



Canadian Cancer
Research Alliance

Alliance canadienne
pour la recherche sur le cancer

TERMS OF REFERENCE

1. Background and Mission

The Canadian Cancer Research Alliance (CCRA) is a unique alliance of organizations that work strategically to co-ordinate and collaborate on most of the cancer research conducted in Canada by fostering partnered initiatives, synergies and collaborations among cancer research funders and identifying joint strategic action that will effectively advance cancer research and cancer control for the benefit of all people in Canada, including equity-denied groups. Together, members strive to maximize the collective impact of their investments in cancer research by supporting cancer research that uncovers factors which may cause cancer and discovers more and better treatments to improve patient and survivor outcomes. For more information and history, please see <https://www.ccra-acrc.ca/about-us/what-we-do/> and <https://www.ccra-acrc.ca/about-us/timeline/>.

The CCRA's work to build a diverse cadre of researchers and research teams and support their innovative and high-calibre cancer research makes it a critical partner in many priorities of the Canadian Strategy for Cancer Control (CSCC). Accordingly, since 2008, the Canadian Partnership Against Cancer (CPAC) as stewards of the CSCC has provided secretariat and other supports to CCRA to enable its members to regularly convene, network, and carry out its core activities.

Core activities of the CCRA include:

- **The Canadian Cancer Research Survey (CCRS)** - an annual snapshot of the cancer research investment by members and other key funding organizations, which assists members in identifying funding gaps and potential areas for new shared investment.
- **The Canadian Cancer Research Conference (CCRC)** - a biennial science meeting, which brings together the Canadian cancer research community for an agenda spanning the research spectrum. The conference provides an opportunity for attendees to hear the latest developments in Canadian cancer research and network across research disciplines.
- **The Patient Involvement in Cancer Research Program (PIP)** - a biennial program embedded in the CCRC that demonstrates and promotes the value of engaged patients to cancer research.
- **PIP MS Teams** - a communications vehicle used to keep PIP alumni connected and up to date on current events, educational opportunities, and developments in the patient engagement space.
- **CCRA Awards** - a biennial program to recognize individuals who have had a remarkable impact on cancer research and the cancer research community.

Periodically, members identify areas of strategic importance, which require the creation of time-limited working groups comprised of members and other experts. The resulting deliverables help catalyze member action and are widely disseminated to benefit the broader cancer research community.

Benefits of membership:

- Regularly convened meetings to share best practices with peer organizations and stay current on news and initiatives relevant to cancer research
- Participation in shaping the CCRC
- Collaborations and partnerships on aligned strategic priorities to address gaps and key issues
- Ongoing analyses of cancer research funding trends to inform organizational priorities and advocacy efforts, where appropriate
- Knowledge transfer and capacity building in cancer research and patient engagement
- Part of a collective voice that advances the important role of cancer research as a key enabler to the Canadian Strategy for Cancer Control and promotes [Canada's Vision for Cancer Research](#)—*“Every person in Canada is part of a bold movement to push the frontiers of cancer research and translate all promising discoveries into maximum health and wellbeing.”*
- Featured as a member organization on the CCRA website

2. Structure and Roles

2.1 Members

Criteria for Membership

Members must:

- subscribe to CCRA’s mission and Canada’s Vision for Cancer Research
- participate in CCRA meetings
- directly fund cancer research and/or cancer control activities
- agree to share research funding information (where a funder) on an annual basis as part of the Canadian Cancer Research Survey and agree to the inclusion of this information in public reporting
- provide financial/in-kind support for the CCRC and/or the Patient Involvement in Cancer Research Program (PIP)
- contribute to frameworks, strategic projects, and other collaborative activities subject to availability of resources and consistent with their own missions and policies
- promote CCRA reports, programs, initiatives, and activities

Prospective members apply for membership and their applications are then vetted and approved by the CCRA Advisory Board.

Membership Categories:

Member: agency/organization that funds cancer research at the national or provincial level using some form of peer review conducted by either itself or its funding partner. Cancer research may be the focus of their research funding efforts or part of the research portfolio that they fund.

By virtue of their role in cancer control, the Canadian Association of Provincial Cancer Agencies (CAPCA), the Canadian Partnership Against Cancer, and the Public Health Agency of Canada (PHAC) are also member organizations.

Patient/family representatives: individuals who have been affected by cancer through their personal experience as patients/survivors or family member/caregivers and who are or want to become advocates for and advisors to cancer research.

Other: Organizational representatives will be engaged as required to provide advice on specific issues of interest to the membership. This includes researchers, hospital foundations, industry representatives, other CIHR Institutes, including the Institute of Indigenous Peoples' Health, and other individuals and organizations as needed.

Roles and Responsibilities

It is expected that member organizations will be represented by a senior decision-maker. Only **one** representative per organization shall be identified as the member. This will be a representative of the organization's choosing.

Members contribute to the overall goals of the CCRA by:

- participating in meetings and sharing information and best practices with other members
- aligning organizational priorities/strategies, where feasible, and helping to advance Canada's Vision for Cancer Research
- providing financial and/or in-kind support for core and priority activities according to strategic alignment
- submitting annual research funding data to the CCRS
- cross promoting the activities of the CCRA through all communication channels including websites, social media channels, etc.
- participating in priority working groups and core committees as appropriate

There is an expectation that members attend or send delegates to at least **one** of the two calls held per year. Follow-up will be initiated with lack of attendance.

Patient/family representatives contribute to the overall goals of the CCRA by:

- bringing the patient voice and patient engagement principles to discussions and ensuring that lived experience is an important consideration in decision-making
- increasing awareness of the importance of patient engagement in research
- planning and delivering on the PIP and other core and strategic priorities, where relevant
- participating in priority working groups and core committees as appropriate

2.2 Secretariat

The Secretariat is led by CPAC's Director of Research and Innovation and is supported by a Program Manager. Additional support is provided by CPAC, including but not limited to legal signatory, procurement, research grant funding, communication, and financial and administrative supports. Since 2008, CPAC has assumed the responsibility for supporting the Secretariat and core functions. Staff are CPAC employees and work at the CPAC office.

The Secretariat:

- leads and delivers on CCRA's strategic direction, including all core activities
- convenes all CCRA-related meetings and actions resulting from Members' decisions, including time-limited priority working groups
- provides administrative support to the Advisory Board, working groups and core committees.
- supports the CCRA website and related social media
- aligns with the priorities of Canadian Strategy for Cancer Control (CSCC) and CPAC reporting accountabilities

2.3 Evaluation

Member surveys and interviews may be conducted periodically by the Secretariat to assess the value of the meetings, products, and processes. Periodically, CCRA will engage in a comprehensive evaluation of its priorities and commitments. CPAC may request specific evaluations to be conducted to facilitate its own reporting to Health Canada.

3. Advisory Board Role and Composition

The mission of CCRA's Advisory Board is to identify strategic priorities for cancer research funding, monitor the investment in cancer research, reinforce the value of research, and strengthen the cancer research community through the support of core activities and research partnerships.

In addition to the roles and responsibilities of members, representatives to the Advisory Board:

- identify emerging priorities for consideration and/or action
- advise the Secretariat on core activities
- facilitate dissemination of CCRA activities and reports
- participate in CCRA awards adjudication
- engage in partnerships/collaborations with other members as appropriate
- determine appropriate policies for CCRA (i.e., website posts, outreach, CCRA logo use)

Advisory Board members are expected to attend or send delegates to at least **three** of four calls per year. Follow-up will be initiated with lack of attendance.

3.1 Advisory Board Composition

The CCRA Advisory Board is comprised of prescribed, elected, and appointed members as follows:

Prescribed

- 3 representatives from among the member Federal government organizations with the highest investments in cancer research
- 3 representatives from among the Provincial government organizations with the highest investments in cancer research
- 3 representatives from among the charitable organizations/associations with the highest investments in cancer research
- 1 CPAC representative
- 1 CAPCA representative

Elected

- 2 members nominated from among the broad membership

Appointed

- 3 patient/family representatives from among PIP participants, representing different jurisdictions in Canada

3.3 Advisory Board Chair

The Chair presides over the Advisory Board and Annual Members' Meetings, works cooperatively with the Secretariat to provide leadership for the Alliance, including assisting with meeting agendas, vetting meeting summaries, and signing external correspondence along with the Director on behalf of the Alliance.

3.4 Elected Representatives

The Chair may self-nominate or be nominated by other members and elected by a voting process. The Chair will be the person who receives the highest number of votes. In the event of a tie, the Director will make the final decision.

There are two elected members to the Advisory Board. They may self-nominate or be nominated by other members and elected by the voting process described above.

Patient/family representatives may self-nominate from among the participants of the PIP. The Chair and Director will select nominees and bring forward their decisions to the full membership for confirmation.

3.5 Terms of Office

The CCRA operates on a calendar year. Elections to the Advisory Board take place in the fall of odd years, with elected members assuming their posts in January of the following year. Chairs serve for a period of two years. Likewise, elected Advisory Board members serve two-year terms. Patient/family representatives serve three-year terms (staggered).

Ad hoc elections will take place if a Chair, or elected Advisory Board member, or patient/family representative departs before the end of their tenure. Terms may be extended upon approval of the membership.

4. Meetings

4.1 Member Meetings

Each year, there are three meetings of the Advisory Board and one meeting of all members—the Annual Members' Meeting. In addition, one of the three meetings of the Advisory Board is made open to all members.

A delegate may attend on behalf of a representative who cannot attend a scheduled meeting. Delegates should be representatives who can speak to questions about their organization and participate in the discussion.

Any member, or group of members, may elect to host an in-person Annual Members' Meeting by contributing space and/or by sponsoring a dinner or other special event. The goal is to rotate across the membership, holding the meetings in different locations with the aim of showcasing local research/initiatives.

4.2 Agenda Development

Agenda items are solicited among the membership. The Secretariat in conjunction with Chair will determine final meeting agendas. Agendas may consist of updates on the implementation of Canadian Strategy for Cancer Control (CSCC), member activities, core activities and/or priorities, and other items deemed important to members.

Hosts of the Annual Members' Meeting are consulted on the respective agenda for their hosted meeting.

4.3 Meeting Summaries

Meeting summaries will be provided by staff of the Secretariat. These summaries are vetted by the Chair prior to seeking approval from Advisory Board members for Advisory Board meeting summaries and the wider membership for summaries from the Annual Members' Meetings.

4.4 Guests

Guests may be invited periodically to CCRA meetings to report on topics of strategic importance to members.

5. Operating Procedures

5.1 Confidentiality and Privacy

Confidential information, draft meeting summaries, draft reports, embargoed press releases and other unpublished/non-public items/information released to the membership are to be kept confidential.

5.2 Conflict of Interest

Conflicts of interest may arise if information discussed during CCRA meetings may further the private interests of a member or is an issue for which a member cannot participate in an unbiased way or which may create a perception of bias (e.g., adjudication of CCRA award nominees). Members and other guests/observers to CCRA meetings who have conflicts of interest with items discussed or recommendations being made by the CCRA are expected to identify these conflicts and recuse themselves from these discussions. The onus is on the member to identify that they have a conflict.

5.3 Code of Conduct

Advisory Board members will be expected to demonstrate fairness and a commitment to open and respectful dialogue. Members unable to attend a meeting shall inform the Secretariat and may send a delegate in their place.

5.4 Compensation for Patient/Family Representatives

Effective 2023, patient/family representatives will be compensated according to CPAC's Patient and Family Advisors compensation policy.

5.5 Travel Reimbursement

Advisory Board members will be reimbursed for reasonable travel and accommodation expenses according to CPAC's travel policies. Non-Advisory Board members will be reimbursed for their travel to Annual Members' Meetings but will be responsible for payment for their own accommodation. Out-of-pocket expenses for patient/family representatives will be covered in accordance with CPAC's travel policies.

6. Adoption and Amendment

The Terms of Reference will be brought forward for review by the secretariat every two years at the Annual Members' Meeting. This review will take into consideration the changing needs of the cancer research system and how CCRA will need to adapt.