expected to finish recruiting at the 	<p>240901/02- Aboriginal & Torres Strait Islander Health WG to implement an action plan to engage the members with ANZDATA support.</p> <p>240901/03- ANZDATA to provide support for members to attend meetings</p> <p>240901/04- JCh to provide contact details of 2 PD nurses to RM for EoI in the PROMS WG.</p>

Item	Matter	Action
	<p>end of this year, followed by a 12-month follow-up period having data either at the end of next year or just slightly into 2026.</p> <ul style="list-style-type: none"> - The WG is considering a new advanced trainee for PROMs audit, for a project to modify and update a paper from six years ago. - RM mentioned a small grant opportunity available that the PROMS working group is looking to apply for, to provide additional support for a PROMS module. - RM updated that the data collection for a qualitative sub-study examining usual care practices in haemodialysis is nearing completion. The study focuses on how nephrologists and other healthcare professionals manage and monitor symptoms. Final interviews are being conducted, with a report expected by the end of the year. <p><u>COVID:</u></p> <ul style="list-style-type: none"> - No updates or written report provided <p><u>SIG – Genetics</u></p> <ul style="list-style-type: none"> - Updates discussed in item 9.1 	<p>240901/05- ANZDATA to put out EoI for general member in the PROMS WG.</p>
4.2	<p><u>Membership</u></p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - There are several vacant positions in various working groups with EOs out. A slide will be presented at ANZSN on ANZDATA Session to highlight this, and ANZDATA has already shared the information. 	
5.	<p>KHA Update</p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - KHA has formally brought the Australian cricketer Cameron Green as an ambassador to help raise awareness of kidney disease. - The ongoing Kidney Health 4 Life RCT is in the data analysis stage and aims to achieve significant results in self-management. The study uses the CKDSM questionnaire as the primary endpoint and the DAS 10 survey to assess knowledge, self-efficacy, and well-being. - KHA is planning the Red Sock Run for October to involve the community and raise awareness and funds to put into other programs. - BR mentioned a successful donor grant to conduct 3 years of research in the Indigenous health space. An Indigenous reference group within KHA will be established to focus on increased engagement and collaboration. - KHA is hosting Kidney Kids Es-Caper events for children with kidney disease in various Australian states, including Perth, New South Wales, Queensland, Victoria, and South Australia. - KHA's peak committee meeting acknowledged discrepancies between the 2009 and 2021 CKD EPI equations for eGFR and decided to continue using the 2009 equation on the website. - There is an MBS consultation open at the moment, which aims to include kidney metrics in chronic disease management checks for primary care, advocating for kidney-specific item numbers and a general health check. 	<p>240901/06- BR to provide MBS consultation link to the members.</p>
6.	<p>ANZSN and ANZDATA</p>	
6.1	<p><u>Dialysis capacity survey</u></p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - ANZDATA has conducted a survey of dialysis units to assess the number of dialysis chairs and the number of patients per chair, which was done around the same time as the end of 2022 patient population data collection. - The survey outcomes have been compiled into a report co-authored with ANZSN including heat maps showing areas with capacity issues. - The report found that overall capacity across Australia is generally okay, but there are significant issues in certain regions, particularly Western Sydney, WA, and the Northern Territory. - The report will be released publicly, with an interactive online version at ANZSN conference. <p>Members DISCUSSED:</p> <ul style="list-style-type: none"> - HE acknowledged that the NZ data and report was not included in the dialysis capacity report, noting that the NZ data had been provided for the report, and there was an expectation from the NZ nephrology community that the NZ data would be included. 	<p>240901/07- ANZDATA to coordinate with the NZ nephrology network about data report decisions.</p> <p>240901/08- ANZDATA to circulate a draft Dialysis capacity report to the members.</p>

Item	Matter	Action
	<ul style="list-style-type: none"> - SK and NG suggested that would be reasonable to inform that the NZ report is underway and for Eric to mention that in your presentation at the ANZSN conference. - BR suggested a briefing for KHA to highlight key points from a report and media release, anticipating media inquiries. - SB emphasised the need to be mindful of how the data on capacity issues in areas with high Aboriginal and Torres Strait Islander populations is presented and interpreted. - The report also highlights the need for improved labelling and marketing of “holiday” dialysis, as it should not solely refer to leisure travel but also encompass significant life events. - PC suggested having more consumer involvement in future reports moving forward. 	
6.2	<p><u>ANZSN trainee engagement</u></p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - ANZDATA is trying to engage more trainees and early-career nephrologists to get involved in ANZDATA projects and working groups, and this has been more challenging than expected, despite efforts to disseminate information and opportunities widely. - EA has developed a draft protocol to try and improve trainee engagement, including strategies to better target, reach trainees and support people who have less statistical support within their unit. - GI, EA and CD have been discussing the development of resources for junior staff focused on career development with ideas for creating materials like coding shifts and instructional videos to help users understand data sets and treatment tables, addressing common struggles reported by individuals in their careers. The goal is to provide support for better access and understanding of these resources. <p>Members DISCUSSED:</p> <ul style="list-style-type: none"> - JCh suggested sharing information through the home network newsletter to reach nurses and potentially other trainees. - NG mentioned plans around creating a half-hour video for the annual data update and report, potentially useful for trainees. - SB suggested designating a single contact person or email address for trainees seeking assistance. - The potential to offer trainee-specific projects or opportunities, such as data analysis or manuscript preparation, to make it more appealing. - The importance of ensuring trainees have adequate support and supervision, both from their local units and from ANZDATA. <p>Members AGREED:</p> <ul style="list-style-type: none"> - ANZDATA will finalize the draft protocol for engaging trainees and early-career nephrologists. - ANZDATA will explore ways to better promote opportunities through channels like the Young ANZSN group and the home dialysis network. 	<p>240901/09- EA to circulate the draft trainee engagement protocol for feedback before the next meeting.</p>
6.3	<p><u>Epidemiology Fellow and projects</u></p> <ul style="list-style-type: none"> - ANZDATA has recruited a new EF (Epidemiology) fellow to take over from Eric next year. 	
7.	<p>Quality Care</p>	
7.1	<p><u>BSI (opt-in for more data, denominator, how to report, nursing engagement)</u></p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - ANZDATA will start collecting BSI data from January 1st, 2025. This will include three data points: date of infection, type of vascular access, and organism. - Some sites have expressed interest in collecting additional optional data points beyond the core three, such as details around hospital admission or ICU stay. This is out of the scope of current development, initially to ensure consistency across all sites rather than allowing individual variations of collection. - This process would also apply to their entire patient group. <p>Members DISCUSSED and AGREED:</p> <ul style="list-style-type: none"> - the burden on nursing staff to collect the additional optional data is out of scope initially, due to concerns about inconsistencies in sites collecting different sets of data. - starting 2025 with three data points, assessing the results over the next year and then exploring additional optional data based on site interest after the initial phase. 	

Item	Matter	Action
7.2	<p><u>Engagement of nephrology community</u></p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - There is a concern that nephrologists are less engaged with ANZDATA as a clinical quality registry compared to the nursing community. - Nephrologists tend to view ANZDATA more as a research database rather than a tool for quality improvement. - There was a previous request from the NZ Nephrologists to reactivate the transplant assessment module, but it's unclear what the outcome of that request was. <p>Members DISCUSSED:</p> <ul style="list-style-type: none"> - The challenge of getting nephrologists engaged in quality improvement initiatives and using ANZDATA data for that purpose, rather than just research. - The need to shift the mindset from viewing ANZDATA as a research database to seeing it as a tool to drive quality of care. - Strategies to better engage nephrologists, such as providing more tailored reporting and feedback at the unit level. - The potential to link ANZDATA data with other datasets, such as aged care assessments, to provide more comprehensive information on patient outcomes. <p>Members AGREED:</p> <ul style="list-style-type: none"> - ANZDATA to explore ways to provide more tailored reporting and feedback to nephrologists to demonstrate the value of ANZDATA data for quality improvement. 	<p>240901/10 - ANZDATA to follow up on the previous request from the transplant working group to reactivate a specific transplant assessment module.</p>
7.3	<p><u>Dissemination of results, especially outliers (is it enough, should ANZDATA communicate to DoH, etc)</u></p> <p>- Not discussed</p>	
7.4	<p><u>Real-time data reports and missing data</u></p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - The quality indicator real-time report for the first 6 months of 2024 was released last week, which includes data on peritonitis, vascular access, transplant waitlisting, and other indicators. - There was evidence that sites had under-reported data, leading to inaccurate performance metrics. For peritonitis, some large PD units reported zero episodes, clearly an underestimate. <p>Members DISCUSSED:</p> <ul style="list-style-type: none"> - PC suggested collecting the number of peritonitis episodes rather than reporting peritonitis episodes as an approach that could allow to identification of any potential underreporting. If no data is submitted, it would indicate that there may be instances of underreporting. - KH clarified that the communication strategy involves sending targeted emails based on monthly real-time reports to address anomalies, rather than sending generic emails that are often ignored. - JC mentioned that the reason for the underreporting usually is due to lack of resources to enter data, other priorities and data being entered after the reporting period. - PC suggested identifying units underreporting data, providing more assistance and contacting them earlier. <p>Members AGREED:</p> <ul style="list-style-type: none"> - Having ANZDATA sessions at the units and/or providing educational content will help engage the staff and make the data useful and relevant. - Choosing exemplary units across Australia and New Zealand and creating profiles of the individuals entering data in those units to demonstrate engagement. - Engaging directly with the groups of quality healthcare within each state since missing data affects multiple registries, and these groups may be able to better address the issue. 	<p>240901/11- ANZDATA team to implement strategies for engagement and education.</p> <p>240901/12- TS to provide with updated list of jurisdictions in NZ.</p>
7.5	<p><u>Dietitian proposal (SGA)</u></p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - The dietitians have proposed adding SGA as a patient outcome measure to be reported in the ANZDATA registry. This nutritional assessment tool is currently used by some, but not all, dialysis units. - The proposal suggests collecting SGA data on all CKD patients, not just those on dialysis. <p>Members DISCUSSED:</p> <ul style="list-style-type: none"> - the challenge in the accuracy of data reported by dietitians, who are responsible for determining and calculating nutritional information. 	<p>240901/13- ANZDATA to follow up with the dietitians to better understand the proposal.</p>

Item	Matter	Action
	<p>concerns about the process, purpose, issues like missing data or poor data reporting, and the visibility in a clinical setting and inconsistencies in practice.</p> <ul style="list-style-type: none"> - JCh suggested waiting for guidance from the ISPD committee, as this may clarify the approach to standardised measures. - MR suggested that the dietitians should propose an easier metric or something that is already collected to measure nutrition. <p>Members AGREED:</p> <ul style="list-style-type: none"> - Follow up with the requestors responsible for this proposal and clarify the discussed points to better understand the rationale, current practices, and potential uses of the data. 	<p>240901/14- JCh to provide feedback from the ISPD committee.</p>
8.	ANZDATA strategy	
8.1	<p><u>Research, trials, registry trials, expanding linkages, sources/opportunities funding</u></p> <p>Members DISCUSSED:</p> <ul style="list-style-type: none"> - JCh suggested fostering real partnerships among various projects and emphasized the importance of integrating different registries to enhance patient-centred data reporting, which could attract more funding grants. She also highlighted the need for better engagement with nurses, who are crucial for data entry and should be more involved in the overall strategy beyond just data collection. - KH clarified that at SAHMRI ANZDATA is quite engaged in a lot of government grants, linkage projects and registry science. - SPM added that The National Health Data Hub is being developed to include connections to clinical quality registries as part of its framework. This initiative follows advocacy efforts and aims to create a more accessible way to link various federal and jurisdictional data sets. However, it is important to note that the cost of data linkage is increasing significantly. - MR highlighted the research limitations of the data being collected and the need for additional data points to improve research outcomes. However, he acknowledged that engaging nephrologists in quality care initiatives and encouraging them to gather extra data is essential, as otherwise, research may rely on previously explored ideas or emerging variables without sufficient engagement. - NG acknowledged the potential to collect other variables, but at the moment there are challenges related to bloodstream infections and hybrid cases to address first, as well as the engagement of nephrologists in quality care - KH suggested having CAP involvement in the future as part of the ANZDATA protocol for a new variable would be worthwhile. - PC suggested that enhancing data collection through linkage is more effective than focusing on collecting new variables and that some data collection efforts should be halted to maintain a manageable and sustainable approach over the long term. 	<p>240901/15 - Members/ANZDATA to gather all suggestions and further discuss the feasibility of these strategies and the next steps.</p>
9.	Data Variables	
9.1	<p>Updates:</p> <p><u>Causes of graft failure</u></p> <ul style="list-style-type: none"> - The Transplant WG has been working on refining new coding and will be ready for circulation soon. <p><u>Genetics</u></p> <ul style="list-style-type: none"> - The genetic variables were reviewed by the Special Interest Genetic Group, with about 40% rate of genetic tests leading to a diagnosis. The group also looked at whether they were aligned with the kidney primary diseases. Overall, as a new variable, the process has gone well and is expected to be helpful. <p><u>PD catheter insertion date</u></p> <ul style="list-style-type: none"> - Around 1400 patients with a catheter insertion date were collected in 2023, and the PD WG is currently deciding how to report the PD/urgent-start date as there is no consensus on the definition. <p><u>Withdrawal from dialysis and if still alive at 3 months –? call renal recovery</u></p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - Since January 1, 2020, data on dialysis withdrawals has been collected. A significant issue arose with individuals withdrawing from dialysis but continuing to live without treatment. - The current process involves ANZDATA chasing units for updates on the status of those who withdraw and no reported date of death, which is creating a significant operational burden. <p>Members AGREED:</p>	<p>240901/16- ANZDATA to update business rule and operating procedures.</p>

Item	Matter	Action
	<ul style="list-style-type: none"> - That continuing to chase units indefinitely for updates on those who withdraw is not a good use of resources. - Stop chasing units for updates after 30 days - Recode those still alive at 30 days as "J - recovered renal function from W – Withdrawal from Dialysis" - Continue to collect the cause of death under withdrawal coding 	
9.2	<p><u>Missingness of data</u></p> <p>Members NOTED:</p> <ul style="list-style-type: none"> - There are significant missingness rates for some variables, such as dialysis adequacy measures, PD-related data, and long-term transplant follow-up. - The missingness rates have been increasing over time in some areas. The potential reasons for that could be competing priorities and lack of dedicated resources at the unit level for data entry; the shift from nurse-led to physician-led data entry in some areas. <p>Members DISCUSSED:</p> <ul style="list-style-type: none"> - Whether certain variables are no longer providing meaningful value and could be discontinued - ANZDATA team to review the variables with high missingness rates and make recommendations to the working groups about which ones may be candidates for discontinuation. - The PD working group will specifically discuss the continued collection of PD adequacy testing data given the high missingness rates. 	<p>240901/17- ANZDATA to circulate missingness report to AAC members' feedback.</p> <p>240901/18- ANZDATA team to review the variables with high missingness rates and circulate to the relevant WG for input.</p>
10.	Next Meeting – 20th November 2024	
11.	Meeting Closed at 5:30 PM	

Action items from the meeting:

Ref No	Item	Responsibility	Status
240901/01	SPM to report back on the outcomes of discussions with the National Renal Strategy Group.	SPM	
240901/02	Aboriginal & Torres Strait Islander Health WG to implement an action plan to engage the members with ANZDATA support.	SB	IN PROGRESS
240901/03	ANZDATA to provide support for members to attend meetings	KH	IN PROGRESS
240901/04	JCh to provide contact details of 2 PD nurses to RM for EoI in the PROMS WG.	JCh	
240901/05	ANZDATA to put out EoI for general member in the PROMS WG.	KH	COMPLETED
240901/06	BR to provide MBS consultation link to the members.	BR	COMPLETED
240901/07	ANZDATA to coordinate with the NZ nephrology network about data report decisions.	KH	COMPLETED
240901/08	ANZDATA to circulate a draft Dialysis capacity report to the members.	EA	
240901/09	EA to circulate the draft trainee engagement protocol for feedback before the next meeting.	EA	IN PROGRESS
240901/10	ANZDATA to follow up on the previous request from the transplant working group to reactivate a specific transplant assessment module.	KH	
240901/11	ANZDATA team to implement strategies for engagement and education.	KH	IN PROGRESS
240901/12	TS to provide with updated list of jurisdictions in NZ.	TS	COMPLETED
240901/13	ANZDATA to follow up with the dieticians to better understand the proposal.	GI/PC	
240901/14	JCh to provide feedback from ISP committee on guidelines for nutritional data capture.	JCh	
240901/15	Members/ANZDATA to gather all suggestions and further discuss the feasibility of these strategies and the next steps.	ALL	
240901/16	ANZDATA to update business rule and operating procedures.	KH	
240901/17	ANZDATA to circulate missingness report to AAC members' feedback.	KH	
240901/18	ANZDATA team to review the variables with high missingness rates and circulate to the relevant WG for input.		