

## **Regulations and Terms of Reference: ANZVASC Registry Committee**

### **1. Role**

a) The Clinical Quality and Disease Registry (Registry) Committee of the Australian and New Zealand Society for Vasculitis (ANZVASC) provides advice to the board of ANZVASC and exercises delegated powers and functions of the Board as set out in these Regulations and Terms of Reference, or as directed by the Board from time to time, in line with the Society's Constitution, including Clauses 17.6-17.8.

b) The purpose of the ANZVASC Registry Committee is to establish, oversee, govern and ensure ongoing funding and maintenance of a Clinical Quality and Disease Registry for Vasculitis in Australia and New Zealand

### **2. Functions**

The Committee's functions are to:

- a) Establish the Governance of an Australian and New Zealand Vasculitis Registry, owned by ANZVASC and initially focused on ANCA-associated vasculitis,
- b) Develop a protocol for the registry
- c) Advise the Board on overarching policy elements in the operation of a registry,
- d) Assist in developing an ethical, practical, flexible and sustainable registry framework that includes the capacity for reporting to participating units, fundamental outcome measurement, research capacity and the potential for adding optional registry projects,
- e) Assist in seeking funding and resources for ANZVASC to establish, run and maintain the registry,
- f) Ensure patient (consumer) input and involvement in a registry,
- g) Liaise as appropriate with other ANZVASC Committees, specifically Education/training and Clinical Trials,
- h) Explore collaborations with other registries, including, but not limited to European Vasculitis Registries using a similar registry structure,
- i) Such other functions as are reasonably determined by the Board of ANZVASC.

### **3. Membership**

The Committee should be composed of people with expertise and/or a specific interest in establishing and running a registry as part of the mission of ANZVASC. The membership should reflect the diversity of the society.

The Committee shall consist of at least 6 and no more than 11 members. All members of the Committee shall be Ordinary Members, aside from the Associate Member or Members specified under 3b.

At least one member of each committee, shall be a Board Member. All members shall have voting rights in the Committee. The membership of the Committee is as follows:

a) Up to 9 Ordinary Members

- i) A Chair, preferably a Board Member
- ii) A Deputy Chair
- iii) One representative of each of the following disciplines (clinician/clinician-scientist or researcher)

- Clinical Immunology
  - Nephrology
  - Rheumatology
- iv) At least one “early career member or trainee” who at the time of appointment is/was within 5 years of obtaining the FRACP (or equivalent) or PhD (or equivalent). This member can also fulfill the criteria specified under iii).
- v) Up to 3 further Ordinary Members

b) At least one (and a maximum of two) Associate Members (excluding overseas members) representing consumers, who shall have voting rights in the context of this Committee.<sup>1</sup>

#### 4. Terms of Appointment

a) Appointment will be for 3 years with the potential for 2 further terms of 3 years at the discretion of the Board. At the commencement of the Committee in 2020, initial terms will be from 2-4 years to mitigate against excessive turnover in any one year.

b) Members will be appointed by the Board after an expression of interest (EOI) process whenever vacancies are due.

c) Members will cease to be a member of the Working Group if they:

- (i) resign from the Working Group, by giving one month's notice in writing to the Chair of the Working Group; or
- (ii) cease to be a member of the Society

d) The Board may, at its discretion, revoke a committee member's appointment to the Committee on the grounds of inadequate meeting attendance (for example in the event <50% attendance without reasons that are acceptable to the board) or repeated disruptive actions or behaviours in the context of the committee.

e) The Board shall have power to fill a casual vacancy or vacancies occurring amongst the Committee.

#### 5. Non-member Temporary Appointments

The Committee may co-opt a person (to a maximum of two people) to the committee who is not an ANZVASC member to assist with specific areas that cannot be provided by the membership. This position will be advisory only and non-voting.

These appointments must have the approval of the Board. It is anticipated that non-member appointments will be for a specific purpose and for less than one year. Appointments must be reviewed by the Board yearly.

#### 6. Meetings

The Committee shall meet at least four times per year.

The Chair (or in their absence the Deputy Chair) is responsible for scheduling meetings and preparing an agenda. Minutes of proceedings/decisions shall be taken and made available to members and the board (under Clause 17.7c of the Constitution).

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<sup>1</sup> Recognizing that consumer involvement in ANZVASC is, in 2020 growing but still relatively small, if no consumer members are available, the position shall remain vacant and be advertised to Associate Members 6 monthly.

A quorum of 5 members is required (if membership is currently 8 or less, the quorum is 4).

#### 7. Reporting to the Board

The Committee's records of meetings are to be provided to the Board. The Chair of the Committee is to report to the Board at each Board Meeting.

#### 8. Confidentiality

Business of the Committee, other than that already in the public domain, is confidential and must be treated as such by the Committee members. Members are not to disclose confidential information without approval of the Chair and the relevant board member.

#### 9. Conflict of Interest

The ANZVASC Conflict of Interest Policy also applies to Committee Members.