

HTAi Patient and Citizen Involvement in HTA Interest Group Terms of Reference

1.0 Purpose

The HTAi Patient and Citizen Involvement in HTA Interest Group (PCIG) is a service to HTAi members who have an interest in patient and public involvement in HTA. This Interest Group is dedicated to:

- Promoting and developing robust methodologies to incorporate patient and citizen perspectives into HTAs and sharing best practice in patient and citizen participation in the HTA process.
- Strengthening HTA by systematic incorporation of patient and citizen perspectives.
- Supporting countries with limited experience of HTA to elicit and incorporate patient and citizen perspectives.

2.0 Establishment

This HTAi Interest Group, PCIG, was established by a resolution of the Board in 2005 and functions according to the HTAi Interest Groups Policy and Procedure reviewed by the Board of Directors from time to time.

3.0 Members of Interest Group

- 3.1 All members of the Interest Group are members of the Society in good standing that are interested in patient and citizen involvement in HTA. In accordance with Bylaw 2.5(a), if an Interest Group member did not pay the membership fees, the member becomes a non-member and cannot participate in the Interest Group. Membership fees are due by December 31 every year.
- 3.2 Individuals who are not members of HTAi (particularly patients/citizen organisation members) can participate in PCIG projects with prior approval of the Interest Group Co-Chairs and the HTAi Executive Director. This shall be supported by a written justification.
- 3.3 Patients and patient organization representatives who are not able to pay the membership fee (please note the discounted fee for patients and volunteers) can apply to benefit from a fee waiver, which will be reviewed by designated representatives of the Interest Group Steering Committee for approval by the Co-Chairs and HTAi Executive Director. This is to be supported by a written justification. A designated representative of the Steering Committee and the Executive Director shall review this matter annually.
- 3.4 Technical Officers who provide administrative support to the Interest Group and who work in accordance with their contract reviewed and signed annually.
- 3.5 HTAi members in good standing who wish to join an Interest Group shall email interestgroups@htai.org to be added to the distribution list.
- 3.6 The Members of the Interest Group can resign at any time by providing the notice to the Co-Chairs.

4.0 Responsibilities

- 4.1 **Members of the Interest Group are responsible for:**
 - a. Familiarising themselves with the Terms of Reference
 - b. Contributing relevant updates to the e-bulletin
 - c. Contributing relevant expertise to PCIG consultations.
- 4.2 **Members of the Interest Group may:**
 - a. Attend Annual Business Meeting of the Interest Group

- b. Nominate themselves for PCIG Steering Committee when a call for Expression of Interest is circulated.
- c. Propose to the PCIG Steering Committee to form and implement new Project Sub-Committees.

4.3 The Steering Committee is responsible for the following:

- a. Provide governance, strategy and oversight of the plans and deliverables of any Project Sub-Committee.
- b. Set up the Steering Committee meeting schedule and adhering to it.
- c. Establish up to eight (8) Project Sub-Committees at any one time. Each Project Sub-Committee shall have a lead and up to 12 members. Members of Project Sub-Committees must be members of the Interest Group.
- d. Schedule two events (webinars or pre-conference workshops) each year and adhere to the schedule.
- e. At least twice a year report to the members of the Interest Group of the current and forthcoming activities.
- f. Yearly conduct the Annual Business Meeting of the Interest Group.
- g. Yearly conduct the Technical Officer evaluation and decide to extend the contract or hire a new Technical Officer.
- h. Complete evaluation of Co-Chairs and Vice-Chair at the end of each term.
- i. Review its Terms of Reference every three (3) years and make a recommendation to the Board of Directors.
- j. Twice a year submit material for the HTAi newsletter.
- k. Develop a work plan that aligns with the objectives of the Society Strategic Plan and adhere to it.
- l. Develop and implement the Interest Group external communications.
- m. Assess and evaluate collaboration opportunities with other organisations working in the field.
- n. Approve funding requests and reports to the HTAi Board.

4.4 Steering Committee members are expected to:

- a. Familiarize themselves with the Interest Group Terms of Reference.
- b. All Steering Committee members are expected to attend as many Steering Committee meetings as possible, and to inform the Co-Chairs and Technical Officer if they are unable to. In this instance, an e-mail response regarding the agenda items may be submitted 48 hours in advance of the meeting when unable to attend. If a Steering Committee member attends less than half the scheduled meetings in any 12-month period, consideration will be given to their other commitments and their ability to support the work of the Steering Committee.
- c. Come to meetings prepared to engage in respectful, meaningful discussion and provide considered, constructive and thoughtful feedback and commentary, express opinions and ask questions to enable the Steering Committee to exercise its best judgment in decision making and advising the Project Sub-Committees.
- d. Act in the best interests of the HTAi in accordance with the Society's Mission, Vision, Values, and Strategic Plan.

4.5 Interest Group Co-Chairs are responsible for the following:

- a. Provide leadership to the Interest Group members and Steering Committee.
- b. Chair the meetings of the Steering Committee and Interest Group.
- c. Set up the agenda for the Interest Group meetings and Steering Committee meetings.
- d. Lead the performance evaluation of the Technical Officer.
- e. Ensure the Interest Group operates in compliance with the Interest Group Policy and Procedure.

- f. Present the report to the Interest Group members at the Annual Business Meeting.
 - g. Ensure timely development and delivery of meeting materials of the Steering Committee and its circulation five (5) days before the meeting.
 - h. Represent the Interest Group at the HTAi Interest Group Steering Committee (or appoint the Vice-Chair to represent the IG) to ensure Committee continuity and meeting attendance consistency. A Co-Chair (or Vice-Chair) must attend at least three (3) out of four (4) Interest Group Steering Committee meetings a year. If neither Co-Chairs can attend, the Vice-Chair may attend instead.
- 4.6 Interest Group Vice-Chair is responsible for the following:
- a. Act as the Vice-Chair of the Interest Group and provide leadership, serve on the Steering Committee.
 - b. Assume the functions and responsibilities for the Co-Chairs in their absence, incapacity, or at the request of the Co-Chairs.
 - c. Exercise such other powers and shall perform such other duties as may from time to time be prescribed by the Steering Committee.
- 4.7 The Project Coordinator is responsible for:
- a. Coordinating any projects and Project Sub-Committees established by the Steering Committee and ensuring that project templates (see Appendix 4) are complete for each project and made available to the Steering Committee.
 - b. Scheduling presentations and updates by Project Sub-Committees to the Steering Committee.
 - c. Providing organisational support for the Project Sub-Committees.
 - d. Ensuring Project Sub-Committee progress reports are received for Steering Committee meetings.

5.0 Accountability

- 5.1 The Patient and Citizen Involvement in HTA Interest Group is accountable to its members and the HTAi Board of Directors.
- 5.2 The individual Project Sub-Committees delivering the Interest Group's work are accountable to the Interest Group Steering Committee.

6.0 Steering Committee Composition

- 6.1 The Steering Committee will consist of the following members:
 - a. Interest Group Co-Chairs
 - b. Interest Group Vice-Chair
 - c. An elected Financial Secretary – responsible for financial issues such as raising funds and managing budgets for meetings.
 - d. The Outgoing Interest Group Chair(s)
 - e. A Project Coordinator who shall be responsible for coordinating any projects and Project Sub-Committees established by the Steering Committee.
 - f. A minimum of 10 Steering Committee members which shall aim for equitable representation based on skills, experiences, education, professional background, geography, gender, ethnicity, stakeholder, including at least two (2) patients or patient advocates/representatives.
 - g. One (1) Technical Officer who supports the Steering Committee but is not a voting member.

7.0 Election Process

- 7.1 The Co-Chairs are elected by the Steering Committee members. In the first instance, the Vice-Chair shall succeed to a Co-Chair position when it becomes available. If there is no automatic succession, the Steering Committee members can self-nominate for the position of Co-Chair. The Steering Committee will elect Co-Chairs by a majority vote. If there are no nominations from among the Steering Committee members, a call for interest will be circulated to the Interest Group members. The Steering Committee shall select Co-Chairs from these nominations by a majority vote.
- 7.2 Any member of the Interest Group who wishes to become a member of the Steering Committee can submit an Expression of Interest when a position becomes available. The Steering Committee shall appoint a new member by consensus or by a majority vote.

8.0 Steering Committee Terms of Office

- 8.1 The term of Co-Chairs and Vice-Chair shall be three (3) years. The Co-Chairs and Vice-Chair may be re-elected for another term of three (3) years for a maximum of two consecutive terms or six (6) years of service. After a period of at least three (3) years has passed after serving a term of six (6) consecutive years, HTAi member in good standing may be elected again.
- 8.2 The term of a Steering Committee Member shall be three (3) years. The Steering Committee Member may be re-elected for another term of three (3) years for a maximum of two consecutive terms or six (6) years of service unless the person has been elected as Co-Chairs or Vice-Chair. For smooth operating, a preference is given to Vice-Chairs and current Steering Committee members when appointing new Co-Chairs.
- 8.3 The Outgoing Chair(s) who support the incoming Co-Chairs, may have up to two further terms.
- 8.4 Technical Officer(s)'s term shall coincide with the terms of their contract.
- 8.5 The term extensions beyond the above shall be approved by the Board of Directors for extenuating situations only.

9.0 Quorum

- 9.1 Quorum for Annual Business Meeting shall be 10 members.
- 9.2 Quorum for Steering Committee meetings shall be 5 members.

10.0 Interest Group Operations

- 10.1 **Annual Business Meeting**
The Interest Group shall hold its Annual Business Meeting at the HTAi Annual Meeting, which is usually held in June. This meeting will be organised by the HTAi Secretariat. Written notice of the time and place of the Annual Business Meeting and an agenda of the business to be transacted shall be given to all members at least seven (7) days in advance. The meeting notes of this meeting shall be circulated to all members of the Interest Group documenting the actions planned for the forthcoming year.
- 10.2 Business between the Annual Business Meetings will be undertaken with the whole Interest Group electronically, using the facilities available to Interest Groups on the HTAi website (list serves, document files, etc.) and by email.
- 10.3 **Annual Face-to-Face Meeting**
The Steering Committee and members of Project Sub-Committees shall meet face-to-face once a year (subject to force majeure), usually in October, for strategic and operational planning, best practice sharing and preparing for the next HTAi Annual Meeting.

- 10.4 **Steering Committee Meetings**
The Steering Committee will meet up to eight times a year.
- 10.5 **Remuneration of Members**
Interest Group Members shall receive no remuneration for their service. However, when specific members are part of funded projects in which members of the Interest Group are paid for their contribution, these members can receive remuneration for their work on the project. The Technical Officer is a contracted position to the Interest Group and receives a small stipend.
- 10.6 **Funding**
The Interest Group will be eligible to request funding for specific projects from HTAi in accordance with the Interest Group Funding Policy and Procedure. The Interest Group may apply for funding with other organisations; however, such funding shall be provided unconditionally, i.e., the funder shall have no influence on the organisation; and the funds allocation shall remain the responsibility of the Steering Committee. These funding agreements shall be supported by signed documentation that shall be retained by the Technical Officer.
- 10.7 **Conflict of Interest Declaration and Management**
Conflict of Interest declaration and management is done in accordance with Board approved Conflict of Interest Policy and Procedure. All Interest Group members should familiarize themselves with it and act accordingly.
- 10.8 All Steering Committee members and Project Sub-Committee members will complete a Declaration of Conflict of Interest upon appointment and update it in January of each year. These declarations will be retained by the Technical Officer in the Members' Register of Interests that will be available on request from the Technical Officer who is responsible for the management of Declaration of Conflict-of-Interest forms and for ensuring that the Members' Register of Interests is current.
- 10.9 **Confidentiality**
The Interest Group members should not disclose confidential information. The Steering Committee Co-Chairs will advise of any confidential information. Any Interest Group member can ask that specific information they bring forward be treated as confidential.
- 10.10 **Chatham House Rule**
Some Interest Group meetings shall be held in accordance with the Chatham House Rule. In this case, the rules and their implications shall be clearly stated to the participants.

11.0 Review

- 11.1 Review of these Terms of Reference shall take place every three (3) years or as directed by the Board of Directors.

Approved date: May 24, 2023

Review date: May 2026