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| **Venue**: | **Teleconference** |
| **Date:** | **Wednesday, 20th November 2019** |
| **Time:** | **9.30am - 3:30pm (ACDT)** |
| **Chair** | **Alan Cass** |

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| **Attendees:** | | |  |
| Alan Cass - (Chair)  Nick Gray - (Deputy Chair)  Stephen McDonald - (Executive Officer)  Phil Clayton - (Deputy Executive Officer)  Kylie Hurst - (Registry Manager)  Matthew Sypek - (Epidemiology Fellow)  Shilpa Jesudason - (KHA Clinical Director)  Michael Collins - (General Member)  Matthew Roberts - (HD WGC)  Rachael Morton - (PROM WGC) | | | Bill Mulley - (Transplantation WGC)  Jaqui Hughes - (A&TSI Health WGC)  Monique Borlace - (PD WGC)  Neil Boudville - (ANZSN Council Rep)  Rachael Walker - (NZ Representative)  **Apologies:**  Amelia Le Page - (Paediatrics WGC) |
| **Minute Taker:**  Brooke Cunningham - (ANZDATA) |
| 1. **Opening, Welcome and Attendance** | | | | |
| The Chair **WELCOMED** the members to the meeting and **WELCOMED** members to the traditional owners of the land. | | | | |
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| 1. **Minutes from Previous Meeting** | | | | |
| Members:  **ENDORSED** the minutes of the 14th August 2019 ANZDATA Advisory Committee meeting. Accepted by Phil Clayton and Matthew Roberts. | | | | |
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| 1. **Action items Outstanding** | | | | |
| Members:  ***140806/04*** - **NOTED** the Executive ToR formation remains ongoing.  ***180530/06*** - **NOTED** the roll out of the Calcium Phosphate forms remains pending IT. On Hold.  ***180808/05*** - **NOTED** that the ANZDATA Advisory Committee ToR remains ongoing.  ***180808/06*** - **NOTED** the ANZDATA Advisory Committee ToR remains ongoing.  ***181121/03*** - **NOTED** the feedback regarding the ANZDATA Working Groups ToR draft remains ongoing.  ***190213/02*** - **NOTED** SPM has had discussions with Nick, Jonothan and Martin regarding a joint meeting with the KPI working group. Also **NOTED** that this progressing and requires the ANZSN Council to have further inhouse discussions. Completed.  ***190213/07 -*** **NOTED** Matt Sypek has agreed to take on this action item and will the discussions regarding the suggested change of gender to sex and will put forward a draft to the NZ Working Group. Ongoing.  ***190515/02*** - **NOTED** the ToR upload to the website is pending action item 181121/03. Ongoing.  ***190515/05*** - **NOTED** the EOI for the chair of the ANZDATA Advisory Committee has been completed.  ***190814/01*** - **NOTED** that KH will follow up with Matthew Jose regarding the removal of ‘Processes and Treatment Targets’ in section 5 of the NZ ToR. Ongoing  ***190814/02*** - **NOTED** that KH will follow up with Matthew Jose regarding the NZ ToR for upload. Ongoing.  ***190814/03*** - **NOTED** that KH will follow up with Matthew Jose regarding the working group ToR for upload. Ongoing.  ***190814/04*** - **NOTED** that the Welcome to the Country has been added as a standing agenda item. Completed.  ***190814/05*** - **NOTED** that the creation of a draft health economics framework would be a large task and should be added as an agenda item for next meeting for further discussions. Also **NOTED** that small working group should be created to to explore the scope of a “Value Framework” for ANZDATA, members who expressed interest in this working group included Rachael Morton, Alan Cass, Jacqui Hughes and Stephen McDonald.  ***190814/06*** - **NOTED** that the letter to the Chair of NRAB has been sent, however no formal response received at this stage. Complete.  ***190814/07*** - **NOTED** that SPM has had discussions with Neil regarding the Committee Recommendation document. Completed.  ***190814/08*** - **NOTED** that RM circulated the Uluru Statement from the Heart to the Committee. Completed.  ***190814/09*** - **NOTED** that the endorsement of the Uluru Statement from the Heart has been put on the ANZDATA website. Completed.  ***190814/10*** - **NOTED** that the HD working group has drafted a community dialysis definition and MR will forward this to the committee. Completed.  ***190814/11*** - **NOTED** that the addition of community dialysis for collection is pending the definition from the HD working group (as per action item 190814/10). Ongoing  ***190814/12*** - **NOTED** that the HD working group intends to request some data to review the collection of quotidian data. Ongoing  ***190814/13*** - **NOTED** that MJ wrote to KHA thanking them for their ongoing support. Complete.  ***190814/14*** - **NOTED** that the RSA EOI was sent to Monique. Completed.  ***190814/15*** - **NOTED** that MB sent the RSA EOI for circulation and has been following this up. Also NOTED that the EOI is being re-circulated. Completed  ***190814/16*** - **NOTED** that there have been further updates to the Center Survey. Ongoing. | | | | |
| **Action** | 191120/01 | Kylie to follow up with Matthew Jose regarding the removal of ‘Processes and Treatment Targets’ in section 5 of the NZ ToR and the status of the ToR’s for upload (action items 190814/01, 190814/02 & 190814/03) | | |
| **Action** | 191120/02 | Health Economics Framework to be added as an agenda item for the February 2020 teleconference. | | |
| **Action** | 191120/03 | MR to forward the HD working group definition of community dialysis to the committee. | | |
| **Action** | 191120/04 | SPM to circulate the updated version of the Center Survey for comment. | | |
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| 1. **Report from Executive** | | | | |
| **4.1 Staffing**  **NOTED** that Shahid resigned in mid-October and is being replaced by Gabriella Lincoln whom is commencing on 21/11/2019. Also **NOTED** that there is an advertisement for a new Post Doctorial Fellow. Also **NOTED** that there are discussions regarding Emily’s role. Also **NOTED** there are a number of PHD students that will be returning/commencing in the near future.  **4.2 IT / Website developments**  **NOTED** that the new website is live, with regular updates occurring. Also **NOTED** the progress into fully changing to SAHMRI IT is slower than expected.  **4.3 Data Collection**  **NOTED** there are no updates at this stage.  **4.4 Data Outputs**  **4.4.1 Individual Hospital Reports**  **NOTED** the individual hospital reports have been released.  **4.4.2 Annual Report**  **NOTED** that there are some chapters that have been published on the ANZDATA website, with additional chapters currently with Phil.  **4.5 ANZDATA Review Progress**  NOTED that there are no further formal updates at this stage. Also **NOTED** that the stakeholders have scheduled a meeting for 22/11/2019 which all have confirmed that they will be attending. | | | | |
| **Action** | 191120/05 | The ANZDATA Review progress to be removed as an action item. | | |
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| 1. **ANZDATA Policies & Governance** | | | | |
| **NOTED** that AOTA have convened a strategic data governance committee, ANZDATA is well represented. The goal of this committee is to increase the availability of data. | | | | |
| **Action** | No Action | | | |
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| 1. **Clinical Directions and Purpose** | | | | |
| **NOTED** that there were no changes since the last meeting. | | | | |
| **Action** | No Action | | | |
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| 1. **Working Group Updates** | | | | |
| **NOTED** that written reports from all working groups were circulated to the committee.  **7.1 Aotearoa New Zealand**  **NOTED** that they have invited Annie Reynolds (nephrologist). Also **NOTED** the group is having a face to face meeting later this month.  **7.2 Haemodialysis**  **NOTED** that the group is keeping a close eye on haemodiafiltration. Also **NOTED** the collection of HDF volume will commence this survey.  **7.3 Aboriginal and Torres Strait Islander Health**  **NOTED** that the NIKTT conference was held in October with support of data sovereignty. Also **NOTED** that Christine Potter from the Australian Indigenous Health Info Net has requested some data, the committee is happy to support and supply the data.  **7.4 Paediatrics**  Not discussed this meeting  **7.5 Peritoneal Dialysis**  **NOTED** there are no new updates, but the group plans to meet in a few weeks.  **7.6 Transplant**  **NOTED** the Bill Mulley has taken over as the convener of the group. Also **NOTED** the group has a number of data collection proposals that they intend to make.  **7.7 Patient Reported Outcome Measures**  **NOTED** the group met in early November. Also **NOTED** that the SWIFT trial has a number of patients with baseline data collected, with the next collection in early December. Also **NOTED** that the consumer engagement at the teleconferences has dropped off, the group plans to look into a better way to engage the consumers. | | | | |
| **Action** | No Action | | | |
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| 1. **Update from Kidney Health Australia** | | | | |
| **NOTED** that KHA gave confirmed their financial commitment to the Registry. Also **NOTED** that KHA will be present at the ANZDATA Review stakeholders meeting. | | | | |
| **Action** | No Action | | | |
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| 1. **Membership** | | | | |
| **9.1 Establishing a direct link between ANZDATA Advisory Committee and the National Renal Advisory Board** | | | | |
| **Action** | No Action | | | |
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| 1. **Any other Business** | | | | |
| **NOTED** that the Dutch Renal Registry are currently running a PROMs program.  **NOTED** that there are a number of vacant positions on the committee that EOI’s will need to go out for.  **NOTED** date claiming for the 2020 ANZDATA Advisory Committee Meetings will commence in December. | | | | |
| **Action** | 191120/06 | EOI’s for the vacant positions on the committee to be circulated. | | |
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| **Meeting Close** | | | | |
| Meeting closed 01.37pm (ACDT). | | | | |