

# ANZDATA ADVISORY COMMITTEE MEETING FACE TO FACE



## Meeting:

Meeting of the ANZDATA Advisory Committee of the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) held by videoconference at 1:00pm – 2:00pm (ACST) on 18<sup>th</sup> November 2020.

## Attendees:

Alan Cass ( <b>Chair</b> )	AC
Nicholas Gray ( <b>Deputy Chair</b> )	NG
Stephen McDonald	SM
Philip Clayton	PC
Kylie Hurst	KH
Matthew Sypek	MS
Neil Boudville	NB
Shilpa Jesudason	SJ
Jaqui Hughes	JH
Michael Collins	MC
Matthew Roberts	MR
Amelia Le Page	ALP
Rachel Morton	RM
Sradha Kotwal	SK
Solomon Meneham	SMH

## Apologies:

Josephine Chow  
Terry Jennings  
Bill Muley  
Monique Borlace

## Minute Taker:

Daniel Meseldzija

## Minutes:

Item	Matter	Action
1.	<b>Welcome, present and apologies</b>  The Chair WELCOMED committee members and acknowledged the traditional custodians of the land. MC provided greetings from NZ. The Chair opened the meeting noting apologies and new members, acknowledging the guest Mandy Farmer (Deputy Registry Manager) as an observer.	
2.	<b>Minutes of Previous Meeting and Actions Arising</b>  Members <b>ACCEPTED</b> minutes of previous meeting held 19th August 2020 and <b>SUPPORTED</b> ANZDATA forwarding the redacted meeting minutes for publishing to the registry website.	<b>201118/01</b> K Hurst to facilitate publishing redacted August Advisory Committee Meeting minutes to ANZDATA Website.
2.1	KH provided an update of standing Action Items as outlined in the provided attachment:  <i>200819/02</i> – KH <b>NOTED</b> Working Group Terms of Reference will henceforth reflect the positive feedback received from advanced trainee members and seek to retain Advanced Trainee engagement within Working Groups.  <i>200819/04</i> – Consumer Remuneration focus group is still for discussion, slated for 2021 development.  <i>200819/06</i> – ANZDATA statistician C Davies is undertaking Quotidian Data analysis with an aim to provide this to M Roberts by weeks end – November 20.	

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	<p>200819/07 – KH <b>NOTED</b> discussions with Paediatric hospitals with a consensus reached that there has, up until this point, been a miscommunication in methods for unit data collection. KH <b>NOTED</b> plans to survey nephrologists within these units to both educate on correct data collection and prevent a similar event in future.</p> <p>200819/09 – KH <b>NOTED</b> that following Working Group Terms of Reference being endorsed/supported at this meeting, expressions of Interest for the Living Kidney Working Group will be circulated</p> <p>200819/10 – KH <b>NOTED</b> the progress undertaken by N Gray in facilitating KPIs as recommended by ANZSN KPI Workgroup.</p> <p>200819/11 – KH <b>NOTED</b> ongoing efforts with Kidney Health Australia in developing consumer Infographics.</p> <p>200819/13 – KH <b>NOTED</b> that implementation of coding updates to 'Other Comorbidities' and 'Primary Renal Disease' are slated for development in 2021.</p>	
3.	<b>Items Arising</b>	
3.1.	<p>The Chair <b>OPENED</b> the discussion to recently reworked Terms of Reference of the ANZDATA Advisory Committee:</p> <p>JH <b>DISCUSSED</b> the potential role of an Aboriginal and Torres Strait Islander Health policy expert as a member of the Advisory Committee. AC asked about ANZSN developments in this space and NB <b>NOTED</b> that ANZSN is undertaking a review of how it might best advocate for and work to support improvements in Indigenous kidney health. The ANZDATA representative on this Committee, and Chairs of the relevant Working Groups might contribute to relevant discussion. KH and NG <b>NOTED</b> that the Annual Report includes a chapter regarding ESKD in Aboriginal and Torres Strait Islander Australians, to which the Working Group has input each year. It was suggested it might be appropriate for the Working Group to consider how the chapter reports about equity in access to and outcomes with care.</p> <p>NB <b>DISCUSSED</b> amending the term 'President of ANZSN' as noted within ANZDATA Governance Documents, to 'President or Council Member' for consistency across Governance Levels. Members <b>AGREED</b>.</p>	<p><b>201118/02</b> Advisory Committee members to advise the Executive of any suggested amendments to Advisory Committee Terms of Reference, to be considered by the Executive prior to publishing on the ANZDATA website.</p> <p><b>201118/03</b> K Hurst to amend ANZSN title 'President' to 'President or Council Member' in ANZDATA Governance documents.</p>
3.2.	<p>Members <b>DISCUSSED</b> the overarching Working Group Terms of Reference, <b>APPROVING</b> and <b>ENDORISING</b> these Terms of Reference for publishing to the ANZDATA website.</p>	<p><b>201118/04</b> J Hughes to provide any suggested edits to Aboriginal and Torres Strait Islander Working Group Terms of Reference. Upon approval, K Hurst to publish to website with all approved ToR as outlined by Advisory Committee Members.</p>
3.3.	<p>JH <b>DISCUSSED</b> the Working Group Terms of Reference specific to the Aboriginal and Torres Strait Islander Health Working Group – noting that these sit with Working Group members for review but have thus far received in-principal <b>APPROVAL</b> and <b>ENDORSEMENT</b>.</p>	
3.4.	<p>MC <b>NOTED</b> that Aotearoa New Zealand Group was currently planning its first meeting since MC admission to Convenor role – members to discuss Terms of Reference specific to this Working Group and report back to Advisory re: fit for purpose.</p>	
3.5.	<p>MS <b>DISCUSSED</b> the implementation and intentions behind the circulated <i>Data Requests Relating to Ethnicity</i> policy, with SM <b>NOTING</b> the influence of 'Catching Some Air' principles in development of this policy. Members <b>ENDORSED</b> the reworked policy be published to the website.</p> <p>MS <b>DISCUSSED</b> the circulated <i>Working Group request Pro-Forma</i>, <b>NOTING</b> the aim is to bring consistency to Working Groups and how they present feedback to requestors. Members <b>NOTED</b> the value this pro-forma brings to regulating Working Group outputs within the requests process, and <b>APPROVED</b> this pro-forma be published to the ANZDATA website.</p>	<p><b>201118/05</b> M Collins to provide WG feedback/comment of Aotearoa New Zealand WG ToR.</p> <p><b>201118/06</b> K Hurst to publish <i>Data Requests Relating to Ethnicity</i> and <i>Working Group request Pro-Forma</i> to the ANZDATA Website</p>

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	MR and MC <b>NOTED</b> a need for Working Group Convenors to be kept abreast of potential overlap of projects and completion status in order to effectively facilitate feedback. Members <b>AGREED</b> .	following WG Convenor approval of the pro-forma.
		<b>201118/07</b> ANZDATA to provide WG Convenors with a list of requests specific to their WG with details of progress.
4.	<b>Report from Executive</b>	
4.1.	SM <b>TABLED</b> the written report from the Executive Officer and <b>NOTED</b> efforts of Registry Staff. SM <b>DISCUSSED</b> ANZDATA funding arrangements, <b>NOTING</b> that there were no major changes to report, and an upcoming meeting with the sponsoring bodies of ANZDATA seeks to develop long term funding strategies with ANZSN.	
4.2	SM <b>NOTED</b> no major ongoing developments.	
4.3	KH <b>DISCUSSED</b> ongoing Data Collections and Outputs, <b>NOTING</b> successful data lock as of September. Attention is now on producing and publishing the Annual Report with Working Group Convenors <b>NOTED</b> to be making progress with feedback in line with anticipated publication date. KH <b>NOTED</b> that Heads of Units have been notified that Individual Hospital Reports will be delivered to Health Service CEOs.	
	KH <b>DISCUSSED</b> Survey 71 deploy, <b>NOTING</b> this is to take place within the second week of December for data capture. Also <b>NOTED</b> for this deploy are new treatment variables: Community Dialysis, Withdrawal from Dialysis, Self-Care Haemodialysis, and the recently reworked Acute Rejection Form. Members <b>SUPPORTED</b> these changes.	
5.	<b>Working Group Convenor Reports</b>	<b>201118/08</b>
	The Chair <b>OPENED</b> discussion to Working Group Convenors to provide their reports.	K Hurst to work with Working Group Convenors to facilitate Expressions of Interest for Working Group Members.
	<b><u>Aboriginal and Torres Strait Islander Health</u></b>	
	JH <b>NOTED</b> ongoing efforts of the Aboriginal and Torres Strait Islander Health Working Group. JH thanked Advisory Committee and Executive Members for circulation of the Letter of Endorsement of <i>Data Requests Relating to Ethnicity</i> , <b>NOTING</b> feedback from the Lowitja Institute was positive. JH <b>SUGGESTED</b> ANZDATA should be recognised for its proactive stance in addressing issues relating to Data Sovereignty.	
	JH <b>NOTED</b> that, subsequent to Working Group Terms of Reference being approved by Working Group members, Expressions of Interest for new members will commence.	
	<b><u>Aotearoa New Zealand</u></b>	
	MC introduced T Sun to Advisory Committee Members and <b>NOTED</b> that the Working Group was in the process of finalising a meeting date and agenda – to be held in mid-December. Subsequently, Working Group Terms of Reference will be finalised. MC <b>NOTED</b> there will be three new members joining the Aotearoa New Zealand Working Group, with further Expressions of Interest to follow.	
	MC <b>DISCUSSED</b> recent changes to the New Zealand Privacy Act, citing this as a potential hinderance to data transfer between Australia and New Zealand. KH <b>NOTED</b> a preliminary investigation, with assistance from the	

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	<p>Ministry of Health, revealed that ANZDATA meets the proposed requirements for this Privacy Act and this should not impact data transfer between countries.</p> <p><b><u>Haemodialysis</u></b></p> <p>MR <b>NOTED</b> that membership remained stable, with an upcoming meeting scheduled in February to discuss future ambitions of the Working Group and Annual Report Chapter. MR also <b>NOTED</b> that Quotidian Data Analysis was being undertaken by ANZDATA with KH confirming that C Davies should have this analysis ready by week ending November 20.</p> <p><b><u>Paediatric</u></b></p> <p>ALP <b>NOTED</b> no further updates to be reported.</p> <p><b><u>Peritoneal Dialysis</u></b></p> <p>Not Discussed.</p> <p><b><u>Transplant</u></b></p> <p>Not Discussed.</p> <p><b><u>Patient Recorded Outcome Measures</u></b></p> <p>RM <b>NOTED</b> ongoing efforts of the Patient Recorded Outcome Measures Working Group. RM <b>DISCUSSED</b> building upon the back-of-house capabilities of ANZDATA to store PROMs as a trial module, <b>NOTING</b> the implementation of QR survey codes in linkage to assist this process. RM <b>NOTED</b> the development of translation materials via SAHMRI and ANZDATA, to be implemented further in SWIFT projects.</p> <p>RM <b>DISCUSSED</b> publishing two Expressions of Interest for Advanced Trainee Members in 2021, <b>NOTING</b> these positions serve to scope the coverage of Patient Recorded Outcome Measures across other registries to build upon ANZDATA's capacity to study this further.</p> <p><b><u>Living Kidney</u></b></p> <p>Not Discussed.</p>	
6.	<p><b>KHA Update</b></p> <p>SJ <b>NOTED</b> confirmation of continued funding from Kidney Health Australia, with subsequent funding body meetings to be held in early 2021. SJ <b>DISCUSSED</b> ongoing developments within the consumer engagement sphere, including a newsletter produced using data from ANZDATA, and <b>NOTED</b> that she would be stepping down from the position of Kidney Health Australia Representative within the ANZDATA Advisory Committee. AC thanked SJ for her contributions.</p>	
7.	<p><b>Other Business</b></p>	
7.1	<p><b>Health Economics Framework</b></p> <p>The Chair and RM <b>NOTED</b> ongoing discussions and work to be done in building a successful Health Economics Framework within ANZDATA.</p>	
7.2	<p><b>ANZSN ASM</b></p>	

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Item	Matter	Action
	SM provided a list of presentations and presenters to speak in the ANZDATA session at the upcoming ANZSN Annual Scientific Meeting. Members <b>SUPPORTED</b> .	
8.	<b>Next Meeting</b> Feb 24 <sup>th</sup> , 2021 Members <b>DISCUSSED</b> the circulated proposed dates for meetings in 2021 and <b>AGREED</b> to provide feedback regarding recurring meeting dates prior to first Advisory Committee Meeting in 2021.	<b>201118/09</b> KH to recirculate ANZDATA Advisory Committee Meeting dates for 2021 and members to confirm their availability.
9.	<b>Meeting Close</b> – 2:05pm	

## Action items from meeting:

Ref No	Item	Responsibility	Due Date	Status
201118/01	K Hurst to facilitate publishing redacted August Advisory Committee Meeting minutes to ANZDATA Website.	K Hurst	TBA	In Progress
201118/02	Advisory Committee members to advise the Executive of any suggested amendments to Advisory Committee Terms of Reference, to be considered by the Executive prior to publishing on the ANZDATA website.	All Members	TBA	In Progress
201118/03	K Hurst to amend ANZSN title 'President' to 'President or Council Member' in ANZDATA Governance documents.	K Hurst	TBA	In Progress
201118/04	J Hughes to provide any edits to Aboriginal and Torres Strait Islander Working Group Terms of Reference by close of month. Upon approval, K Hurst to publish to website with all approved ToR as outlined by Advisory Committee Members.	J Hughes & K Hurst	30/11/2020	Complete
201118/05	M Collins to provide WG feedback/comment of Aotearoa New Zealand WG ToR	M Collins	TBA	In Progress
201118/06	K Hurst to publish <i>Data Requests Relating to Ethnicity and Working Group request Pro-Forma</i> to the ANZDATA Website following WG Convenor approval of the pro-forma.	K Hurst	TBA	In Progress
201118/07	ANZDATA to provide WG Convenors with a list of requests specific to their WG with details of progress.	ANZDATA	01/12/2020	In Progress
201118/08	K Hurst to work with Working Group Convenors to facilitate Expressions of Interest for Working Group Members.	K Hurst	TBA	In Progress
201118/09	KH to recirculate ANZDATA Advisory Committee Meeting dates for 2021 and members to confirm their availability.	K Hurst	24/02/2021	In Progress