AUSTRALIA AND NEW ZEALAND HEART TRANSPLANT REGISTRY

CLINICAL ADVISORY COMMITTEE

Terms of Reference

1. Role/Purpose

The Clinical Advisory Committee will provide advice and guidance about arrangements of establishing a Australia and New Zealand Heart Transplant Registry. The Clinical Advisory Committee's particular focus is on clinical matters and relationships with clinical stakeholders. The primary responsibility of the Clinical Advisory Committee is to;

- Provide clinical expertise and governance oversight of members represented transplant units to the Registry Secretariat/Registry Centre Executive
- Determine policy regarding data collection including frequency, quantity, quality, and type of data collected as well as methods of collection
- Dissemination of information from the Registry in the form of reports and publications
- Release of data from the Registry to contributors, government, industry and others seeking access registry data
- Function and membership of any required working groups
- Report formally to key stakeholders including contributing units, funding bodies and professional bodies on activities of the registry
- Fostering collaboration between the registry and external stakeholders
- Ensure that the data collection and database management comply with the appropriate privacy legislation and regulations as they apply in Australia and New Zealand and their jurisdictions

2. Membership

The Clinical Advisory Committee will comprise of the following:

- The Chairperson; Clinical Quality Registry Expert, ANZORRG Operations Executive Officer
- Two (2) Representative from each contributing unit, as nominated by unit.
    - Membership for general members will be, for a 3-year term with the option to renew for a second three (3) year term.
- Two (2) consumer representatives, through EOI will be appointed for a term of 3-years
- Funders (1)
- Data contributors/managers are recognised as guests of the Committee and are not considered formal members

3. Meetings

- All meetings will be chaired by the appointed Chairperson

- A meeting quorum will comprise of half of membership +1 of the Clinical Advisory Group
    - A proxy representing general members absence from meeting's is desirable
- There will be a minimum of four (4) meetings each year, held on a quarterly basis
- Members will be expected to attend a minimum of three (3) meetings each calendar year
- Meeting agendas, meeting papers and minutes will be prepared and provide by registry Administration Officer
- Decisions made by consensus (i.e., members are satisfied with the decision even though it may not be their first choice). If consensus not reached, Clinical Advisory Committee chair determines final decision
- If required working group meetings will be arranged outside of these times at a time convenient to working group members

4. Amendment, Modification or Variation

- This ToR may be amended, varied, or modified in writing after agreement by Clinical Advisory Group Members
- This ToR will be reviewed every 12 months by the Clinical Advisory Committee

5. Document History

Revision	Date	Description
2022.v0.1	20/06/2022	Creation
2022.v1.0	13/09/2022	Endorsed by Clinical Advisory Committee
2025.v0.1	16/06/2025	Draft update
2025.v1.0	14/08/2025	Updated membership