

1. Rationale

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) is a clinical quality registry that collects, analyses and reports on data related to kidney failure requiring dialysis or transplantation across both Australia and New Zealand (Australia and New Zealand Dialysis and Transplant Registry, n.d).

Recognising the importance of lived experience, ANZDATA established the Consumer Advisory Panel (CAP) to ensure that the voices of people affected by kidney disease help shape the direction, priorities and communication of the Registry's work.

2. Purpose

The CAP provides strategic advice to ANZDATA to ensure that lived experience perspectives shape how data is collected, used and communicated.

Specifically, the CAP will provide guidance on:

- What data is collected and why
- Future research priorities
- How the data can inform clinical care and quality improvement
- How the data is used by external stakeholders
- The development of accessible and user-friendly outputs (e.g., reports, plain language summaries, infographics)
- What information matters most to consumers
- Strategies to support consumers to lead their healthcare through access to relevant data
- Ensuring registry priorities, communication, and direction reflect what matters most to the people they serve.
- Integrating lived experience to shape registry priorities, communication, and decision-making.

3. Membership Structure and Composition

The CAP will comprise of approximately 8-12 members from Australia and New Zealand with personal experience with kidney disease, including:

- People currently receiving dialysis

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- Kidney transplant recipients
- Individuals who have donated a kidney
- Carers, family members, or support persons of an individual living with kidney disease

The CAP is committed to diversity in membership and will aim to include members with a broad demographic (e.g., age, gender, cultural background, language, socio-economic status, and geographic locations).

4. Roles and Responsibilities

The CAP is responsible for:

- Ensuring lived experience is reflected in ANZDATA's data collection, reporting and research agenda.
- Collaborating with ANZDATA staff to co-design consumer-focused materials.
- Advising on emerging issues relevant to consumer engagement in kidney health and clinical quality registries.
- Providing input into ANZDATA's consumer involvement strategies.
- Supporting the ongoing evaluation of consumer involvement.

5. Governance and Communication Protocols

- The CAP operates in an advisory capacity. While it does not have decision-making authority, its input informs strategic planning and initiatives.
- The CAP reports to the ANZDATA Executive Director(s).
 - The Chairperson and/or Deputy Chairperson will provide updates at ANZDATA Advisory Committee meetings and other meetings as required.
- Meeting notes and recommendation will be shared with relevant stakeholders, while maintaining member confidentiality.
- The Chairperson and Deputy Chairperson will lead meetings, with support from the ANZDATA Patient Engagement Officer (PEO).
- The PEO will provide administrative and liaison support.

6. Meetings

- At least four (4) virtual meetings per year, with additional ad hoc meetings as needed.
- Members are expected to attend regularly, participate respectfully, maintain confidentiality, and declare any conflicts of interest.

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- Agenda papers will be circulated in advance by the PEO.
- Meeting minutes will be circulated within seven (7) business days for members to review and then forwarded to the ANZDATA Executive Director/s.

6.1 Quorum

- Quorum is 50% of appointed members (excluding members on approved leave), with the Chairperson and Deputy Chairperson included in this count.
- If quorum is not met, decisions may be made via out-of-session voting.
- Members unable to attend a meeting are not required to designate a proxy.
- Decisions will be made through consensus. Divergent views and rationales will be documented in the meeting minutes.
- The final approval authority lies with the ANZDATA Executive Director(s).

7. Terms of Appointment

- Participation is voluntary.
- Initial appointment is for two (2) years, with the option to continue based on mutual agreement, panel needs, and member interest.
- There is no fixed limit on consecutive terms a member may serve.
- Former members may reapply at any time.

7.1 Member Obligations

- Members are required to:
 - Sign a Consumer and Community Involvement Agreement.
 - Declare any potential or apparent conflicts of interest.
 - Maintain the confidentiality of all sensitive information.
 - Indicate their media consent preferences.
 - Prepare for meetings by reviewing meeting materials in advance.

7.2 Leave of Absence

- Members may request up to six (6) months' leave (extensions considered on case-by-case basis)
- Member are encouraged to stay in communication during leave periods to discuss ongoing involvement and support needs.
- If a break is required beyond twelve (12) months, members are encouraged to consider stepping down and reapplying when they are able to fully re-engage.

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7.3 Membership Review

- Every two (2) years, the PEO, Chairperson, and Deputy Chairperson will meet with each member to reflect on their experience and discuss their continued involvement with the CAP.
- Continuation will be considered based on factors such as their members interest, ongoing availability, level of participation, contributions to the panel, and the evolving needs of the CAP.
- Confirmation of continued participation will be confirmed in writing.

7.4 Offboarding Process

- Members unable to maintain regular attendance may be invited to discuss their ongoing involvement.
- Members may resign at any time with written notice to: community@anzdata.org.au
- The PEO will conduct periodic reviews to identify members who may no longer be actively participating or contributing effectively.
- Offboarding will be handled with transparency and sensitivity.
- Offboarded members will be formally acknowledged for their contributions.
- Members will be invited to complete a brief exit survey to help inform ongoing improvement.

8. Recruitment and Orientation

- Expressions of interest can be submitted via the ANZDATA website or directly through the PEO.
- Applications are reviewed by the PEO, Chairperson, and Deputy Chairperson, with final endorsement by the ANZDATA Executive.
- Successful applicants will receive an orientation pack and be invited to attend a one (1) virtual orientation session.
- Orientation will be provided by the PEO remunerated as per section 9. Remuneration’.

9. Selection and Succession of Chairperson and Deputy Chairperson

9.1 Selection Process

- Elected by CAP members through majority vote.
- Self-nominations or nominations with consent are accepted.
- Elections facilitated by the PEO and may include confidential voting.

9.2 Eligibility

- Nominees should have at least six (6) months active CAP membership
- Desired qualities include inclusive leadership, strong communication skills, and a commitment to respectful collaboration.

9.3 Succession and Term Review

- Terms are typically two (2) years
- Members may serve beyond this period with support of the CAP.
- Role reviewed periodically (e.g., every two years) to ensure continued alignment with CAP goals and member preferences.
- The Deputy Chairperson may act as interim Chairperson if the Chairperson steps down
- If both roles are vacant, the PEO may appoint an interim Chairperson until elections are held

9. Remuneration

- Members will receive \$35 per hour, covering:
 - One (1) hour for meeting preparation (reviewing materials in advance)
 - One (1) hour for meeting attendance
- All payments will be processed in accordance with the SAHMRI Consumer and Community Engagement Policy for Reimbursement and/or Sitting Fees of Advisory Groups.
- Members must submit the necessary forms (e.g., Community Engagement Expense Claim Form and Statement by Supplier) within 4 weeks of each meeting to receive payment.
- Out-of-pocket reimbursements are not generally applicable due to the virtual format.

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10. Review

These Terms of Reference will be reviewed every two (2) years or earlier if required. Amendments may be made in consultation with CAP members and the ANZDATA Executive Director(s). Changes will be documented and adopted after agreement by both parties.

Version	Version Date	Endorsement Date	Outcome
v1	19/08/2021	Not available	Initial version endorsed by the CAP
v2	26/08/2023	Not available	
v3	23/09/2025	24 October 2025	Major review – updated structure and processes.

11. Associated Documents

- SAHMRI Consumer and Community Engagement Policy for Reimbursement and/or Sitting Fees of Advisory Groups
- Consumer and Community Involvement Agreement
- Conflict of Interest Form
- Media Consent Form
- ANZDATA CAP Application Form
- Orientation Booklet
- Statement by a Supplier Form
- Consumer Engagement Expense Claim Form

12. References

Australia and New Zealand Dialysis and Transplant Registry. (n.d.). About Us. Retrieved 17 July 2025, from <https://www.anzdata.org.au/anzdata/about/>