

Australia & New Zealand Lung Transplant Registry (ANZLUNG)

CLINICAL STEERING COMMITTEE

Terms of Reference

1. Role/Purpose

The Clinical Steering Committee (CSC) will provide advice and guidance about arrangements of establishing and ongoing operations of a Lung Transplant Registry. The CSC's is the governing body of the Australia and New Zealand Lung Transplant Registry (ANZLUNG), providing strategic oversight, guidance and decision making for the registry. Additionally, the CSC provides clinical expertise to the development of the registry.

The CSC function includes but is not limited to the below responsibilities:

- 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
- Determine reporting and dissemination of information from the registry
- 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 as required to key stakeholders including contributing units, funding bodies and professional bodies on activities of the registry
- Foster collaboration between the registry and external stakeholders

2. Term

The Term of Reference (ToR) is effective from date of endorsement and will be for an initial term of 12 months, aligning with funding schedule. The ToR will be reviewed in 12 months by the CSC.

3. Membership

The CSC will comprise of the following:

- The Chairperson; Clinical Quality Registry Expert, ANZDATA Group of Registries Executive Officer
 - Review of chairperson post pilot phase, aligned with ToR review in 12 months.
- General Member, representing each contributing unit.
 - Each contributing unit should be represented at a minimum by 1 general member, with no more than 2 general members from each contributing unit.
- Two (2) consumer representatives, through EOI will be appointed for a term of 3-years
- Funders (1)

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4. Meetings

- All meetings will be chaired by the appointed Chairperson
- A meeting quorum will comprise of five (5) members of the CSC
 - 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 required 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 support

5. Decision Making

- The CSC will operate based on a consensus model of decision making
 - o The term *consensus* is defined as agreement by **all** members during decision making
- Each member (representative of a contributing transplant unit) is able to exercise a power of veto in regard to decision making within the committees remit
- Sound justification must be provided when power of veto is utilised

6. Amendment, Modification or Variation

- The ToR may be amended, varied, or modified in writing after agreement by CSC Members
- The ToR will be reviewed in 12 monthly by the CSC

7. Document History

Revision	Date	Description
2021.v0.1	01/03/2022	Draft
2023.v0.2	29/03/2023	Amendment to ToR to include decision making consensus clause and committee name change
2023.v1.0	27/07/2023	Endorsed at Clinical Steering Committee meeting