

RVA – Scientific and Medical Advisory Committee (SMAC)			
Terms of Reference			
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PURPOSE AND ROLE

- The Scientific and Medical Advisory Committee (Committee) will operate in accordance with these Terms of Reference. The Committee will bring a national scientific and medical perspective to inform RVA’s work. Its role will include support, facilitation, advice and expert opinion to the Board to:
 - progress implementation of the National Strategic Action Plan for Rare Diseases;
 - highlight risks and opportunities related to RVA’s vision, mission, aims, objectives and work plan;
 - develop linkages and networks among RVA stakeholders (this may include supporting/promoting activities across their own networks); and
 - flag initiatives and emerging issues that are important to achieving RVA’s vision and mission.

MEMBERS

- The Committee will consist of at least 8 and no more than 12 Members. Committee membership will aim to reflect the diversity of people involved in health services, rare disease disability and medical research that serve Australians 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;
 - Rare disease disability;
 - Adult health and child health;
 - Precision medicine;
 - Bioethics;
 - Epidemiologists, registry and data specialists;
 - Expertise regarding links to rare disease Centres of Excellence/Expertise, rare disease clinical services or flagships, or rare disease research consortia/flagships;
 - Expertise around Australian medical reimbursement systems/processes;
 - Data expertise;
 - Priority population (e.g., Aboriginal and Torres Strait Islander people and culturally and linguistically diverse communities) health research.
- Eligibility criteria for membership requires members to:
 - have extensive experience in the areas of clinical care and/or research aimed at improved diagnosis, treatment, education, patient care and/or health services and health technology assessment that align with RVA’s vision and mission.
 - if health professional/researcher: must have a formal role with a recognised Australian hospital/health service or research institution, or appointment to a Government medical/research advisory board/committee.

- If not a health professional/ researcher: must have demonstrated high-level expertise in an area pertinent to SMAC e.g. HTA, health policy, rare disease disability.
 - be committed to working towards the best outcomes for Australians living with a rare disease, their families, and carers.
 - be knowledgeable about respectful approaches to obtain and incorporate patient/consumer perspectives.
4. Member positions are voluntary (non-paid) roles.

Appointment of the Committee Chair

5. 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 ensure that the Committee fulfils its purpose, duties and responsibilities.
6. The RVA Board has the right to remove the Chair in consultation with the RVA CEO.

Appointment of Members

7. The Chair will appoint Members and, if required, a Deputy Chair, in consultation with the RVA Board and RVA CEO.
8. 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. Member appointments will consider the overall skills mix, gender, organisation and geographic expertise across States/Territories, including consideration of having nominated representative(s) from national professional networks or special interest groups, and linkages to international expertise or networks including Orphanet, IRDiRC, EURORDIS, European Reference Network and the Global Alliance for Genomics and Health.
9. The RVA Board has the right to remove a Committee Member after consultation with the Chair and the RVA CEO. Absence from three consecutive Committee meetings without prior arrangements made with the Chair/RVA's CEO will be grounds for retiring a Member and appointing a replacement to the resulting Committee vacancy.
10. At the discretion of the Committee, Sub-committees and Working Parties may be established for finite periods to undertake specific tasks/activities and the Committee may co-opt additional people and expert bodies as required.

Terms

11. The Chair's term will be for a duration of three years plus two re-appointments (maximum of nine years). This aligns with the maximum term of a RVA Director, and will help facilitate succession planning. The Chair's re-appointment will be reviewed as required, and at least every three years, at a Board meeting prior to the first SMAC meeting of the calendar year, of the Chair's re-appointment year.
12. Members' terms will be for a duration of four years plus two re-appointments (maximum of twelve years). The Members' (non-Chair) re-appointments will be reviewed as required, and at least every four years, at the first SMAC meeting of the calendar year, of the Member's re-appointment year.
13. A Member who has served the maximum number of consecutive terms is eligible for re-appointment following a period of not less than 3 years after their appointment ended.
14. 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.

DUTIES AND RESPONSIBILITIES

15. Members are expected to provide independent scientific and medical advice on topics related to their expertise and knowledge.

16. Members should stay current with developments in their field which are relevant to RVA, including through contact with their professional bodies, academic institutions and research communities.
17. Members will be required to pre-read meeting documents and as required, may be consulted by the Chair or RVA's CEO (or the CEO's delegate) on an ad hoc basis, between meetings.
18. Members are required to respect the confidentiality of information disclosed and discussed at meetings. Members may meet with external stakeholders to discuss matters tabled at SMAC meetings with the approval of the SMAC Chair and 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.
19. Members have an obligation to comply with RVA's Conflict of Interest Policy and disclose any conflicts of interest relating to any issue before the Committee. This may include not participating in agenda items or decision making when such matters are discussed.

MEETINGS

20. The Committee will:
 - meet quarterly by teleconference/virtually.
 - as appropriate, arrange additional face to face committee meetings.
21. RVA will incur the costs associated with hosting and facilitating such meetings. Where Members are requested to attend in-person meetings (or otherwise incur out-of-pocket costs), RVA will reimburse participants if this is pre-approved and in accordance with RVA's internal policies.
22. 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.
23. A quorum shall comprise five (5) Members including the Chair (or delegated Chair). In the absence of a quorum, any decisions will require ratification by the Members.
24. RVA will provide executive support and secretariat duties for the Committee. All information relating to the Committee meetings will be provided in an appropriate and timely manner, usually at least one week prior to the Committee meeting.

ACCESS TO MANAGEMENT

25. The Committee will provide advice to the RVA Board through RVA's CEO or representative. 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.

REPORTING TO THE BOARD

26. 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.
27. The Committee will evaluate its activities annually. The SMAC Chair will report on this during RVA's Strategic Planning.

REVIEW

28. The Committee Terms of Reference are to be reviewed regularly. All amendments to the Terms of Reference must be approved by the RVA Board in consultation with the SMAC Chair and the RVA CEO.