

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 19th May 2020.

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
Josephine Chow	JC
Tina Sun	TS

Guests:

Chris Forbes	KHA
Breonna Robson	KHA
Mandy Farmer	Deputy Registry Manager

Apologies:

Bill Mulley	BM
Matthew Jose	MJ
Monique Borlace	MB
Sradha Kotwal	SK
Terry Jennings	TJ

Minutes:

Item	Matter	Action
1.	Welcome, present and apologies	
	The Chair WELCOMED committee members and acknowledged the traditional custodians of the land. T Sun provided greetings from NZ. The Chair opened the meeting noting apologies and new members, acknowledging the guests Breonna Robson as representing Kidney Health Australia and Mandy Farmer (ANZDATA Deputy Registry Manager) as an observer.	
2.	Minutes of Previous Meeting and Actions Arising	
	Members ACCEPTED minutes of previous meeting held 24th February 2021 and SUPPORTED ANZDATA forwarding the redacted meeting minutes for publishing to the registry website.	
3.	Items Arising	
3.1	Members provided an update of pending Action Items as outlined in the provided attachment:	
	20118/05 Pending discussion within ANZ WG Report - CLOSED	
	210224/01 COMPLETE	
	210224/02 Pending discussion within ANZ WG Report - CLOSED	
	210224/03 Pending discussion within HD WG Report - CLOSED	
	210224/04 COMPLETE	
	210224/05 Pending discussion within PROMs WG Report - CLOSED	

Item	Matter	Action
4.	Report from Executive	
4.1.	<p>S McDonald provided a verbal report from the Executive Officer, NOTING:</p> <ul style="list-style-type: none"> • Employment of K Marshall within ANZDATA and provided a description of role and aims to scope ANZCOTR Project within ANZDATA. • K Hurst provided an update on current Survey Data Collection, NOTING positive engagement across all units. • M Sypek NOTED complete publication of the ANZDATA 43rd Annual Report, with the Haemodialysis Chapter to act as a pilot chapter of Working Group changes - including changes in ethnicity reporting by KDIGO Guidelines. 	<p>210519/01 K Hurst to circulate KDIGO nomenclature guidelines to members out of session.</p>
	<p>S McDonald invited N Gray to speak to the ANZSN Quality Indicator and Registry Subcommittee re: KPI Working Group Development, who NOTED:</p> <ul style="list-style-type: none"> • Preliminary test runs have highlighted areas of KPI reporting and data analysis still to be refined. 	
	<p>ANZDATA has responded to the Quality Indicator and Registry Subcommittee (QIRSC) of ANZSN who wish to explore ethnicity and socio-economic status variables by recommending they approach and work with relevant Working groups.</p>	
	<p>S McDonald NOTED contact from ANZSN requesting ANZDATA Head of Unit contact details for sharing.</p> <ul style="list-style-type: none"> • Members AGREE that releasing this information without proper consideration will have adverse effects on ANZDATA's relationship with contributing units – sharing of this information should be specific to select groups subject to inquiry by ANZDATA. • Members AGREE that ANZDATA Executive discuss this strategy internally feedback to the Advisory Committee. 	<p>210519/02 ANZDATA Executive to discuss sharing of HOU contact details and strategies for ensuring this information is not mis-used.</p>
	<p>S McDonald NOTED recommendations to involve consumer representation within subsequent Advisory Committee with members AGREEING to invite Shyam Muthuramalingam to the next meeting.</p>	<p>210519/03 S McDonald to extend meeting invitation to Shyam for August meeting.</p>
4.3	<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>A Cass provided an update of membership, meetings held and current projects within the Working Group, in place of M Jose, NOTING successful applications and appointment of Working Group Members as of 2021.</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"> • Ongoing review of the Working Group Terms of Reference are nearing completion with a motion to receive endorsement. Members ENDORSE the current changes to the Terms of Reference – to be reviewed internally by ANZDATA Executive Committee prior to effectuation. • The Working Group is currently generating a <i>Guidance for Requests Relating to Patient Ethnicity</i> specific to Māori and Pacifica data, with a motion to follow the same endorsement pathway as the Working Group Terms of Reference. Members SUPPORT. 	<p>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.</p>

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	<ul style="list-style-type: none"> M Collins DISCUSSED feasibility of Cancer Survey Data Collection with members AGREEING that the time-consuming nature of data collection, and variability in recorded data, required attention. K Hurst NOTED that the Registry is already assessing options to curtail this internally. 	
	<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 is currently finalising a pilot draft of the Haemodialysis Annual Report Chapter to implement changes proposed by the Group. This will be circulated to the ANZDATA Executive for review prior to effectuation. M Roberts provided an UPDATE of the Quotidian Data Analysis, NOTING that analysis was still continuing. M Roberts NOTED that currently there is no observable change in survival numbers and, as a result, the Working Group has decided to remove the quotidian figure from the Annual Report Chapter. 	
	<p><u>Paediatric</u></p>	<p>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.</p>
	<p>A Le Page provided an update of membership, meetings held and current projects within the Working Group, NOTING:</p>	
	<ul style="list-style-type: none"> 3 publications since the last meeting in February. No Projects currently underway. The Working Group is currently reviewing the Paediatric Survey to scope extended data capture for measures including cardiovascular status and anti-hypertensive medication in paediatric patients. 	
	<p><u>Peritoneal Dialysis</u></p>	
	<p>K Hurst provided an update of membership, meetings held and current projects within the Working Group, in place of M Borlace, NOTING:</p>	
	<ul style="list-style-type: none"> TEACH PD Trial is progressing well. Members have raised suggestions for changes to data collection with a motion for members to review out of session and provide comments directly to the Working Group. 	
	<p><u>Patient Recorded 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"> 1 publication since the last meeting in February. Discussions with Queensland and New South Wales district health committees regarding further PROMS and PREMs roll-out. SWIFT: 157 patients have been recruited across a number of haemodialysis centres, with translation of key SWIFT instruments underway into 7 languages. R Morton NOTED conversations surrounding translation of SWIFT Study instruments into Māori and Tongan dependant on study success in New Zealand. Participating units have expressed interest in reviewing the cost-effectiveness of SWIFT Study. The Working Group is actively screening for an Advanced Trainee member to join the group. 	

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	<u>Transplant</u>	
	Not Discussed.	
	<u>Living Kidney</u>	
	P Clayton NOTED no further updates to be provided. Expression of Interest for General Members and Advanced Trainees have been circulated and Working Group Ethics Approval is in progress.	
5.	KHA Update	
	B Robson provided a report as representative for Kidney Health Australia, NOTING:	210519/06 B Robson to circulate KHA annual review to members out of session when available.
	<ul style="list-style-type: none"> • KHA annual review and financial reports are due to be released. • A new clinical director has been elected – with a goal to establish a clinical advisory committee board with contributions from both ANZSN and TSANZ. • Phase two of the early detection of CKD campaign is due to roll out in July with further attention being provided to collaborative research approaches; socio-economic impacts on CKD is a topic of interest to stake holders. 	
6.	Other Business	
	KH NOTED expected timeframe for data lock is late July with extension to provide for the month of August, but no later, if necessary.	
7.	Next Meeting August 11 th , 2021	
	Members NOTED the circulated proposed dates for meetings in 2021.	
8.	Meeting Close – 1:37 pm	

Action items from meeting:

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	Pending
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	Pending
210519/03	S McDonald to extend meeting invitation to S Muthuramalingam for August Face to Face.	S McDonald	11/08/2021	Pending
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	Pending
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 Peadiatric WG	Pending
210519/06	B Robson to circulate KHA annual review to members out of session when available.	B Robson	31/5/2021	Pending