

# ANZDATA ADVISORY COMMITTEE

## MINUTES OF MEETING



Meeting of the Advisory Committee of the Australian and New Zealand Dialysis and Transplant Registry held by videoconference at 12:30pm – 1:30pm (ACST) on Wednesday 20 May 2020.

### Members:

|                  |  |
|------------------|--|
| Alan Cass        | Chair  |
| Nick Gray        | Deputy Chair   |
| Stephen McDonald | ANZDATA Executive Officer                              |
| Kylie Hurst      | ANZDATA Registry Manager                               |
| Philip Clayton   | ANZDATA Editor   |
| Matt Sypek       | Fellow in Epidemiology                                 |
| Shilpa Jesudason | Kidney Health Australia                                |
| Michael Collins  | General Member   |
| Neil Boudville   | ANZSN  |
| Matthew Roberts  | Haemodialysis WG Convenor                              |
| Rachael Morton   | PROMS WG Convenor                                      |
| Bill Mulley      | Transplantation WG Convenor                            |
| Jaqui Hughes     | Aboriginal & Torres Strait Islander Health WG Convenor |
| Monique Borlace  | Peritoneal Dialysis WG Convenor                        |

### Apologies:

|                |                        |
|----------------|------------------------|
| Terry Jennings | RSA Representative     |
| Amelia Le Page | Paediatric WG Convenor |

### Vacant Positions:

Aotearoa New Zealand WG Convenor  
 General Member  
 General Member

### Acknowledgement of Country:

I would like to acknowledge this land that we meet on today as the traditional lands for the Kaurna people and we respect their spiritual relationship with their country. As a group across Australia and New Zealand, We acknowledge the traditional custodians of the lands throughout Australia and Aotearoa, their culture and heritage. We pass our respect to their elders, past and present.

### Māori Welcome

Tena koutou, tena koutou, tena koutou, katoa - Greetings, Greetings, Greetings to you all.

### Minutes

| Item | Matter  | Action                                 |
|------|---|--|
| 1.   | <b>Welcome, present and apologies</b><br>Apologies: Noted<br>Guest/s: Nil.  | Nil.                                   |
| 1.1. | <b>Acknowledgment of Country and Māori Welcome</b>  |  |
| 2.   | <b>Minutes of previous meeting</b><br>Endorsed by N Boudville, seconded by M Roberts.   | <b>200520/01</b><br>publish to website |
| 3.   | <b>Action Items Outstanding (<a href="#">Attach 3</a>)</b> <ul style="list-style-type: none"> <li>191120/06 – <b>NOTED</b> the EOI's for two General Members were circulated through ANZSN, TSANZ, RSA, ANZDATA Website and scheduled Registry weekly notifications with the closing date 6 June 2020.</li> </ul> |  |

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| Item      | Discussion  | Action   |
|-----------|---|--|
| <b>4.</b> | <b>Report from Executive</b>  |  |
| 4.1.      | <p><u>Staffing</u></p> <p>S.McDonald <b>NOTED</b> ANZDATA staff are still working from home and some staff members will be (or are currently on) maternity leave. Approximately 20 extra VPN licences have been acquired, and assistance has been provided to ensure staff home workstations are well equipped.</p>   | <p><b>200520/02</b></p> <p>K Hurst to email 2018 data HD Annual Report Chapter to R Morton for review.</p> |
| 4.2.      | <p><u>IT Websites</u></p>   |  |
| 4.3.      | <p><u>Data Collection</u></p> <p>K.Hurst <b>NOTED</b> the Survey data is 82% completed, with over <math>\frac{3}{4}</math> of Units completing data entry online or via electronic submission.</p>  |  |
| 4.4.      | <p><u>Data Output</u></p> <p>K.Hurst <b>NOTED</b> the Annual Report is published with HD Chapter the final one for release this month.</p> <p>(Note: data requests discussed in item 5)</p>   |  |
| <b>5.</b> | <p><b>Policies &amp; Governance</b></p> <p>S.McDonald:</p> <ul style="list-style-type: none"> <li><b>NOTED</b> AOTA's broad reaching data governance strategy has been developed with increasing interest in consistent data governance and access to deidentified data across all outcome registries.</li> <li><b>NOTED</b> that the ANZSN commissioned 'Cranshaw Review' with the report completed although yet to be acted on. It identified clarity of the relationship between ANZSN and ANZDATA with clear recommendations regarding advisory roles on KPI's and centre reporting of ANZSN. J.Hughes congratulated S.McDonald and N.Boudville on progress made to date on this.</li> <li><b>NOTED</b> progress of work and discussions on ATSIH WG data governance, policies and approaches to data requests. Discussions re WG involvement are ongoing with work still to be done on documentation and operationalising the framework internally at ANZDATA. Expected to lead to better engagement of ATSI people &amp; community more broadly and ability to document lessons learned through the process.</li> </ul> | Nil  |
| <b>6.</b> | <p><b>Clinical Directions &amp; Purpose</b></p> <p>N.Gray <b>NOTED</b> the area of focus for the KPI WG will be oversight of Individual Hospital Reports and KPI's produced by ANZDATA, to be discussed at next meeting councils WG. Consideration for sharing of reports.</p> <p>N.Boudville further <b>NOTED</b> the clarity the Cranshaw report provides the Society keen to develop a model to 'close the loop' for ANZDATA and Society</p> <p>S.McDonald <b>NOTED</b> ANZDATA will establish a Committee for review of KPI's and Reports. It will contain of technical and clinical representation and how units and stakeholders responsible for hospital performance, working with Society on how outliers are advised or communicated to.</p> <p>S.Jesudason <b>NOTED</b> it is important to understand how patients would like their data used and reported, showing that KPI's are being met. There is ongoing work in the Registry with dedicated resources on engagement of Patients and ways to improve visibility of Registry's work.</p>   | Nil  |

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| 7.   | <b>Updates from Working Groups</b>  | Nil  |
| 7.1. | <p><u>Aotearoa/New Zealand</u></p> <p>M.Collins tabled a written report and provided discussion around:</p> <ul style="list-style-type: none"> <li>Capacity is low in the group with vacancies of convenor of the WG and current members stretched;</li> <li>EOI to come from ANZDATA to NZ Chapter (S.Palmer) the circulated. Aim to establish better relationships with NRAB in NZ;</li> <li>The Aotearoa NZ WG Strategic Plan 2020 - 2025 has been prepared by the Working Group (back in December 2019);</li> <li>Shared the Aotearoa/NZ WG guidance for ANZDATA requests to be provided for requests involving NZ patients who have shared their health information with ANZDATA.</li> </ul>   | <p><b>200520/03</b></p> <p>K.Hurst to coordinate a meeting on NZ WG capacity issue and EOI</p>   |
| 7.2. | <p><u>Aboriginal and Torres Strait Islander Health</u></p> <p>J Hughes provided verbal report updating on:</p> <ul style="list-style-type: none"> <li>The last WG meeting held on 7 May 2020; Currently 3 members of the WG; Seeking additional members; Executive member representative has joined the committee (M.Jose);</li> <li>a letter of support for an EIO on the NHMRC Research Network has progressed to the next stage;</li> <li>WG Resources have been uploaded to website;</li> <li>Contributed to the AIHW Report regarding Chronic Kidney Disease on Aboriginal and TSI peoples;</li> <li>Progression of Screening Tool (whilst recognising that it is still in the pilot phase) – any feedback provided to J Hughes out of session;</li> <li>The new infographic has been approved for publication to website and agreed to be publish for next 4 years (as per agreed licencing);</li> <li><b>NOTED</b> WG TOR still to be reviewed and confirm that they are consistent with the WG’s operational requirements;</li> <li><b>NOTED</b> the updated request process is yet to be finalised and released for advice to contributors.</li> </ul> | <p><b>200520/04</b></p> <p>J.Hughes to make enquiries and feedback to Executive Committee specifics on how they can explore engaging in the <b>Close the Gap Campaign</b>.</p> |
| 7.3. | <p><u>Haemodialysis</u></p> <p>M.Roberts provided the following updates:</p> <ul style="list-style-type: none"> <li>The last HD WG Meeting was held on 12 February 2020;</li> <li>Quotidian variable is for further analysis <b>NOTED</b> ANZDATA Registry staff to assist the analysis.</li> </ul>   | <p><b>200520/05</b></p> <p>M.Roberts to provide an update next meeting.</p>  |
| 7.4. | <p><u>Peritoneal Dialysis</u></p> <p>M.Borlace provided a summary via email:</p> <ul style="list-style-type: none"> <li>PD WG meeting held 5 May 2020;</li> <li>Number of projects outlined - NSW cross sectional survey to determine how patients on APD with peritonitis are managed in Aust. &amp; NZ; Survey PD Unit looking at pharmacokinetics with APD &amp; IPAB, as ISPD research/recommendations in CAPD regarding pharmacokinetics; project looking at association between peritonitis and CV mortality in patients on PD;</li> <li>Very early stages of leading a project on Technique failure on PD for Aboriginal &amp; Torres Strait Islanders; plans to consult with ATSIH WG &amp; invite the Working Group members to collaborate on the Research Project.</li> </ul>   | <p>Nil.</p>  |

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| 7.5. | <p><b>Transplant</b></p> <p>B.Mulley provided the following updates:</p> <ul style="list-style-type: none"> <li>The last Tx WG Meeting was held 13 May 2020;</li> <li>Project on Chronic Allograft Nephropathy;</li> <li>proposed changes of data collection on CAN and Acute rejection.</li> </ul> <p><b>NOTED</b> feedback yet to be received on proposed changes submitted to Executive last Dec.</p> <p><b>NOTED</b> by S.McDonald the process and implementation of data collection changes are to be submitted to Executive for feedback; timelines of responses back from Executive can depend on the change requested.</p> <p><b>NOTED</b> by KHurst that in the next survey period the proposed changes will be implemented, internal work continues, and an update will be provided in a few weeks.</p> | <p><b>200520/06</b></p> <p>B.Mulley to receive feedback on proposed changes.</p>   |
| 7.6. | <p><b>Paediatrics</b></p> <p>(A.Le Page an apology)</p>   | <p>Nil</p>   |
| 7.7. | <p><b>PROMS</b></p> <p>R Morton provided the following updates:</p> <ul style="list-style-type: none"> <li>The last PROMs WG Meeting was held 13 May 2020, a consumer representative joined the meeting;</li> <li>SWIFT Pilot Discovery update – an outcome regarding the application for funding for a SWIFT trial should be received soon;</li> <li>Verbal report on Home Therapies Conference (Consumer Panel) on patient experiences and thoughts about providing PROMs and PREMs measures;</li> <li>SWIFT Pilot Study completed and feedback sought from committee on peer reviewed publishing of the Pilot Study results, possibly in the Annual Report or a supplement.</li> </ul>   | <p><b>200520/07</b></p> <p>Strategic initiatives from Pilot findings to be presented and further discussed at Aug F2F AAC meeting</p>                          |
| 8.   | <p><b>Updates from KHA</b></p> <p>S Jesudason <b>NOTED</b> the <a href="#">National Strategic Action Plan for Kidney Disease</a> was launched on March 12<sup>th</sup> 2020. Funding secured for ANZDATA to continue Consumer Engagement work in research.</p> <p>KHA has recently been re-purposed during the COVID-19 pandemic and broadened its services to the Community.</p> <p>Thank you to ANZDATA for the support and accurate reporting of COVID-19 data provided to KHA throughout this busy period.</p>  | <p>Nil.</p>  |
| 9.   | <p><b>Other Matters</b></p>   | <p><b>200520/08</b></p>  |
| 9.1. | <p>Health Economics Framework</p> <ul style="list-style-type: none"> <li>A.Cass, R.Morton and S.McDonald to meet and discuss out of session.</li> </ul>   | <p>S.McDonald to coordinate a meeting</p>  |
| 10.  | <p><b>Next Meeting – 19 August 2020</b></p> <ul style="list-style-type: none"> <li>Virtual meeting (via Zoom) will take place of Annual face-to-face meeting;</li> <li>A significant portion of time on the Agenda will be allocated to Strategic discussions;</li> <li>Any suggestions/agenda items please email K.Hurst and S.McDonald - draft Agenda will then be distributed for review.</li> </ul> <p>M.Collins <b>NOTED</b> in final questions data collection burden experienced in NZ by contributors and requested enhance data linkage with NZ Health be explored.</p>  | <p><b>200520/09</b></p> <p>K.Hurst coordinate feedback for next meeting</p> <p><b>200520/10</b></p> <p>K.Hurst to follow up with NZ Health on data linkage</p> |
| 11.  | <p><b>Meeting Close – 1:45pm</b></p>  |  |

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### ACTION ITEMS

| Ref No    | Item   | Responsibility                    | Due Date     | Status/<br>Comment |
|-----------|--|-----------------------------------|--------------|--------------------|
| 200520/01 | Publish minutes of previous meeting to website   | K.Hurst                           | 31/5/2020    | Completed          |
| 200520/02 | 2019 HD Annual Report Chapter (2018 Data) to R Morton for review.  | K.Hurst                           | ASAP         | Completed          |
| 200520/03 | S McDonald, A Cass and K Hurst to meet out of session and discuss NZ WG Capacity issue, and EOI process to be sent to all members.       | S.McDonald,<br>A.Cass,<br>K.Hurst | TBD          | In progress        |
| 200520/04 | J.Hughes to make enquiries and feedback to Executive Committee specifics on how they can explore engaging in the Close the Gap Campaign. | J.Hughes                          | Next Meeting | In progress        |
| 200520/05 | K Hurst to facilitate M.Roberts analysis of quotidian data with Registry statistical support   | K.Hurst                           | Next Meeting | In progress        |
| 200520/06 | B.Mulley to receive feedback on proposed changes.  | K.Hurst                           | ASAP         | Completed          |
| 200520/07 | Strategic initiatives from Pilot findings to be presented and further discussed at Aug F2F AAC meeting                                   | R.Morton                          | Next Meeting | In progress        |
| 200520/08 | Coordinate a meeting via Zoom for a discussion re Health Economic Framework (R.Morton, A.Cass & S.McDonald)                              | S.McDonald                        | Next Meeting | In progress        |
| 200520/09 | Coordinate feedback for next meeting agenda and format   | K.Hurst                           | Next Meeting | In progress        |
| 200520/10 | Commence discussion with NZ MoH re on data linkage with NZ Health data   | K.Hurst                           | Next Meeting | In progress        |