



Expert Reference Group Charter

OBJECTIVES

The main objectives of the Expert Reference Group¹ (the "**Group**") are to:

- (i) through advice and guidance, bring a wide range of research, clinical, scientific, and other, skills and expertise to the Australian Twin Registry (as represented by the Director) ("**ATR**") to enhance its ability to facilitate and support current and future medical and scientific studies that involve the participation of twins and/or their relatives;
- (ii) promote use of the facilities of the ATR by Australian researchers;
- (iii) promote the registration of volunteers with the ATR;
- (iv) promote the use of the special characteristics of twins in medical and scientific studies;
- (v) promote an informal network of Australian researchers interested in the use of the characteristics of twins in medical and scientific studies;
- (vi) provide mentoring to, and assist in the education and training of, Australian researchers wishing to use the special characteristics of twins in their medical and scientific studies; and
- (vii) review the applications of researchers, and provide recommendations to the ATR, regarding use of the facilities of the ATR.

DUTIES AND RESPONSIBILITIES

Expert Scientific, Clinical & Research Advice and Guidance

The Group will provide expert advice and guidance to the ATR and the Advisory Board on scientific, clinical and research matters.

Review of Applications to use the facilities of the ATR

Members of the Group will make themselves available on reasonable notice to review, and provide advice and guidance on, the proposed research of applicants to ensure that the research (a) has scientific merit, and (b) is an effective use of the facilities of the ATR. Through the review, the Member will also have the opportunity to provide advice and guidance to the researcher, with a view to providing the researcher with the benefit of the Member's own research experience.

¹ The Executive Committee of the Australian Twin Registry was formed in the 1980s. It was renamed the Scientific Committee in 2005. In accordance with this Charter, and to better reflect its role, it has been renamed the Expert Reference Group.

Representation on the Advisory Board

The Advisory Board recognises that there are those better placed to provide insight on the needs of the primary stakeholders. For this reason, a nominee of the Group will be invited to serve as a members of the Advisory Board. The Group will elect one of its Members to represent the Group on the Advisory Board. The elected Member must satisfy the requirements of, and comply with, the Advisory Board Charter

Promoting use of the ATR

The Group will promote use of the facilities of the ATR by Australian researchers, and promote their use of the special characteristics of twins in their medical and scientific studies.

Promoting registration of volunteers with the ATR

The Members of the Group will use their best efforts to increase the registration of volunteer twins and their families. Where a Member has recruited, or recruits, twins or family members of twins, independent of the ATR, the Members will obtain the consent of those twins and family members to be registered with the ATR and to be available to participate in the activities of the ATR. Such consent will comply with the 'Consent Policy' of the ATR published from time to time.

With the prior agreement of the ATR obtained at the relevant time, Members will be reimbursed all reasonable costs associated with recruiting volunteers to the ATR.

Mentoring, Education and Training

The members of the Group are expected to be proactive in providing mentoring to, and assist in the education and training of, Australian researchers wishing to use the special characteristics of twins in their medical and scientific studies.

With respect to education and training, the Group will for example:

- (i) Facilitate twin research workshops (e.g., the "It Runs in the Family" series) for twin researchers and those interested in twin research; and
- (ii) Identify training opportunities and financial support for students and other researchers.

EXPECTATIONS OF THE GROUP

Consideration of its advice and guidance by the receiver

The Group expects that any advice or guidance it gives will be carefully and respectfully considered by the receiver and that the receiver will provide the Group with a reasonably detailed explanation if the advice or guidance is not followed.

Access to information and stakeholders

The Chair will have unlimited access to senior management of the ATR and Advisory Board.

Access to external advice

Should the Group decide it reasonably necessary, it may ask the Advisory Board to obtain independent professional advice, including legal advice, on specific issues detailed by the Group. If the Advisory Board believe (in its discretion, acting reasonably) that such advice is reasonably necessary, it will seek that advice in accordance with the Advisory Board Charter.

REPORTING

The Group, through the Chair, will provide advice and guidance to the ATR, on matters falling within the scope of its responsibilities. Such advice and guidance may be in the form of minutes of its meetings, supporting papers, and written or oral reports to the ATR and Advisory Board. The ATR will distribute such advice and guidance to Advisory Board as and when directed to do so by the Group (through the Chair).

DUTY AND VALUES

Duty

Members of the Group agree that in the exercise of their duties as a Member, they have a duty to, and will, act in the best interests of the ATR and Australian twin researchers taken as a whole.

Values

Members of the Group agree that in the exercise of their duties as Members, they will act in good faith and in an open, honest, professional and courteous manner consistent with the values of the ATR, as published from time to time.

ADMINISTRATION

Composition

The Group will consist of at least ten, and no more than twenty, people (the "Members"), including the Director and Deputy Director of the ATR. Each member must continue to satisfy the eligibility requirements set out below for the duration of their appointment as a Member.

Appointment

The Director of the ATR will, in consultation with the Chair, appoint researchers to the Group, provided the eligibility requirements referred to below are satisfied.

Eligibility

A person is eligible to be a Member if he/she:

- (a) is, or has been within the previous five years, a senior clinician and/or researcher
- (b) is committed to the ethical conduct of human research;
- (c) is prepared to comply with the provisions of this Charter.

Retirement and Resignation of Members

A Member may retire or resign his/her office at any time and is requested to provide written notice to the Chair of his/her decision to do so.

The Director may, acting reasonably, and in consultation with the Chair, retire a Member in the following circumstances:

- (a) if he/she receives a recommendation by majority vote of the Group that a Member should be removed;
- (b) if he/she has reasonable grounds to believe that a Member is not complying with this Charter or is otherwise not acting in the best interests of the ATR;
- (c) if he/she has reasonable grounds to believe that a Member no longer satisfies the eligibility requirements; or

(d) as part of the annual review of the Group (*see 'Annual review and confirmation of membership' below*).

If any Member retired by the Director feels the retirement is unfair, he/she may exercise his/her rights to have the matter addressed in accordance with the Dispute Resolution Process.

Chair

The Group will appoint a Chair and Deputy Chair of the Group from amongst its Members.

If the Chair is not present at a meeting of the Group, the Deputy Chair will act as Chair for that meeting.

If the Chair and Deputy Chair are not present at a meeting of the Group, the Members present may elect another Member to act as Chair for that meeting.

The role of the Chair (in collaboration with the Deputy Chair) is to:

- determine the agenda for meetings of the Group in conjunction with the Director of the ATR and the Secretary of the Group;
- chair meetings of the Group and take reasonable steps for the proper functioning of the Group, including ensuring proper conduct of meetings, facilitating an appropriate level of discussion, ensuring that every Member's views are considered, and where possible seeking consensus amongst the Members;
- take reasonable steps regarding the adequate flow of relevant information to, and from, the Group;
- advise the Director of the ATR on the Group's recommendations on matters falling within the scope of the Group's responsibilities;
- review the minutes of meetings of the Group for circulation to and approval of the Group and sign the approved minutes; and
- act under a delegation of the Group.

The Group may at any time vote to replace the Chair and/or Deputy Chair.

Annual review and confirmation of membership

The Director reserves the right, in consultation with the Chair, to review the composition of the Group and to make such changes as are reasonably necessary to ensure that the Group has the right mix and breadth of skills and is sufficiently representative of the community of researchers to whom the ATR is available to provide services. This review may on occasions result in Members being retired from the Group or additional Members appointed.

Fees and Expenses

Except with the prior approval of the Director, Members will not be entitled to fees for their service on the Group.

Members who undertake representative duties for the ATR will, with the prior approval of the ATR, be reimbursed by the ATR all reasonable expenses which the Member cannot reasonably have reimbursed by the Member's own organisation.

Periodic Reviews

A review of the Charter and its continuing adequacy will be undertaken by the Group periodically together with periodic, but at least annual, evaluations of the Group's performance and the extent to which the Group has met the requirements of its Charter. Any proposed amendment to the Charter will be submitted to the Advisory Board for review and, if appropriate, approval.

MEETINGS

Frequency of meetings

The Group will hold at least two (2) meetings each year (either in person or by teleconference) and such additional meetings as the Chair deems appropriate in order to fulfil its duties. In addition, the Chair is required to call a meeting of the Group if requested to do so by:

- any Group Member; or
- the Director of the ATR.

Given the large number of Members, and so as not to burden the ATR with excessive administrative costs, all meetings may be conducted by teleconference organised and paid for by the ATR. The Director may, in his/her discretion, choose to fund 'in person' meetings if he deems it reasonably necessary.

Nothing in this Charter prevents the Group from convening 'in person' meetings provided all costs associated with that meeting, including travel and accommodation costs, are borne by the members of the Group.

Attendance by non-members

Parties external to the ATR may be invited to attend any meeting of the Group or part thereof but will have no voting rights.

Meetings other than in person

Meetings and subsequent advice, guidance and determinations may occur via written resolution or conference call or other electronic means of audio, audio-visual or visual communication.

Secretary

The Co-ordinator of the ATR (or delegate as approved by the Group) will act as Secretary of the Group and will be responsible, in conjunction with the Chair and the Director of the ATR, for drawing up the agenda (supported by explanatory documentation) and circulating the Group papers to Members prior to each meeting. Members may request papers for, or from, any meeting and will be notified in advance of the agenda of forthcoming meetings.

The Secretary will also be responsible for keeping the minutes of meetings of the Group.

Preparation of Minutes

As soon as reasonably practicable following a meeting of the Group, the Secretary will prepare a draft of the minutes of that meeting. The minutes are not intended to be a verbatim transcript of the meeting but rather a true and objective summary of key areas of discussion, any opposing views on an issue and key actions and recommendations.

The Secretary may contact Members to confirm the Secretary's understanding of what was discussed during the meeting. In relation to any matter discussed in a meeting, the Secretary will summarise the issues raised, the majority recommendation of the Group and a summary of any dissenting positions. Likewise, the minutes will clearly summarise any actions the Group, or the Director, agrees to take as well as clearly identify those individuals taking responsibility for the action and the timeframe in which the action is to be completed.

The Secretary will circulate the draft minutes to all Members and will accommodate all return comments in the next draft of the minutes, clearly attributing content to the person who provided it.

Declarations of Conflicts of Interest (or Vested Interests)

It is important for each Member of the Group to declare conflicts of interest (or vested interests) so that his/her comments are put in context during his/her participation in meetings or while performing duties on

behalf of the ATR. A declared conflict will not necessarily exclude a Member from participating in any discussion.

At the beginning of each meeting, each Member will declare any conflict of interest he or she may have which has arisen since the last meeting or likely to arise with respect to the agenda for the present meeting, and which will impact or could reasonably be perceived to impact his or her ability to fulfil his or her duties in an independent and objective manner in the best interests Australian twin researchers taken as a whole.

No Member is required to restate a conflict which has previously been declared by that Member and recorded in previous minutes.

The fact that a Member is an Australian twin researcher will not of its-self be considered a conflict of interest and need not be declared.

If a conflict of interest arises during a meeting of the Group or while performing any duties as a Member, they should be immediately brought to the attention of the Chair and the Director.

Quorum

A quorum will consist of six (6) Members.

Voting

A motion shall be passed by a:

- (i) simple majority of votes cast in favour by Members present and eligible to vote; or
- (ii) resolution in writing signed by the majority of Members eligible to vote.

In the event of an equal number of votes being cast for or against a motion, the Chair will exercise a casting vote.

If a Member has a conflict of interest in relation to any motion, he or she must abstain from voting for or against the motion.

Chair, Advisory Board

Approved by the Board on 9 August 2006