



# Terms of Reference for Australia and New Zealand Transplant and Cellular Therapies Limited Registry Committee

## 1. Background

The ANZTCT is a professional association that represents healthcare professionals involved in transplantation and cellular therapies in Australia and New Zealand. Data is collected by the ANZTCT Registry to monitor haemopoietic stem cell transplant and cell therapy activity and outcomes in Australia and New Zealand. This data is used by the ANZTCT to monitor clinical practice, inform best practice guidelines and inform patient care. The registry is also used to support quality management and TCT accreditation, support clinical research in TCT in Australia and New Zealand and to participate in enhancement of global knowledge of the field. As a part of ANZTCT, the Registry Committee is responsible for providing guidance and recommendations on issues related to the ANZTCT Registry. The ANZTCT Registry Committee reports directly to the ANZTCT Board.

## 2. Role of the Registry Committee

The ANZTCT Registry Committee will provide leadership, education, and support to data managers and other professionals involved in the collection and use of data relating to transplantation and cellular therapy. The Committee is responsible for identifying and addressing issues related to data management in order to align with international standards in data collection and reporting to support the ANZTCT goals.



### **3. Objectives of the Registry Committee**

- 3.1 To provide expert management of registry activities to operate as a clinical quality registry for Australia and New Zealand
- 3.2 To support alignment of ANZTCT Registry data with international TCT registry standards
- 3.3 To ensure that appropriate ANZTCT Registry data is available and accessible to address the administrative, regulatory and clinical needs of Australia and New Zealand
- 3.4 To facilitate TCT quality management and accreditation in Australia and New Zealand
- 3.5 To support reporting of disease specific TCT outcomes in Australia and New Zealand
- 3.6 To support evidence based clinical practice improvement and ANZTCT guideline development
- 3.7 To support TCT research in Australia and New Zealand and globally
- 3.8 To promote and advocate for the highest standards of TCT data collection, management and reporting
- 3.9 To support TCT outcome benchmarking for Australia and New Zealand that aligns with international benchmarking standards
- 3.10 To support and maintain TCT statistical expertise in the registry
- 3.11 To support database design, maintenance and future proofing
- 3.12 To provide TCT stakeholders including government bodies with reports that facilitate TCT service, delivery, planning and design
- 3.13 Optimise registry funding use to deliver on the registry objectives
- 3.14 Maintain the security, confidentiality, and integrity of registry data in compliance with Australian and New Zealand privacy and data protection regulations.



#### **4. Responsibility**

The responsibilities of the Registry Committee for the ANZTCT is to meet regularly to and achieve the following:

- 4.1 Support registry staff with data collection forms and protocols review
- 4.2 Support registry staff in communications with data contributors when required
- 4.3 Support registry staff with data quality control processes, validation checks, and corrective actions to maintain data integrity
- 4.4 Review reporting outputs of the registry, such as those associated with service agreements and benchmarking
- 4.5 Discuss Australia and New Zealand outcomes and trends through registry reports and benchmarking activities
- 4.6 Prioritise and approve ethically sound TCT research in Australia and New Zealand and regional contributions to international reporting and or research
- 4.7 Liaise and collaborate with other international registries, professional organisations and societies in the field of TCT
- 4.8 Collaborate with relevant ANZTCT committees and special interest groups to align registry activities with broader ANZTCT objectives and activities
- 4.9 Facilitate sharing and dissemination of knowledge gained from registry activities through publications and presentations
- 4.10 Provide recommendations and advice to the ANZTCT Board on matters related to the registry
- 4.11 Provide reports to the ANZTCT Board on the activities of the Registry Committee
- 4.12 Manage and maintain the finances of the Registry, including preparing and presenting a budget report to the ANZTCT Board.
- 4.13 To set up subcommittees and special interest groups to facilitate delivery of the Committee objectives



## 5. Membership and Appointment

Membership of the Registry Committee is open to all professionals who are members of the ANZTCT. Members of the committee will be appointed by the board in response to a call out for expressions of interest. Composition of the committee will include the registry manager and balance ANZTCT board membership, diversity in disease expertise, professional disciplines, registry science expertise, autologous and allogeneic haematopoietic stem cell transplantation expertise, CART and other cellular therapy expertise and geographic representation. The Committee will include a Chairperson, Deputy chair and Secretary, who are appointed by the ANZTCT Board, for a period of 3 years with the option to renew for a maximum of 3 terms.

5.1 Chairperson: The chairperson will be the ANZTCT chair or a delegated board member and is responsible for the overall direction and coordination of the Committee. Their specific responsibilities include:

5.1.1 Setting the agenda and chairing meetings of the Committee

5.1.2 Coordinating the Committee's activities and ensuring they align with the ANZTCT's strategic objectives

5.1.3 Representing the Committee at the ANZTCT Board on four appointed meetings per calendar year, and reporting back to the Committee on Board activities and decisions

5.1.4 Facilitating communication and collaboration among Committee members

5.1.5 Encouraging the participation of all Committee members in the Committee's activities

5.1.6 Liaising with other ANZTCT committees and Committees on matters related to the registry

5.1.7 Preparing and presenting the Committee's annual report at the ANZTCT Annual General Meeting



5.2 Deputy Chair: The Deputy Chair works closely with the Chairperson to help manage the activities and operations of the group. They provide support and share the workload, contributing to decision-making, planning, and execution of tasks. Their specific responsibilities include:

5.2.1 Serving as a backup to the Chairperson so that in their absence they lead meetings, make decisions, and ensure that the group's work continues smoothly.

5.2.2 They may liaise with other Committee members, stakeholders, and external parties to ensure that the group's tasks are completed on time and information is effectively shared.

5.2.3 May be asked to represent the Committee.

5.3 Secretary: The secretary is responsible for keeping records of minutes and activities for liaising with the ANZTCT Board on behalf of the Committee. Their specific responsibilities include:

5.3.1 Preparing and distributing agendas and minutes of Committee meetings

5.3.2 Maintaining a record of Committee activities and decisions

5.3.3 Coordinating and communication among Committee members, including sharing relevant information from the ANZTCT Board and other committees.

5.3.4 Liaising with the ANZTCT Board on behalf of the Committee, including presenting reports and recommendations

5.3.5 Assisting the Chairperson with the preparation and presentation of the Committee's annual report



## **6. Meetings and quorum**

The Registry Committee shall meet at least six times per year, or as necessary to address emerging issues related to the registry. Meetings may be conducted in person or virtually, as determined by the Committee Chair. A quorum shall be at least 50% plus one.

## **7. Reporting**

The Registry Committee shall report to the ANZTCT Board on a regular basis, providing updates and recommendations on its activities. The Registry Committee shall also prepare an annual report on its activities and financial statements for presentation at the ANZTCT Annual General Meeting

## **8. Confidentiality and Data Security**

All members shall adhere to strict confidentiality and data security protocols to ensure the protection of patient information and sensitive data.

## **9. Accountability**

To fulfil responsibilities as outlined in the Terms of Reference.

## **10. Compliance with ANZTCT Policies and Procedures**

The Education, Practice Standards and Guidelines Committee and its members are required to adhere to all ANZTCT policies, procedures, and governance frameworks in carrying out their responsibilities. This includes compliance with ethical, financial, operational, and strategic directives as set by the ANZTCT Board.

## **11. Amendments**

These Terms of Reference will be reviewed every 3 years and maybe amended by a two-thirds majority vote of the Committee, provided that notice of the proposed amendment has been given to all members of the Committee at least 14 days prior to the vote. Any amendments must also be approved by the ANZTCT Board.



## Approval

Approved on behalf of the ANZTCT Board of Directors by:

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