Patient Partner Circles

Terms of Reference Summary

This page provides a summary of the Diabetes Action Canada Patient Partner Circles Terms of Reference.

It explains what the Circles are, who can join, what members may do, how meetings will work, how members are compensated, and how Diabetes Action Canada will support respectful and meaningful participation.

A full Terms of Reference document is also available for anyone who would like more detail.

Purpose

Diabetes Action Canada's Patient Partner Circles bring together people with lived and loved experience of diabetes to help shape our work.

Patient Partners include people living with diabetes, as well as family members, caregivers, and loved ones of people living with diabetes.

The Circles help make sure Diabetes Action Canada's research, resources, communications, training, governance, and patient engagement work are informed by the people most affected by diabetes and its related complications.

Circle members are not expected to represent an entire community. Members are invited to bring their own experience, knowledge, questions, and priorities.

The Three Patient Partner Circles

Diabetes Action Canada supports three Patient Partner Circles.

Collective Patient Circle

The Collective Patient Circle is a national Circle for Patient Partners across Canada.

This Circle brings together people with different types of diabetes, lived and loved experiences, backgrounds, regions, and roles in diabetes research, care, policy, and community work.

Indigenous Patient Circle

The Indigenous Patient Circle is a dedicated space for Indigenous Patient Partners, including First Nations, Inuit, Métis, and other Indigenous people living in Canada who bring lived or loved experience of diabetes.

This Circle is co-run with the Indigenous Diabetes Health Circle.

The Indigenous Patient Circle will respect Indigenous self-determination, relational ways of working, and the need for culturally safer engagement.

The Indigenous Patient Circle is not a single consultation body for all Indigenous peoples, communities, or Nations. When work is specific to a Nation, community, geography, or Indigenous population, appropriate local relationships, approvals, and engagement processes are still required.

Francophone Patient Circle

The Francophone Patient Circle is a dedicated space for Francophone Patient Partners living in Canada who bring lived or loved experience of diabetes.

This Circle will help strengthen Francophone engagement, French-language resources, communications, and research partnerships.

Meetings, materials, and communications for this Circle should be available in French.

What Circle Members May Do

Circle members provide advice, feedback, and recommendations to Diabetes Action Canada.

This may include:

- sharing what matters to people affected by diabetes
- giving feedback on research ideas, proposals, and priorities
- reviewing plain-language summaries, resources, forms, and recruitment materials
- advising on accessibility, tone, language, cultural relevance, and communication
- helping identify topics where practical resources are needed
- suggesting themes for blogs, webinars, tools, stories, or public communications
- helping shape Patient Partner town halls
- advising Diabetes Action Canada staff, researchers, committees, and working groups
- helping improve patient engagement processes, including onboarding, training, compensation, and closing the loop

Circle members may choose to write, review, present, facilitate, or support resource development, but this is not required. Any additional work requested by Diabetes Action Canada will be discussed and compensated in advance.

Who Can Join

Each Patient Partner Circle will aim to include approximately 12 to 16 members.

Members must:

- live in Canada
- bring lived or loved experience of diabetes
- be interested in helping shape diabetes research, resources, and patient engagement
- be willing to participate in respectful and collaborative discussions

Lived or loved experience may include experience with type 1 diabetes, type 2 diabetes, gestational diabetes, LADA, MODY, prediabetes, or other forms of diabetes.

Loved experience may include being a family member, caregiver, friend, partner, or loved one of someone affected by diabetes.

You do not need research experience to apply.

Diabetes Action Canada will aim to build Circles that include a range of diabetes experiences, ages, genders, races and ethnicities, languages, disabilities, income levels, geographies, caregiving experiences, and experiences with research, healthcare, policy, or community work.

Recruitment and Selection

Members may be recruited through:

- open calls for applications
- outreach to communities underrepresented in Diabetes Action Canada's Patient Partner network
- referrals from Patient Partners, researchers, community organizations, and Network members
- shorter application pathways for people who recently completed a similar Diabetes Action Canada application process

Some applicants who recently applied to the Research-to-Action Fellowship may not need to complete a full written application again. They may be asked to complete a shorter form to confirm their interest, eligibility, Circle preference, availability, and updated information.

Final membership decisions will be made by Diabetes Action Canada's Patient Engagement team, with input from Patient Partners where appropriate.

Term of Membership

Members will initially be invited to serve a one-year term.

After the first year, Diabetes Action Canada will aim to move toward staggered three-year terms. This means some members will finish their term each year, while others continue. This helps create continuity while also making space for new members and new perspectives.

Members may be invited to renew their term depending on their interest, Circle needs, attendance and participation, representation gaps, available spaces, and opportunities for new Patient Partners to join.

Co-Chairs

Each Patient Partner Circle will have two Co-Chairs.

For each Circle, one Co-Chair position will be reserved for a youth member. For this role, youth generally means someone who is 31 years old or younger, with some flexibility depending on the Circle and applicant pool.

The youth Co-Chair will have the same authority, voice, and decision-making role as the other Co-Chair. This is not a symbolic or junior role.

Co-Chairs help guide the work of the Circle, with support from Diabetes Action Canada staff.

Co-Chairs may help:

- set meeting agendas
- support respectful and inclusive discussions
- make space for different ways of participating
- summarize key discussion points and follow-up items
- help identify Circle priorities
- advise Diabetes Action Canada staff on issues raised by the Circle
- welcome and mentor new members
- support youth leadership and succession planning

Co-Chairs will be selected through a confidential nominations process. Circle members may nominate themselves or someone else.

Co-Chair terms will usually be one year, with one opportunity to renew.

Meetings

Most meetings will happen online.

As a starting point:

- the Collective Patient Circle will meet approximately 6 to 8 times per year

- the Indigenous Patient Circle will meet approximately 4 to 6 times per year
- the Francophone Patient Circle will meet approximately 4 to 6 times per year

Meetings are usually 60 to 90 minutes.

Additional optional meetings may happen for town hall planning, researcher presentations, resource review, communications planning, cross-Circle collaboration, or urgent advice.

Meeting frequency may change based on the priorities, needs, and capacity of Circle members.

Accessibility and Participation

Diabetes Action Canada will aim to support accessible and flexible participation.

This may include:

- meeting agendas in advance
- plain-language materials
- accessible documents
- clear expectations for preparation
- flexibility around camera use and participation style
- options to give input outside of meetings where possible
- interpretation, translation, or accessibility supports where feasible and needed

Each Circle may also define its own communication norms, including expectations around email, shared documents, meeting preparation, response timelines, and collaboration between meetings.

Decision-Making

The Patient Partner Circles are advisory groups.

This means their role is to provide guidance, recommendations, feedback, and community-informed advice to Diabetes Action Canada.

The Circles will aim to make decisions by consensus whenever possible.

When consensus is not possible, a Circle may use a vote. Voting processes should be explained clearly in advance. Minority views, concerns, and unresolved questions should be documented where relevant.

Compensation

Diabetes Action Canada recognizes Patient Partners as contributors with expertise.

Circle members will receive $95 per Circle meeting. This includes meeting attendance, preparation time, and document review.

Circle members who cannot attend a meeting for exceptional reasons, but who review the materials and provide written comments by email, may receive $50.

Co-Chairs will receive $195 per Circle meeting. This includes meeting attendance, preparation time, agenda planning, meeting leadership, and follow-up connected to the Co-Chair role.

Additional requested work outside regular Circle meetings will be discussed in advance and compensated according to Diabetes Action Canada's Patient Partner compensation policy.

This may include writing, reviewing major documents, presenting, facilitating, advising on a grant, co-developing a resource, or participating in additional consultations.

To receive compensation, Patient Partners must complete the required payment process through University Health Network. This may include payroll enrolment, banking information for a Canadian financial institution, and a Social Insurance Number.

Patient Partners who receive more than $500 in compensation in a calendar year may receive a T4A. Patient Partners receiving social assistance or income assistance may wish to understand how compensation could affect their benefits.

Confidentiality and Respectful Participation

Circle members may receive information that is confidential, sensitive, early-stage, or not yet public.

Members are expected to:

- respect confidentiality when requested
- not share private stories or personal information from other members without consent
- participate respectfully
- make space for different perspectives
- disagree in ways that do not harm or target others
- avoid speaking on behalf of communities they do not belong to
- recognize that lived and loved experience is expertise

Diabetes Action Canada staff and Co-Chairs are responsible for helping maintain a respectful, inclusive, and safer meeting environment.

Representation and Authority

Circle members are welcome to share that they are members of a Diabetes Action Canada Patient Partner Circle, if they wish.

Circle members do not speak on behalf of Diabetes Action Canada unless they have been specifically invited and supported to do so.

Circle members and Co-Chairs do not have the authority to commit Diabetes Action Canada to legal agreements, funding commitments, partnerships, public statements, endorsements, conference participation, or other organizational decisions.

Conflicts of Interest

Circle members should share any real, potential, or perceived conflict of interest when discussing specific projects, organizations, funding opportunities, or decisions.

Having lived or loved experience of diabetes is not a conflict of interest.

Being paid for patient partnership work is not a conflict of interest when it is disclosed and managed appropriately.

Closing the Loop

Diabetes Action Canada will make reasonable efforts to close the loop with Circle members.

This means sharing back:

- what advice was received
- what changed because of Circle input
- what could not be changed and why
- what decisions were made
- what future opportunities are available

When advice is sensitive, Circle members should be told how it will be used and whether it will be anonymized or attributed.

Review and Updates

This Terms of Reference Summary will be reviewed at least once per year.

Feedback from Circle members will be used to improve the Circles and update this summary.

Substantive changes should be brought back to the relevant Circle for discussion before being finalized.

Full Terms of Reference

This summary is meant to make the Patient Partner Circles easier to understand before applying.

For more detail about membership, Co-Chair roles, compensation, meetings, decision-making, confidentiality, respectful participation, and annual review, please read the full Terms of Reference.

[Read the full Terms of Reference]