

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 10:00am – 4:00pm (ACST) on 19th August 2020.

Attendees:

Alan Cass (Chair)	AC	Michael Collins	MC
Nicholas Gray (Deputy Chair)	NG	Matthew Roberts	MR
Stephen McDonald	SM	Monique Borlace	MB
Philip Clayton	PC	Bill Mulley	BM
Kylie Hurst	KH	Amelia Le Page	ALP
Matthew Sypek	MS	Rachel Morton	RM
Neil Boudville	NB	Sradha Kotwal	SK
Terry Jennings	TJ	Solomon Meneham	SMH
Jaqui Hughes	JH	Josephine Chow	JC

Apologies:

Shilpa Jesudason

Guest:

Mandy Farmer

Minute Taker:

Daniel Meseldzija

Minutes:

Item	Matter	Action
1.	Welcome, present and apologies 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.	Minutes of Previous Meeting and Actions Arising	
2.1.	Members ACCEPTED minutes of previous meeting held 20th May 2020 and ENDORSED the redacted meeting minutes for publishing to the registry website	
2.2.	Actions Arising KH NOTED two action items (200520/07, 200520/08) in pending completion and for further discussion in today's meeting agenda.	Nil
3.	Report from Executive	
3.1.	SM TABLED the written report from the Executive Officer and NOTED efforts of Registry Staff. The Chair opened the item for comment or discussion. Members DISCUSSED broader registry growth and engagement. RM NOTED clarity needed regarding ACTA Registries special interest group role within registry, SM NOTED ongoing discussion of ACTA role in Registry science provided opportunity for future registry development and further unity between Registry and Trials. MC & RM NOTED the capacity for further registry development looks feasible provided that plans are developed prior to funding allocations.	Nil

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	<p>The Chair NOTED that there is a capacity for SM to highlight work of Registry in consumer engagement to appropriate funding parties, to further Registry growth.</p> <p>Members DISCUSSED Registry sustainability into the future – SM NOTED that McNeil Report identified Registry current model regarding lack of paid senior medical staff as being unsustainable in the long term. SM NOTED need for growth in both size and expertise to enhance critical mass. There is a possibility of the AU & NZ Heart and Lung Transplant Registry (ANZCOTR) data to be hosted by ANZDATA provided potential for this some growth.</p> <p>SM NOTED funding halt for Epidemiology Fellow position – RM, MS & SM DISCUSSED applications of Tied v Untied Grants to assist Registry function in a similar capacity. Members AGREED that capacity needs to be maintained</p>	
4.	Committee Terms of Reference (TOR)	
4.1.	<p>Members DISCUSSED the TOR of Advisory Committee re: Fit for Purpose.</p> <p>JH NOTED potential of Aboriginal Health Leadership within the Advisory Committee to support the Bridge the Gap campaign - key development and directions are facilitated by ANZDATA</p> <p>MC NOTED amendments to be made to both Working Group name and New Zealand Representative member role, NZ Rep – ANZSN Chapter.</p> <p>JC DISCUSSED strategic capacity of Working Groups in securing funding and potential research avenues i.e. COVID, Calciphylaxis Incidence. Members AGREED that strategic input is a key role of Advisory Committee and this is an avenue worth further expansion into and would discuss future prospects.</p> <p>Members AGREED that TOR be updated and recirculated prior to next Advisory Committee Meeting, with a view to approval out of session of consensus reached.</p>	<p>200819/01</p> <p>TOR for Advisory Committee to be updated and recirculated prior to next Advisory Committee Meeting</p>
5.	Working Group	
5.1	Working Group Terms of Reference Review	<p>200819/02</p> <p>K Hurst to follow-up with Advanced Trainee (AT) members about their experiences and WG Convenors for feedback about the contribution of AT members.</p>
	<p>The Chair raised whether the structure and TOR of Working Groups are still fit for purpose.</p> <p>RM DISCUSSED amendments to WG TOR calling for Advanced Trainee/Early Career Researcher positions within future EOIs. Members AGREED that Advanced Trainee Membership is necessary for active succession planning and dedication to seeing projects through to completion. ECR opportunities should arise through current mechanisms as part of achieving diversity within groups.</p> <p>Members DISCUSSED and AGREED that WG Convenors should have the authority to appropriately facilitate the retirement of members who are no longer contributing to the group. Members AGREED that future EOI's need to express importance of active contribution from future members, noting that the nature of this contribution will vary with the skills and expertise of members.</p> <p>BM and MC NOTED that retiring senior WG members costs WG expertise and productivity. Members AGREED that TOR should be amended to allow Convenors capacity to extend WG contracts for senior members to improve WG functionality – however, members NOTED this must not block the intake of new members. It was NOTED there is no fixed limit on WG numbers.</p> <p>Members NOTED positive engagement and experiences with advanced traineeship members – JH DISCUSSED creation of a Survey Monkey to assess experience and engagement of Advance Trainee members and Convenors, to steer future direction of WG members and projects.</p>	

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	<p>Members AGREED that TOR be updated in line with Working Group expectations of future members and modified to allow Convenors the capacity to renew senior membership if they see fit.</p>	<p>200819/03</p> <p>ANZDATA to re- draft WG TOR to include succession planning, active participation from members, capacity for renewing senior membership and expectations for working group.</p>
5.2	<p>Working Group Convenor Reports</p> <p>Chair NOTED all WG Convenor reports were circulated in meeting papers and deemed as read by Members.</p> <p>Working Group Convenors provided an update surrounding membership, current projects and publications and data collection changes.</p>	
6.	<p>KHA Update - No Discussion.</p>	<p>Nil</p>
7.	<p>Clinical Directions and Purpose</p>	
7.1.	<p><u>ANZSN ‘Cranshaw’ Report & KPI’s</u></p> <p>NG NOTED meeting papers circulated and provided an update regarding the role of ANZDATA and ANZSN governance structures - specifically recommendation to combine CPAC & Dialysis Advisory Committee into a <i>Policy Safety and Quality Committee</i>, which includes a Clinical and Quality Indicators and Registries Sub-Committee.</p> <p>NB NOTED further collaboration with ANZSN and ANZDATA re: setting KPI structure - members NOTED the need for transparency in reporting lines and communication.</p> <p>SM provided an outline of current reporting lines and governance structure and NOTED that the process of clarification of lines of communication of ANZDATA Exec within ANZSN at a committee level was in process. SM NOTED the report clarified that there is no “ownership “of ANZDATA’s data by ANZSN, and the relationship is one of two closely allied groups. NB seconded that ANZSN was committed to a strong ongoing relationship with ANZDATA and further discussions about shared strategic aims are planned.</p> <p>MC DISCUSSED KPIs related to transplant listings re: Index Groups.</p> <p>Members NOTED that how “Index Groups” for comparison purposes are chosen will frame discussions of inequities, particularly groups of patients are excluded based on ethnicity, presence of comorbidities or age - Members AGREED that KPIs need to highlight critical disparities in access to transplant/dialysis services – to improve data output of registry.</p> <p>Members DISCUSSED KPI re: transplant waitlisting at 6 months as a crucial KPI.</p> <p>JH NOTED the need to engage deeply with Indigenous patients and communities to understand their experiences within the system. Will need to consider the relevance and appropriateness of KPIs for Indigenous communities re: access to services, outcomes, and further care. Members AGREED that this approach should be pursued.</p> <p>NG NOTED re: Recommendation 5 in meeting agenda ‘Forging Strategic Partnerships’ that; the Advisory Committee will consider feedback from KPI WG and notify relevant Heads of Units and District Health Boards of relevant KPIs of their centres in an effort to further close the gap between the Registry and units.</p>	<p>200819/10</p> <p>Registry to partner with ANZSN Clinical Quality Indicators and Registries Sub-committee in monitoring the implementation of agreed KPIs.</p>

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	<p>RM NOTED re: above, that peer review and feedback is also necessary in conjunction with feedback from Heads of Units/District Health Boards, allowing the Registry to support or endorse data reports that show variation.</p> <p>Members NOTED the need to create awareness of Transplant and Standardized Mortality KPI's to ANZSN to accurately gauge individual unit performance. Members NOTED that again, the Registry requires more transparent communication and reporting lines to ANZSN.</p> <p>Members AGREED for further KPI discussion around Consumer Engagement; KH DISCUSSED the idea of taking KPI's and turning them into Infographics to be displayed in units for further engagement with consumers and public. Members AGREED that this was a viable avenue to pursue and NOTED KHA may be interested in assisting within this sphere.</p> <p>NG DISCUSSED a KPI for units to report every twelve months to remove wide variation in data produced by smaller units – data to be assessed by KPI WG before takeover and then compared to newly produced data to compare outputs.</p> <p>Members DISCUSSED adding a KPI on timeliness and completeness of data submission to eliminate missing data submissions – NOTED to have had success in VIC and QLD.</p>	<p>200819/11</p> <p>KH to be in further contact with KHA re: development of infographics in units summarising KPI's of the Registry for communication with the public.</p>
7.2	<p><u>Data Requests Relating to Ethnicity</u></p> <p>MS NOTED the revised policy regarding how data requests should address patient ethnicity has progressed on the work initiated by the Aboriginal Torres Strait Islander Health and Aotearoa New Zealand Working Groups. Where ethnicity is a focus of the entire request or a variable in analysis, this will require researchers to outline their approach to engagement, capacity building, data sovereignty, and knowledge translation. Members AGREED.</p> <p>Members ENDORSED the decision to move forward with the revised policy.</p>	<p>200819/12</p> <p>Revised policy to be circulated and published to website.</p>
7.3	<p>Data Collection/Projects</p>	
7.3.1	<p><u>'Primary Renal Disease' Coding:</u></p> <p>SM NOTED that current coding for 'Primary Renal Disease' on the survey is out of date – current process to identify and modify incorrect coding is underway, to be compared with new coding to see if fit for purpose. KH DISCUSSED to take committee feedback re: coding and bring to Exec to discuss internally as feedback from patients and broader nephrological society is needed before a decision is reached. Potential EOI for initial canvassing of nephrology and consumer community re: are small changes to coding over time more effective than complete overhaul?</p> <p>Members AGREED for Exec to manage updates and adjustments to coding re: Primary Renal Disease, Other Comorbidities and Gender; and to reach out to nephrology, nursing unit and consumer communities for feedback prior to reconvene with Advisory Committee.</p>	<p>200819/13</p> <p>Registry to establish a Working Group to advise updates to coding for primary Renal Disease and Other Comorbidities. Report will be brought back to Advisory Committee for consideration in 2021.</p>
	<p><u>9.1.2. 'Other Comorbidities' Coding:</u></p> <p>Members NOTED lack of use of this function on survey. Various options were discussed including deleting the item and having specific data collections. It was NOTED that there is some utility in having one area of the data collection to report 'free text.' Members AGREED that this function needs further refining.</p>	
	<p><u>9.1.3. 'Gender' Coding</u></p> <p>MS NOTED that 'Gender' coding on survey is also out of date – Members AGREED and SUPPORTED a change to the standardized coding suggested by MS to include 'Transgender' and 'Other' as opposed to just 'Intersex'.</p>	<p>200819/14</p> <p>Registry to establish a Working Group to advise updates to coding for Gender Coding. Report will be brought back to Advisory</p>

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	<u>9.1.4. 'Ethnicity Analysis':</u> KH NOTED implementation of the second ethnicity option on survey to account for all ethnicities recorded will impact analysis. Members AGREED further discussion internally by Exec is warranted	Committee for consideration in 2021.
10.	Other Business	Nil
11.	Next Meeting 18 November 2020	
12.	Meeting Close – 4:00pm	

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Action items from meeting:

Ref No	Item	Responsibility	Due Date	Status
200819/14	Registry to establish a Working Group to advise updates to coding for Gender Coding. Report will be brought back to Advisory Committee for consideration in 2021.	Exec	TBA	
200819/13	Registry to establish a Working Group to advise regarding updates to coding for primary Renal Disease and Other Comorbidities. Report will be brought back to Advisory Committee for consideration in 2021	Exec	18/11/2020	
200819/12	Revised policy to be circulated and published to website.	ANZDATA	TBA	
200819/11	KH to be in further contact with KHA re: development of infographics in units summarising KPI's of the Registry for communication with the public.	KH	18/11/2020	
200819/10	Registry to partner with ANZSN Clinical and Quality Indicators and Registries Sub-committee in monitoring the implementation of collection ok agreed KPI's.	Exec	1/2/2021	
200819/09	Registry to facilitate discussions around Living Kidney WG development, with P Clayton as WG Convenor.	KH	18/11/2020	
200819/08	ANZDATA to publish Transplant Working Group publication to website.	ANZDATA	TBA	
200819/07	K Hurst to investigate missing patient data re: mortality rates up to three months in paediatric units and report back to A Le Page.	KH	30/09/2020	
200819/06	K Hurst to provide update re: Quotidian Dialysis Collection Survey completion and implementation for 2020 survey at next advisory.	KH	TBA	
200819/05	K Hurst to inform MC of unit contacts in NZ to facilitate EOI for NZ WG	KH	18/11/2020	
200819/04	S McDonald & K Hurst to assess feasibility of consumer remuneration scheme for Aboriginal Torres Strait Islander Health WG and report back to Advisory Committee prior to possible implementation.	SM	18/11/2020	
200819/03	ANZDATA to re-draft WG TOR to include succession planning, active participation from members, capacity for renewing senior membership and expectations for working group.	ANZDATA	18/11/2020	
200819/02	K Hurst to follow-up with Advanced Trainee Members about their experiences and WG Convenors for feedback about the contribution of AT members.	KH	18/11/2020	
200819/01	TOR's for Advisory Committee to be updated in line with recommendations discussed at the meeting and re-circulated to Members membership if they see fit.	Exec	18/11/2020	