

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 11th August 2021.

Attendees:

Alan Cass (Chair)	AC
Nicholas Gray (Deputy Chair)	NG
Stephen McDonald	SM
Philip Clayton	PC
Matthew Sypek	MS
Michael Collins	MC
Matthew Roberts	MR
Amelia Le Page	ALP
Rachael Morton	RM
Solomon Meneham	SMH
Bill Mulley	BM
Monique Borlace	MB
Sradha Kotwal	SK
Terry Jennings	TJ

Guests:

Chris Forbes	KHA
Breonna Robson	KHA
Mandy Farmer	Deputy Registry Manager
Shyamsundar Muthuralingam	ANZDATA Consumer Engagement Officer

Apologies:

Matthew Jose	MJ
Tina Sun	TS
Josephine Chow	JC

Minutes:

Item	Matter	Action		
1.	Welcome, present and apologies The Chair WELCOMED committee members and acknowledged the traditional custodians of the land. The Chair opened the meeting noting apologies and acknowledging the guests.			
2.	Minutes of Previous Meeting and Actions Arising Members ACCEPTED minutes of previous meeting held 19 th May 2021 and SUPPORTED ANZDATA forwarding the redacted meeting minutes for publishing to the registry website. Members provided an update of pending Action Items Members DISCUSSED the change of wording from renal to kidney recommended KDIGO and NOTED that the use of renal may get used in error on occasion.			
Ref No	Item	Responsibility	Due Date	Status
210519/01	K Hurst to circulate KDIGO nomenclature guidelines to members out of session.	K Hurst	31/5/2021	Completed
210519/02	ANZDATA Executive to discuss sharing of HOU contact details and strategies for ensuring this information is not mis-used.	ANZDATA Executive	11/08/2021	Completed

Ref No	Item	Responsibility	Due Date	Status
210519/03	S McDonald to extend meeting invitation to S Muthuramalingam for August Face to Face.	S McDonald	11/08/2021	Completed
210519/04	M Collins to provide final draft of ANZ WG ToR and Requests Relating to Patient Ethnicity to Executive for review and publication prior to next Advisory Meeting	M Collins	11/08/2021	Completed
210519/05	A Le Page to further scope data collection changes within the Working Group and report back to the Advisory Committee at the next meeting.	A Le Page	Next Meeting of Paediatric WG	Completed
210519/06	B Robson to circulate KHA annual review to members out of session when available.	B Robson	31/5/2021	Completed

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3.	Report from Executive	
3.1	Executive Officer Report SM tabled a written report as the Executive Officer. SM thanked everyone for their hard work over the past 12 months.	
3.2	Centre Survey Report SM shared the special centre survey report. NOTING <ul style="list-style-type: none"> The report would be done annually with some changes. The survey would need to be broad, but not deep and not take more than 5-10 minutes to complete. Going forward survey would include standardised core questions for comparison year to year. Large rural units would not be captured in the report currently, however this will likely change when the 3-tier unit hierarchy is introduced. The report will likely prompt data requests. The report will help justify units to secure extra funding. 	210811/01 Centre survey report to be circulated to all Working Group members for comment.
3.3	<ul style="list-style-type: none"> Some units had more than one response. The response rate was a bit patchy, with no response from any unit in Northern Territory. 	
4.	Advisory Committee Terms of Reference The Chair OPENED discussion to the Advisory Committee Terms of Reference. Members NOTED Executive have regular meetings with AOTA and NZ MOH - There is no current representation on the Advisory Committee. Members ENDORSED the Advisory Committee Terms of Reference as they stand.	
5.	Working Group Convenor Reports	
5.1	The Chair OPENED discussion to the Working Group Terms of Reference. Members NOTED that there is a cap of 2 advanced trainees and no limit on early career researchers. The Chair OPENED discussion to Working Group Convenors to provide their reports.	
	<u>Aboriginal and Torres Strait Islander Health</u>	

Item	Matter	Action
	<p>M Jose was an apology for the meeting and no written report was submitted. A Cass advised there was some renewal of membership and that there had been a lot of movement within the group.</p>	
	<p><u>Aotearoa New Zealand</u></p>	<p>210811/02 New Zealand specific patient information and Privacy and Consent forms to be uploaded to the ANZDATA website.</p>
	<p>M Collins provided an update of membership, meetings held and current projects within the Working Group, NOTING:</p> <ul style="list-style-type: none"> • MC will be moving to Adelaide in January 2022 but would temporarily remain on the working group to assist Tina Sun with transition into the role of convenor. • Members ENDORSED the changes to the Terms of Reference and the Guidance for data requestors. 	
	<p><u>Haemodialysis</u></p>	
	<p>M Roberts provided an update of membership, meetings held and current projects within the Working Group, NOTING:</p> <ul style="list-style-type: none"> • The Working Group's focus has been the annual report chapter and the analysis on quotidian data. 	
	<p><u>Paediatric</u></p>	
	<p>K Hurst provided an update of membership, meetings held and current projects within the Working Group, in place of A Le Page.</p>	
	<p><u>Peritoneal Dialysis</u></p>	
	<p>M Borlace provided 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. • Group members are reviewing ultrafiltration collection data 	
	<p><u>Patient Reported Outcome Measures</u></p>	
	<p>R Morton provided an update of membership, meetings held and current projects within the Working Group, NOTING:</p> <ul style="list-style-type: none"> • The groups focus has been the SWIFT trial with further roll out across QLD and SA soon. • Tablet and bedside collection of data opens up an array of future opportunities. 	
	<p><u>Transplant</u></p>	
	<p>B Mulley provided an update of membership, meetings held and current projects within the Working Group, NOTING:</p> <ul style="list-style-type: none"> • There has been some change with membership • The group has been working on the Antibody Mediated Rejection project with funding from Astellas – this is currently in development with aims to begin data collection next Survey Period. • The group has discussed more frequent collection of serum creatinine, both annually and at time of rejection. 	
	<p><u>Living Kidney</u></p>	

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	<p>P Clayton NOTED no further updates to be provided. Expression of Interest for General Members and Advanced Trainees have been circulated, currently have a senior, two early career researchers and a transplant nurse. Also NOTED that he would circulate a list of members when finalised.</p>	
6.	<p>KHA Update</p> <p>B Robson & C Forbes provided a report as representative for Kidney Health Australia, NOTING:</p> <ul style="list-style-type: none"> • Kidney disease is not as high profile as it should be. • KHA are looking at the economic impact of kidney failure in Australia. • Phase two of the early detection of CKD campaign has been rolled out • The Red Socks appeal to raise funds has commenced, however some other fundraising is being affected by COVID restrictions (National Walks and Car Rally) • The Clinical Advisory Committee has been re-established at KHA. • There is an article to be published in November on treating CKD. • KHA is currently involved in the update of the cardiovascular risk guidelines to ensure kidneys are considered. 	
7.	Strategic Discussion	
7.1	<p>Quality Indicators</p> <p>Members NOTED that Chris Davies has been working on the KPI report and NOTED that there are a few issues coming out of the reports which will be discussed at DNT Meeting. Members DISCUSSED future versions of the report including having a consumer version and if it should be published publicly.</p> <p>Members NOTED that the 2019 data will go out by DNT with the 2020 data to follow shortly after DNT. Members DISCUSSED how Aboriginal and Torres Strait Islander patients are captured and NOTED that ethnicity can be self-identified, or unit identified.</p> <p>Members NOTED that there is a degree of under reporting of new patients and events in real time.</p>	
7.2	<p>Data quality, validity and completeness</p> <p>Members NOTED that there has not been a formal audit of data in ANZDATA, although some studies have compared data obtained through various sources, such as comparisons of causes of death as entered in ANZDATA with death certificate information. Members AGREED that an audit would be a large and challenging process and would require funding. Members NOTED that Georgie Irish will be looking at primary renal disease and comorbidities.</p>	<p>210811/03</p> <p>SM to write a generic statement for the website stating that ANZDATA has not gone through a formal external data audit.</p>
<p>Members DISCUSSED and NOTED to focus on key variables including commencement of renal replacement therapy, treatment modality and mortality with further clarification on comorbidities and primary renal disease. Also NOTED that working groups could identify variables for improvement and provide education.</p>		
7.3	<p>Data Collection</p> <p>Members DISCUSSED the collection of specific data fields including uncorrected calcium and phosphate and NOTED that guidance from CARI regarding the relevance of these measures would be useful.</p>	<p>210811/04</p> <p>SM to write to Rathika regarding if CARI have any plans to review biochemical guidelines.</p>
7.3.1	<p>Members also DISCUSSED if there was any scope for capturing patients who never start dialysis due to patient choice or were never referred.</p>	<p>210811/05</p> <p>Working groups to look at collected data variables and discuss how relevant it is going forward.</p>
	Quotidian Data	

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7.4	<p>MR shared his findings regarding quotidian data collection. Members DISCUSSED the collection of quotidian data and AGREED to have a poll after the presentation at ANZSN to get the input of contributors before considering discontinuing collection.</p> <p>ANZDATA Opportunities and Focus Consumer Engagement</p> <p>Shyamsundar Muthuralingam presented to the committee regarding his work around consumer engagement at ANZDATA. Members NOTED that infographics continue to be developed and that work was being done to produce NZ specific infographics.</p> <p>Members NOTED that development of a consumer advisory panel was in the works. Also NOTED that it would be good to have formalised consumer input of what data is/is not collected by the Registry.</p>	<p>210811/06</p> <p>MR to have a poll after ANZSN presentation to get input from contributors regarding ongoing collection of quotidian data.</p>
8.	<p>Reflection</p> <p>Members NOTED that there is a lot that can be discussed and taken back to working groups. Also NOTED that virtual meetings appear to be more effective.</p>	
9.	<p>Next Meeting</p> <p>November 24th, 2021</p>	
10.	<p>Meeting Close – 3:55 pm</p>	

Action items from meeting:

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210811/01	Centre survey report to be circulated to all Working Group members for comment.	K Hurst	12/08/2021	Completed
210811/02	New Zealand specific patient information and Privacy and Consent forms to be uploaded to the ANZDATA website	K Hurst	TBD	Pending
210811/03	SM to write a generic statement for the website regarding that ANZDATA has not gone through a formal external data audit.	S McDonald	TBD	Pending
210811/04	SM to write to Rathika regarding if CARI have any plans to review biochemical guidelines.	S McDonald	11/8/2021	Completed
210811/05	Working groups to look at collected data variables and discuss how relevant it is going forward.	Working Groups	TBD	Pending
210811/06	<p>MR to have a poll after ANZSN presentation to get input from contributors regarding ongoing collection of quotidian data.</p> <p><i>No poll occurred at the ANZSN ANZDATA Session on August 31, no input from contributors was obtained, and the decision by the ANZDATA Executive was to discontinue</i></p>	M Roberts	02/09/2021	Superseded