Venue:	**SAHMRI Boardroom Level 4 Offices, Adelaide - Face to Face**
Date:	**Wednesday, 8th August 2018**
Time:	**9.30am - 3:00 pm (CST)**
Chair	**Matthew Jose (MJ)**

Attendees:

Stephen McDonald – (Executive Officer)
Kylie Hurst - (Registry Manager)
Phil Clayton - (Editor)
Matthew Sypek - (Epidemiology Fellow) (Video)
Shilpa Jesudason - (KHA Clinical Director)
Wai Lim - (Transplantation WGC)
Amelia Le Page - (Paediatrics WGC) (Video)
Michael Collins - (General Member)
Bill Mulley - (General Member)
Rachael Walker - (NZ Representative)
Matthew Roberts - (HD WGC)
Monique Borlace - (PD WGC)
Rachael Morton - (PROM WGC)
Kathy Hill - (RSA Representative)
Jaqui Hughes - (Indigenous Health WGC) (Video)

Apologies:

Nigel Toussaint - (ANZSN Council Rep)

Minute Taker:

Brooke Martin - (ANZDATA)

1. Opening, Welcome and Attendance
The Chair **WELCOMED** the members to the meeting.
The Chair **ACKNOWLEDGED** Tim Matthew, a founder of the Registry, who has recently passed away.

Action	No Action

2. Minutes from Previous Meeting
Members:
NOTED CPAP should be amended to CPAC throughout the previous minutes.
ENDORSED the minutes of the 15th February 2018 ANZDATA Steering Committee meeting. Accepted by Bill Mulley and seconded by Monique Borlace.

Action	No Action

3. Action items Outstanding

Members:

Action Item 140806/03 - **NOTED** will look to have item done by the next meeting.

Action Item 140806/04 - **NOTED** this will require significant changes after discussions around Governance.

Action Item 150220/03b - **NOTED** this item is complete.

Action Item 170908/05 - **NOTED** nothing to report at this stage. **DISCUSSED** putting the meeting minutes from the Steering Committee Meeting on the ANZDATA website, excluding the working group reports. **NOTED** Shilpa will do a summary for the Consumers.

Action Items 180215/06, 180215/07 and 180530/01 - NOTED these items are complete.

Action Item 180530/02 - **NOTED** item has been superseded by Action Item 180808/02

Action Item 180530/03 - **NOTED** item has been superseded by Action Item 180808/02

Action Item 180530/04 and 180530/05 - **NOTED** these items are complete.

Action Item 180530/06 - **NOTED** item not discussed.

Action Item 180530/07 - **NOTED** this item is complete.

Action Item 180530/08 - **NOTED** this item is now on hold until further notice.

Action	180808/01	Meeting minutes to be published prospectively once approved by the committee. (working group updates to noted but not published)
Action	180808/02	Write to Commissioners of Review regarding the presentation at the ANZSN ASM

4. Report from Executive

4.1 Staffing

NOTED that there has not been much change to staffing in the last 12 months. **NOTED** that Emily Duncanson joined the team as a part time employee for BEAT CKD projects. **NOTED** that change in staff rolls and skill set development is an ongoing process.

4.2 Finance

DISCUSSED that the Registry still has funding on a 12 month contract. **NOTED** that the funding from AOTA and NZ MOH are due for renewal in June 2019. **NOTED** funding from KHA is ongoing.

4.3 IT Developments

NOTED the Registry has received a small amount of funds for scope in moving to the SAHMRI IT Service. **NOTED** that only in the initial scoping stage, full process could take up to 3 years.

4.4 Data Collection

NOTED the survey is currently 75% complete with 97 of 105 parent renal units returning forms, completing online or electronically transferring data. **NOTED** the 2016 survey at the same time last year was only at 51%. **NOTED** that the data lock should occur approximately two months earlier than previous years. **NOTED** that WA has the highest number of online users.

4.5.1 Individual Hospital Reports

NOTED the Individual Hospital Reports go out at the end of the year/early the following year. **DISCUSSED** ensuring the output is fit for purpose. **NOTED** the Reports do not always get passed onto the people who actually provided the data (e.g. nursing staff).

4.5.2 Annual Report

NOTED each chapter now has a summary. **DISCUSSED** the use of explanatory videos to provide an easier understanding of the data. **NOTED** there are currently some videos that have been recorded by Registry staff, these will be available on the website when they are finalised.

Phil Clayton **PROPOSED** that any chapter changed should be requested before the end of October.

KPI Reports

NOTED these are still being circulated to the HOU's, with underreporting being an issue. **NOTED** approximately 60% is reported quarterly.

4.6 ANZDATA Review Progress

NOTED that there has not been any formal input from the review commissioners. **NOTED** there were a number of comments regarding the Governance Structure of ANZDATA. **NOTED** Stephen McDonald shared a proposed Governance Structure Model with the Committee. **NOTED** and **DISCUSSED** a key proposal in the review was to have a Medical Director 0.5 FTE within ANZDATA.

Stephen McDonald **PROPOSED** a change in the Committee's name from 'ANZDATA Steering Committee' to 'ANZDATA Advisory Committee'. Members **AGREED** to the name change. **NOTED** the ANZDATA Executive Committee will need to update the ToR to include the new name of the Committee.

4.7 Consumer Engagement

DISCUSSED moving away from having one consumer on the committee to having a Consumer Panel. **NOTED** there have been three consumer workshops since the last Steering Committee face to face meeting. **NOTED** there is a consumer session at the ANZSM ASM. **NOTED** the PROMS Working Group would like some consumer involvement.

Action	180808/03	Discuss with the RSA committee regarding ANZDATA Report output communication.
Action	180808/04	Working group conveners to feedback changes to Annual Report Chapters by data lock.
Action	180808/05	ToR to be updated with name change to ANZDATA Advisory Committee (AAC) and draft circulated to the committee.
Action	180808/06	ToR for AAC to include diversity statement.

5. ANZDATA Policies & Governance

Members:
DISCUSSED gender equity and diversity within the Committee and Working Groups. **NOTED** that the ToR should include a statement regarding diversity.

Action	180808/06	ToR for AAC to include diversity statement.

6. Clinical Directions/Purpose

6.1 Review of data collected in ANZDATA
NOTED this was also discussed 12 months ago. **NOTED** the Review states moving to a 'rib and spine' data collection model, however wait for the Commissioners input prior to reinvigorating a change. **NOTED** IT Funding will also need to be considered with any changes.

6.2 Registry-based trials
NOTED there are currently two registry based trials active within ANZDATA (BEAT CKD & RESOLVE). **NOTED** any future trials would need to be self funded. **NOTED** and **DISCUSSED** that two upcoming registry based trials are TEACH PD and SWIFT.

6.3 PDOPPS proposal
NOTED that the study's funding has expired. **NOTED** AKTN decided not feasible to keep running as a trial without any formal support.

6.4 Data lock-out period for Data linkage studies
NOTED arose from a specific question. **NOTED** that some data linkage projects can take many years. **NOTED** in practice the Registry is acting in a way to enable requestors are working complimentary to each other even outside of the 6 month data lockout. **AGREED** that there would be no changes to the 6 month data lockout at this stage.

Action	No Action

7. Working Group Updates

7.1 New Zealand

7.2 Haemodialysis		
7.3 Indigenous		
7.4 Paediatrics		
7.5 Peritoneal Dialysis		
7.6 Transplant		
7.7 Patient Reported Outcome Measures		
Action	180808/07	Infographics use across Working Groups and ANZDATA documentation to be explored.

8.	**Membership**		
Members: **NOTED** the list of membership to be circulated to all committee members. **NOTED** members agreed that they would like to continue having advanced trainees on the Working Groups. **SUGGESTED** to have a project proposal with EOI for advanced trainees. **NOTED** the experience should be beneficial for both the trainee and the Registry.			
Action	180808/08	Committee membership list to be circulated	
Action	180808/09	Contact the Working Group Trainees to get feedback on inclusion in WG	

9.	**Any other Business**
Members **NOTED** the next meeting is a teleconference meeting scheduled for Wednesday, 21st November 2018. Meeting **CLOSED** at 2.55pm.	

Ref No	Item	Responsible	Due Date	Status/ Comment
140806/03	ToR for Working Group membership be written by Chair of SC 170809 -- remains on hold pending the ANZDATA review	Matthew Jose	By next meeting (Nov 2018)	Ongoing
140806/04	Formation of ToR for Executive Committee 170809 remains on hold pending the ANZDATA review	Matthew Jose	Post External Review	Ongoing
150220/03b	Create a document around the governance of the ANZDATA SC including membership remains 170809	Matthew Jose	Post External Review	Completed
170908/05	Provide a report to ANZSN and KH to publish the same report to Registry Website. - Ongoing	Matthew Jose & Kylie Hurst	February 2018	Completed
180215/06	Seek EOI's for a position on the paediatric WG to replace Tonya Kara's position.	Amelia LePage	May 2018	Completed
180215/07	EOI's to be sought for two members of the ANZDATA Steering Committee to replace Tonya Kara and Simon Roger's positions.	Matthew Jose	May 2018	Completed
180530/01	Add the Consumer Reference Group as a standing agenda item on the Steering Committee agenda.	Julie Adams	June 2018	Completed
180530/02	Steering Committee will check the Commissioner's response as to whether the spine and rib approach to reporting is the direction ANZDATA wish to proceed.	Matthew Jose	June 2018	Superseded 180808/02
180530/03	ANZDATA review outcomes be discussed/presented at the ANZSN ASM in September.	Matthew Jose	September 2018	Superseded 180808/02
180530/04	In the next CPAC meeting SJ will raise that there should be a CPAC representative on the Steering Committee.	Shilpa Jesudason	June 2018	Completed
180530/05	Steering Committee will check the Commissioner's response as to whether the rib and spine approach to	Matthew Jose	June 2018	Completed

	reporting is the direction ANZDATA wish to proceed.			
180530/06	Begin the roll out of the CaPhosforms gradually and as an opt in option, beginning with Calciphylaxis.	Matt Roberts	June 2018	On Hold
180530/07	Notify the new Transplant WG members.	Matthew Jose	June 2018	Completed
180530/08	Re-advertise for EOI's for the Indigenous Health WG.	Matthew Jose	November 2018	On Hold
180808/01	Meeting minutes to be published prospectively once approved by the committee. (working group updates to noted but not published)	All	November 2018	
180808/02	Write to Commissioners of Review regarding the presentation at the ANZSN ASM	Stephen McDonald | Matthew Jose	August 2018	
180808/03	Discuss with the RSA committee regarding ANZDATA Report output communication.	Kathy Hill		
180808/04	Working group conveners to feedback changes to Annual Report Chapters by data lock.	All working groups	October 2018	
180808/05	ToR to be updated with name change to ANZDATA Advisory Committee (AAC) and draft circulated to the committee	Executive		
180808/06	ToR for AAC to include diversity statement	Executive		
180808/07	Infographics use across Working Group and ANZDATA documentation to be explored	Phil Clayton		
180808/08	Committee membership list to be circulated	Brooke Martin	August 2018	

| 180808/09 | Contact the Working Group Trainees to get feedback on inclusion in WG | Matthew Jose | | |