

Meeting:

Meeting of the ANZDATA Advisory Committee of the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) held by videoconference at 12:30pm – 1:30pm (ACDT) on 24th November 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
Tina Sun	TS
Josephine Chow	JC
Breonna Robson	BR

Guests:

Kelly Marshall
Georgina Irish

Apologies:

Matthew Jose MJ
Amelia Le Page ALP

Minutes:

Item	Matter	Action
1.	<p>Welcome, present and apologies</p> <p>The Chair WELCOMED committee members and acknowledged the traditional custodians of the lands throughout Australia and Aotearoa, their culture and heritage. The Chair opened the meeting noting apologies and acknowledging the guests.</p> <p>No Declarations of Conflict of Interest were NOTED.</p>	
2.	<p>Minutes of Previous Meeting and Actions Arising</p> <p>Members ACCEPTED minutes of previous meeting held 11th August 2021 and SUPPORTED ANZDATA publishing minutes to the website, no redactions noted.</p>	
3.	<p>Actions Arising</p> <p>NOTED no further comments to add for action items.</p>	

Item	Matter	Action
4.	<p>Report from Executive</p> <p>4.1. Organisation and Developments NOTED that Gabriella Lincoln resigned, a replacement has been appointed for start in mid-December, in the meantime Kathryn Dansie has temporarily increased from 2 to 4 days.</p> <p>4.2. Ongoing Developments NOTED that the Individual Hospital Reports are due to be released. SM also NOTED;</p> <ul style="list-style-type: none"> • NIKTT - progressing well • BEAT CKD - there will be an interesting evolution with the collaboration due to the program grant stopping at the end of this year. • ANZOD – continues as a critical source for the Organ and Tissue Authority (OTA). • A formation of an ANZOD specific Working Group is currently in the works. • Funded by OTA to produce a report regarding the Cardiovascular Transplant Registry which has been done • SAHMRI – there has been an increasing consolidation in the registry space with 3 other main registries. • SM is a co-chair of a Registry Special Interest group at ACTA, who hosted a registries day at the ACTA Annual Scientific Meeting. 	
5. 5.1	<p>Working Group Convenor Reports</p> <p>The Chair OPENED discussion to Working Group Convenors to provide their reports.</p> <p><u>Aboriginal and Torres Strait Islander Health</u></p> <p>M Jose was an apology for the meeting, a summary report will be available for circulation.</p> <p><u>Aotearoa New Zealand</u></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 has his resignation coming up however would remain on the group to assist with a smooth transition. • A New Zealand paediatric unit was using the Australian version of the consent form, this has since been rectified. • The group plans to meet one more time before the end of the year. <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 have put in a number of report change requests, therefore the HD chapter will look quite different this year • Quotidian dialysis was presented at ANZSN, however nothing has progressed further from there • Collection of quotidian data will cease from 01/01/2022 	<p>211124/01</p> <p>MC to have a discussion with Chanelle regarding closing the loop of the use of the correct consent forms for NZ</p>

Living Kidney

P Clayton provided an update of membership, meetings held and current projects within the Working Group, **NOTING:**

- The Working Group had their first meeting in September which was mostly brainstorming
- **The group plans to meet again in the next few couple of months.**

Paediatric

A Le Page was an apology for the meeting, a summary report will be available for circulation.

Peritoneal Dialysis

K Hurst provided an update of the Working Group for M Borlace, **NOTING:**

- The working group is reviewing PET and Adequacy data to look at the feasibility of ongoing collection

Patient Reported Outcome Measures

R Morton provided an update of membership, meetings held and current projects within the Working Group, **NOTING:**

- The groups had not met since last Advisory meeting due to availability
- SWIFT is going well and is due to start in Queensland and South Australia soon
- Lavern Greenham has been fantastic
- Implementation of self-reported data is not easy, there has been a lot of operational learning.
- The group will look to have an injection of new members soon.

Transplant

B Mulley provided an update of membership, meetings held and current projects within the Working Group, **NOTING:**

- The group has been meeting quarterly
- A notification to heads of unit regarding the additional collection of AMR is due to be sent soon
- The group has proposed to include an annual collection of serum creatinine which is currently being scoped for cost and development prior to discussing implementation.

6. **KHA Update**

B Robson a verbal update as representative for Kidney Health Australia, **NOTING:**

- KHA have a comprehensive program of work
- It is currently an interesting time of year as KHA finish up and finalised the plan for 2022
- Factsheets and information books are being finalised for publication
- Within the community KHA have a renal nurse ambassador program and a buddy (peer support) program
- The kidney busses should be back in operation in 2022

7.	<p>Other Matters</p> <p><u>Data Collection and Variable Updates – Primary Kidney Disease Coding</u></p> <p>G Irish presented her proposal for updating the PKD coding NOTING;</p> <ul style="list-style-type: none"> • A number of coding options were reviewed including ERA-EDTA, SNOW MED and ICD10 • ERA-EDTA are more clear in comparison to others and codes can be searched on the ERA-EDTA website • Some mapping isn't clear, these may be best left unmatched <p><u>Other</u></p> <p>R Morton NOTED that there is a large amount of missing data relating to trials patients, members briefly DISCUSSED that some data linkage including with Births, Deaths and Marriages could help with some of this, however members AGREED to discuss further.</p>	<p>211124/02</p> <p>GI to circulate mapping of PKD codes to members and working groups</p> <p>211124/03</p> <p>Members to provide feedback to GI regarding the PKD code mapping</p>
8.	<p>Next Meeting</p> <p>February 23rd, 2022</p>	
9.	<p>Meeting Close – 1:33 pm (ACDT)</p>	

Action items from meeting:

Ref No	Item	Responsibility	Due Date	Status
210811/02	New Zealand specific patient information and Privacy and Consent forms to be uploaded to the ANZDATA website	K Hurst	TBD	Completed
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	Completed
210811/05	Working groups to look at collected data variables and discuss how relevant it is going forward.	Working Groups	TBD	Pending
211124/01	MC to have a discussion with Chanelle regarding closing the loop of the use of the correct consent forms for NZ	Michael Collins	TBD	
211124/02	GI to circulate mapping of PKD codes to members and working groups	Georgie Irish	25/11/2021	
211124/03	Members to provide feedback to GI regarding the PKD code mapping	All Members	10/12/2021	