

Request for Consumer Participation

About the ANZORRG Consumer Interest Register

ANZORRG coordinates a Consumer Interest Register — a way for individuals to stay connected and engaged with our work. By joining, consumers receive updates about ANZORRG initiatives, upcoming events, and opportunities to participate in registry activities such as focus groups, resource development, surveys, and other forms of input. We particularly welcome expressions of interest from people across Australia and Aotearoa New Zealand who have lived experience with organ failure. This includes individuals who:

- have received dialysis or a transplant (kidney, heart, or lung)
- have received a tissue or eye graft
- are currently on a waitlist
- are caregivers, donors, or family members of someone affected

No special qualifications are required — just lived experience and a willingness to contribute.

ANZDATA Consumer Advisory Panel (CAP)

The ANZDATA Consumer Advisory Panel (CAP) was established in 2023 to ensure that the voices of people affected by kidney disease inform and guide the Registry's direction, priorities, and communication.

Each member of CAP has been personally impacted by chronic kidney disease — as a patient, caregiver, family member, or donor. Their collective experience provides valuable insights that help improve the quality of care and outcomes for individuals with kidney failure in Australia and Aotearoa New Zealand.

Accessing Consumers through ANZORRG

We receive a high number of requests from external organisations and researchers seeking to engage with consumers in our network. To ensure we respect consumers' time and avoid overburdening them, we may need to prioritise requests. Please note that while we do our best to connect you with suitable participants, consumer participation cannot be guaranteed, as involvement depends on individual circumstances and availability.

Requestor Contact Details	
Name	
Position	
Program/Organisation	
Phone	
Email	
Details of Request and Activity	
Level of Consumer Engagement <i>(tick all that apply)</i>	☐ Partnership* - Consumers are active partners in decision-making (e.g. committee or governance roles) ☐ Involving- Consumers are engaged in aspects of design, delivery, or review ☐ Consulting- Consumers are asked to provide feedback or input on specific topics

	<i>*Please note that for committee roles, it is best practice to appoint at least two consumers</i>
Name of project/initiative	
Why are you seeking consumer involvement for this project?	
Timeframe and Commitment Required (Please specify so consumers can assess their availability. For example: 2 x 1-hour online meetings plus 1 hour of reading time.)	Start date: End date: Estimated total hours:
Location/Format of Activity (e.g. online, in-person meetings, specific venues)	
Key Stakeholders Involved (List individuals and/or organisations)	
Desired Consumer Qualities or Experience (E.g. specific age group, dialysis modality, cultural background, areas of interest)	
How will you communicate with participating consumers?	
Reimbursement	
In line with international good practice, requestors should consider offering consumers payment (honorarium) for their time and/or reimbursement for any out-of-pocket expenses (e.g. travel, accommodation, respite, childcare). Guidance on suggested payment rates and reimbursement options is available on our website. Providing some expenses up front (for example, gift cards) may help ensure a more diverse and inclusive group of participants. Reimbursement of consumers is the responsibility of the requestor. It is helpful to discuss early in the process how consumers would like to be acknowledged or paid. Wherever possible, the payment process should be simple and accessible, with clear information on who to contact for assistance.	
Are funds available for consumer payment/reimbursement?	
How will consumers be reimbursed?	

Once complete, please send this form to:

 community@anzdata.org.au