



<b>Terms of Reference</b>		
Scientific and Medical Advisory Committee	<b>Approval Date:</b>	<b>Sept 2020</b>
<b>Responsible Officer: Chair of SMAC</b> <b>Authorising Officer: RVA Chair</b>	<b>Approved by:</b>	<b>Board</b>
	<b>Review Date:</b>	<b>##</b>
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## 1. Purpose and Role

The Board of Directors (**Board**) of Rare Voices Australia (**RVA**) has constituted the Scientific and Medical Advisory Committee (**Committee**), which is to operate in accordance with these Terms of Reference.

The committee will provide support, facilitation, advice and expert opinion to the Board of RVA.

- to progress implementation of the National Strategic Action Plan for Rare Diseases;
- to highlight issues and opportunities related to RVA's vision, mission, aims, objectives and work plan;
- to develop linkages and networks among RVA stakeholders; and
- to flag initiatives and emerging issues that are important to achieving RVA's vision and mission.

## 2. Members

### 2.1 Composition

The Committee will have between 8 and 12 Members.

- Committee membership will reflect the diversity of people involved in health services and medical research that serve people living with rare diseases. These areas include:
  - Biomedical, clinical, public health, allied health, health systems policy and programs;
  - Genetic services;
  - Medical devices, therapeutics, diagnostics;
  - 'Omics' – genomics, phenomics, proteomics, metabolomics;
  - Bioinformatics and health information systems;
  - Clinical service models and continuity of care;
  - Adult health and child health;
  - Paediatric and familial cancer.
- Committee Members will be committed to working towards the best outcomes for people living with a rare disease, their families, and carers. Members will be knowledgeable about respectful of for patient/consumer perspectives. Additionally, members will have extensive experience in the areas of clinical care and/or research aimed at improved diagnosis, treatment, patient care and/or health services that align with RVA's vision and mission.

## 2.2 Appointment of the Committee Chair and Members

A Chair will be appointed by the RVA Board on the recommendation of the RVA CEO. The primary role of the Chair will be to promote and inform the broader priorities of RVA.

The Chair will appoint members and, if required, a Deputy Chair, in consultation with the RVA Board.

The Chair, in consultation with the Chair of the RVA Board and RVA's CEO, will exercise judgement to achieve a diverse membership, while not constraining the ability to appoint outstanding individual candidates. Appointments will give consideration to gender, organisation and geographic balance, and linkages to bodies such as Orphanet, IRDiRC, and the Global Alliance for Genomics and Health.

The RVA Board has the right to remove a Committee member under certain conditions after consultation with the Chair of the Committee.

At the discretion of the Committee, Sub-committees and Working Parties may be established for finite periods to undertake specific task/activities, and may co-opt additional people and expert bodies as required. The size and membership of these groups will be prescribed by their operational requirements.

## 2.3 Terms

The Committee members' positions will be time-limited to 3-4 years, with this tenure to be regularly reviewed by and at the discretion of the RVA CEO and SMAC Chair. Retiring members may apply for a second term.

To enable continuity of membership, where possible changes in Committee membership will be staggered and planned. Incoming Committee members help to revitalise and re-energise the Committee, but this should not be done at the expense of group development and momentum.

In coordination with the RVA's CEO, the Committee will participate in an annual review of its ongoing operational role and coordinating functions.

## 3. Duties & Responsibilities

Members will be required to pre-read meeting documents and, as required, may be consulted by the Chair or RVA's Chief Executive Officer (CEO) on an *ad hoc* basis, between meetings.

Absence from three (3) consecutive Committee meetings without prior arrangements made with the SMAC Chair/RVA's CEO will be grounds for retiring a Member and appointing a replacement to the resulting Committee vacancy.

Members will reflect on their discussions at each meeting to assess their quality of participation and the decisions taken, and to ensure the underlying motivations of discussions support RVA's vision and mission.

Committee members may meet with external stakeholders with the approval of the SMAC Chair or RVA's CEO.

Members, while free to make any comments publicly about matters related to rare diseases, may not speak on behalf of RVA or the Committee. Only the Chair, after consultation with

RVA's CEO, may engage in commentary on behalf of the Committee. In general, this should be the exception rather than the rule, with most public comment focused through RVA's CEO.

#### **4. Meetings**

The Committee will:

- Meet quarterly by teleconference;
- limit the duration of meetings to one hour; and
- determine appropriate meeting times among its members; and
- as appropriate additional face to face committee meetings maybe arranged.

RVA will incur the costs associated with hosting and facilitating such meetings.

RVA's CEO or representative will attend the committee meetings with the right to participate in discussions and present a report on RVA's activities.

A quorum shall comprise five (5) members including the Chair. In the absence of a quorum, any discussion or decisions will require ratification by the Committee members, either via circular resolution or by being held over for discussion and voting at the next meeting.

RVA will provide executive support and secretariat duties for the Committee.

All paperwork relating to the Committee meetings will be provided in an appropriate and timely manner, usually at least one week prior to the Committee meeting.

#### **5. Access to Management**

The Committee will provide advice to the RVA Board through RVA's CEO. In addition, the SMAC Chair will be invited to participate in bi-monthly RVA Board meetings on an ex-officio basis. This will facilitate two-way direct communication between the RVA Board and SMAC.

#### **6. Reporting to the Board**

The SMAC Chair will provide a report of SMAC activity at each RVA Board meeting either in person, in writing or through the CEO.

SMAC minutes will be made available to the RVA Board.

The Committee will evaluate its activities annually. The SMAC Chair will report on this during RVA's Strategic Planning.

#### **7. Review**

The Committee Terms of Reference are to be reviewed annually. All amendments to the Terms of Reference must be approved by the SMAC Chair.