

Meeting:

Meeting of the ANZDATA Advisory Committee of the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) held by videoconference at 10:00am – 4:00pm (ACDT) on 24th August 2022.

Attendees:

Alan Cass (Outgoing Chair)	AC
Nicholas Gray (Incoming Chair)	NG
Sradha Kotwal (Incoming Deputy Chair)	SK
Stephen McDonald	SPM
Philip Clayton	PC
Breonna Robson	BR
David Johnson	DJ
Terry Jennings	TJ
Matthew Roberts	MR
Amelia Le Page	ALP
Tina Sun	TS
Jenny Chen	JHC
Rachael Morton	RM
Bill Mulley	BM
Solomon Meneham	SMH
Josephine Chow	JC
Michael Collins	MC

Guests:

Mandy Farmer ANZDATA

Apologies:

Matthew Sypek
Kylie Hurst
Kelly Marshall
David Johnson AM Session
Michael Collins PM Session
Breonna Robson PM Session
Rachael Morton PM Session

Minutes:

Item	Matter	Action
1.	<p>Welcome, present and apologies</p> <p>The Chair WELCOMED committee members and acknowledged the traditional custodians of the land. AC ACKNOWLEDGED that his 3-year term as Chair had come to an end with Deputy Chair NG to assume the role of Chair. Following an EOI process SK has been appointed Deputy Chair. AC congratulated and welcomed SK to the role.</p> <p>NG to assume Chair for today's meeting.</p> <p>Members NOTED no conflict of interest.</p>	
2.	<p>Minutes of Previous Meeting and Actions Arising</p> <p>Members ACCEPTED minutes of previous meeting held 15th June 2022 and SUPPORTED ANZDATA publishing to the registry website with no redactions.</p> <p>Members provided an update of pending Action Items</p>	
Ref No	Item	Action
220615/03	<p>Discuss Editorial Board concept at the ANZDATA Executive Committee Meeting</p> <p><i>Update:</i></p> <p>Members DISCUSSED membership and contributions to the report AGREEING that a chair be appointed for oversight, report consistency and strategy. PC NOTED his availability to convene the board. It was NOTED that not all WG Chairs would be available and that convening a smaller group of interested members would be the way to move forward. It was also NOTED that a</p>	Ongoing

rotating board with a 12-month commitment could be an option for members. It was **NOTED** that there was not funding available to resource a project officer to undertake the work.

RM **NOTED** consideration of a PROM's Chapter in future years, depending on the outcome of SWIFT. Also **NOTING** that a Clinical Quality register collecting PROMs could happen in the next year or two.

220615/03	<p>Discuss Cancer reporting at the ANZDATA Executive Committee Meeting</p> <p><i>Update:</i></p> <p>It was NOTED that the Cancer WG disbanded some time ago. Members DISCUSSED the accuracy of current reporting, a minimum data set and the option of data linkage to lessen the burden of data collection. GI NOTED that cancer data was regularly requested from ANZDATA.</p>	Ongoing
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3.	Advisory Committee Terms of Reference	
3.1	<p>Advisory Committee ToR were tabled with no changes. MC NOTED that he no longer meets the requirements of the committee membership and that he would tender his resignation from the committee. It was NOTED that there are 2 general member vacancies and 1 NZ general member vacancy</p>	<p>220824/01 ANZDATA to commence EOI process for new members</p>
4.	Executive Officer Report	
4.1	<p>SPM tabled a written report as the Executive Officer.</p> <p>SPM thanked everyone for their hard work over the past 12 months ACKNOWLEDGING the contribution to ANZDATA of Matthew Jose who has stepped off all ANZDATA committees and to Alan Cass for his term as Chair and ongoing contributions to ANZDATA.</p> <p>RM noted the growth of ANZDATA staffing and ASKED the current FTE of ANZDATA and projections of growth</p>	<p>220824/02 ANZDATA to circulate FTE, positions and position funding to members</p>
4.2	Centre Survey Report	
	The centre survey report (dated 12/08/2022) was tabled. NOTING two units have not submitted data (PIND and WSLY) and had been escalated for follow up	
5.	Working Groups	
5.1	Working Group Terms of Reference	
	<p>WG Generic Terms of Reference were tabled. NOTING one change of the addition of a quorum. There was DISCUSSION on terms and it was NOTED that if members were contributing in a positive fashion that they could have ongoing membership.</p> <p>The Chair OPENED discussion to Working Group Convenors to provide their reports.</p>	

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5.2	<p><u>Aboriginal and Torres Strait Islander Health</u> Matthew Jose has stepped down as chair of the ATSIH WG and a suitable replacement has not yet been appointed therefore no written report was submitted.</p>	<p>220824/03 ANZDATA to identify suitable Convenor of ATSIH WG</p>
5.3	<p><u>COVID-19</u> SM and SK as co-chairs of the inaugural ANZDATA COVID-19 WG tabled a report NOTING</p> <ul style="list-style-type: none"> • The WG had recently had their first meeting. • A subcommittee has produced an updated minimum data set for discussion at 7.1 during the afternoon session. 	
5.4	<p><u>Haemodialysis</u> MR tabled an update of new membership, meetings held and current projects within the Working Group, NOTING: Classification of dialysis membranes for reporting in ANZDATA</p> <ul style="list-style-type: none"> • Classification of dialysis membranes for reporting – to add footnote defining non high flux • New AT member Su Jen Chua will be undertaking a research project on Self Care 	
5.5	<p><u>Paediatric</u> ALP tabled an update of membership, meetings held and current projects within the Working Group, NOTING:</p> <ul style="list-style-type: none"> • A desire to step down as chair, so far there has been no interest in a successor • How to increase contribution from paediatric ANZDATA users/authors? Members DISCUSSED options and it was AGREED that it was reasonable to “tap people on the shoulder” who were regular beneficiaries of ANZDATA to join the WG. • How to increase ANZDATA visibility for trainees? Discussed at 7.5 • Data collection to be discussed at 7.2 	
5.6	<p><u>Peritoneal Dialysis</u> JC as new WG Chair tabled an update of membership, meetings held and current projects within the Working Group, NOTING:</p> <ul style="list-style-type: none"> • TEACH PD Trial is progressing well with 1100 participants • EOI currently out for one general member and one AT member • Hybrid Data Collection to be discussed at 7.2 • Inclusion of the first catheter insertion date for PD start to be discussed at 7.2 	
5.7	<p><u>Patient Reported Outcome Measures</u> RM tabled an update of membership, including two advanced trainees, meetings held and current projects within the Working Group, NOTING:</p> <ul style="list-style-type: none"> • SWIFT trial: Symptom Monitoring With Feedback trial – recruitment almost complete in NSW and QLD, (700 participants enrolled) recruitment to start in SA, feasibility surveys sent out for VIC, with TAS and WA to follow • EMPATHY trial, preliminary results 	

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	<ul style="list-style-type: none"> Currently in year 5 of WG chair position, RM is keen to continue and questioned process. BM noted that a term specifically for chair was not outlined in the current ToR. Members SUGGESTED that an EOI process be undertaken with RM able to reapply 	220824/04 Chair Term confirmation to be taken to Executive Committee
5.8	<p><u>Transplant</u></p> <p>BM provided an update of membership, meetings held and current projects within the Working Group, NOTING:</p> <ul style="list-style-type: none"> EOI for transplant surgeon to join the group ABO incompatible paper to be added to report tabled 	
5.9	<p><u>Aotearoa New Zealand</u></p> <p>TS tabled an update of membership, meetings held and current projects within the Working Group, NOTING:</p> <ul style="list-style-type: none"> Membership still requiring an Advanced Trainee WG would like to reshape Māori chapter Finding it difficult to recruit Māori representation to join WG New Zealand Individual Hospital Reports and “New Zealand” as an adjustment factor and the rationale behind it- Feedback from NRAB meeting 10 August is predominantly home-based sites are significantly higher SMRs than other sites and suggested other analysis methods assessing the effect of Home Dialysis for NZ but keeping other variables the same as before. 	220824/05 Meeting with NRAB and SPM later today to discuss further
5.10	<p><u>Living Kidney</u></p> <p>P Clayton NOTED that membership remained unchanged and met for the first time this year on the 16th of June NOTING:</p> <ul style="list-style-type: none"> Looking at national linkage Comparative analysis including NZ cohorts No ethics yet for LKD collection with an opt in consent likely with central consent run out of Adelaide <p>Projects</p> <ul style="list-style-type: none"> GI and MC – “Live Donate Study” LKD in NZ and their outcomes GI and Amali – LK Donor whose relative have Alport’s syndrome and their outcomes 	
6.	KHA Update	
	<p>B Robson, as representative for Kidney Health Australia, tabled KHA 5-year strategy NOTING:</p> <ul style="list-style-type: none"> Research alliance with KHA and ANZSN is currently conducting a research mapping project looking back over the last 5 years, clinical trials, funding and data research. National Priorities discussion with a “save the date” coming out soon for 11th October in the evening and a day session on 26th October. These discussions will dictate funding. The Kincaid-Smith medal will be awarded for the first time since 2018. KHA highest accolade to an Australian citizen or resident for outstanding clinical and scientific achievement in research into the treatment of diseases of the kidneys and urinary tract. CARI Indigenous Guidelines consultation has come to an end with a launch scheduled for 16th October in Sydney. 	

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	<ul style="list-style-type: none"> KHA Red Socks Run in October <p>NG ACKNOWLEDGED the work of nursing staff and their commitment to ANZDATA</p> <p>TJ NOTED that she is the chair of NZ RSA and that there have been changes within the Australian RSA who will be having a re-launch.</p> <p>TJ NOTED that nursing staff enjoy seeing the reports that come back for the work that they put in, particularly the infographics.</p>	
7.	Strategic Discussion	
7.1	The Future of ANZDATA COVID-19 Data Collection	
	<p>Members REVIEWED the current data collection form and the new streamlined data form proposal. Discussion NOTED:</p> <ul style="list-style-type: none"> The burden on units for data collection Supportive of a streamlined minimum data set Uncertainty of relevance of COVID data collection going forward Missingness of current data reporting / under reporting Good process to have in place for “next pandemic” Difficult to align with the WHO measure of severity What will be the data collection expectation in Paediatrics Reporting not happening in a timely manner With the new variants there is more COVID meaning more burden on collection No strain information is being collected <p>SM asked that streamlined data be collected for 2022 and assess the data collection and work that the COVID WG has undertaken in future.</p>	
	<p>Members AGREED to poll on COVID Data Collection at ANZSN ASM</p>	<p>220824/06 If discussed at ANZSN ASM present preliminary COVID Data analyses</p>
7.2	Data Collection Relevance	
	Hybrid Dialysis	
	<p>Members DISCUSSED how to report Hybrid Dialysis in ANZDATA NOTING:</p> <p>The two pathways moving forward are</p> <ol style="list-style-type: none"> A tick box providing a snapshot of dichotomous data at annual census with no granularity Add in course of treatments with several variables including type of HD and PD – this would require more resources and time to implement Add in course of treatments as a simple modality without further detail 	
	<p>Members AGREED that option c) be implemented</p>	<p>220824/07 ANZDATA to investigate implementing “hybrid” as an option in course of treatment</p>

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	<p>Paediatric Data Collection</p> <p>Members DISCUSSED</p> <ul style="list-style-type: none"> • Recurrent disease in graft • Uncorrected calcium reporting – why is it collected this way • Peritonitis/exit site infections • Genetic testing – possibility of including genetics question at primary cause. A yes / no option if yes a drop down box with further variables • Data collection burden will fall to paediatric community • Genetic kidney disease is on the rise and worth noting that a working group could be formed in the future 	<p>220824/08 ALP to discuss further with the paediatric community</p>
	<p>Inclusion of the first catheter insertion date for acute PD start</p> <p>Members DISCUSSED</p> <ul style="list-style-type: none"> • Urgent start on PD is on the rise • Infection prior to first use of PD catheter • Members reached CONCENSUS that PD catheter insertion date be included in data collection 	<p>220824/09 ANZDATA to implement catheter insertion date</p>
7.3	<p>How to manage HIF inhibitors with data collection</p> <ul style="list-style-type: none"> • Currently recording haemoglobin and EPO agent yes / no cross sectional at the 31st of December. • Interest in who is on these agents – minimalist approach. Instead of yes / no could have a 3-category no / EPO / HIF Inhibitor once a year reporting • Members AGREED on a 3-category minimalist approach 	<p>220824/10 ANZDATA to implement HIF 3-category reporting change</p>
7.4	<p>Working Group outputs</p> <p>NG noted the working groups workload consisted of request review, data queries, annual report chapter review and presentations. WG Convenors NOTED that they were not overburdened. Members NOTED that it is becoming more difficult to identify studies as ANZDATA was becoming more widely used by investigators outside of the working groups.</p>	
7.5	<p>Education and engagement of trainees</p> <p>Members DISCUSSED concerns around ANZDATA awareness amongst the trainee community NOTING</p> <ul style="list-style-type: none"> • Barriers are awareness, lack of statistical support and mentorship • All members are keen to increase awareness and engagement with yANZSN and RACP crucial to reaching the audience. • JHC ADVISED that she would raise this at yANZSN tomorrow (25/08/2022) 	<p>220824/11 ANZDATA to engage with yANZSN</p>

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	<ul style="list-style-type: none"> • A trainee presentation at ANZSN ASM would promote ANZDATA to trainees more widely • An annual award could be offered to trainees to garner interest • Education Options • Working groups to tap into trainee or PhD candidate resource 	

7.6 Items for ANZSM ASM

The draft schedule consists of 10-minute talks followed by a 20-minute Q&A and polling. Speakers are

1. Nick Gray
2. Stephen Mc Donald
3. Sradha Kotwal
4. Dominic Keuskamp
5. Georgie Irish
6. Adam Steinberg

Ideas for polling (including from today's discussion) are

- COVID Data Collection
- Uncorrected calcium reporting
- Hybrid Dialysis
- Pregnancy WG appetite
- In centre HD Capacity
- PROMS

SPM **THANKED** DJ for ANZSN's ongoing support for ANZDATA to have a session at the ASM. DJ **COMMITTED** continued support and **NOTED** ANZDATA session is always a top 3 attended session.

It was **NOTED** that there has been pressure to remove ANZDATA from the line up to accommodate smaller groups. DJ **CONFIRMING** the ANZSN Councils position of several core elements in every **ANZSN** ASM those being ANZDATA, AKTN and CARI. SM **NOTED** that a policy be implemented from the ANZSN Council stating this so that other groups are aware.

8. Next Meeting

November 23rd, 2022 – 12:30pm – 1:30pm ACDT Placeholder already in calendars

9. Meeting Close 3:45pm ACST

Action items from meeting:

Ref No	Item	Responsibility	Due Date	Status
220824/01	ANZDATA to commence EOI process for 2 x general and 1 NZ general Advisory Committee members	ANZDATA		
220824/02	ANZDATA to circulate FTE, positions and position funding to members	ANZDATA		Complete
220824/03	ANZDATA to identify suitable Convenor of ATSIH WG	ANZDATA		
220824/04	WG ToR - Chair Term confirmation to be taken to Executive Committee	SPM		
220824/05	New Zealand Individual Hospital Reports and “New Zealand” as an adjustment factor and the rationale behind it – NRAB and SPM meeting later today to discuss further	SPM	24/08/22	
220824/06	If COVID data collection is to be discussed at ANZSN ASM present preliminary COVID Data analyses	ANZDATA		
220824/07	ANZDATA to investigate implementing “hybrid” as an option in course of treatment	ANZDATA		
220824/08	ALP to discuss genetic testing data collection further with the paediatric community	ALP		
220824/09	ANZDATA to implement catheter insertion date	ANZDATA		
220824/10	ANZDATA to implement HIF 3-category reporting change	ANZDATA		
220824/11	ANZDATA to engage with yANZSN	ANZDATA		