



2023-2024 Annual Report



Letter from the Co-chairs

At the Patient Advisors Network (PAN), our vision is clear: to bring the passion, knowledge, and lived experiences of patients and caregivers into every aspect of healthcare—policy, research, service delivery and education. This vision is the foundation of our work, and we believe working together in healthcare is key to achieving it. We know that it's not easy to open up new conversations and include new voices, but it's necessary.

Over the past year, PAN has made significant progress in our community growth. We formed new partnerships, had our voices heard in important discussions, strengthened our education series and worked on projects that align with our mission. These efforts are not only laying the groundwork for the future but also building on what PAN has already established. Each project moves us on the path to our goal of a more inclusive, people-centered healthcare system.

Our Community of Practice evolved as we supported our members through education and capacity development. Our webinars covered a wide range of topics, from the practical aspects of being a patient or caregiver partner (such as preparing a CV), to understanding emerging healthcare issues (such as AI in healthcare). These sessions explored how patient partners can participate in and impact these areas, further strengthening our community and enhancing our collective knowledge.

Looking ahead, we will continue to grow our Community of Practice and support and learn from our members. As a grassroots organization, we are optimistic and determined. We will keep building on our successes and remain committed to continuous improvement. We will strengthen our partnerships and stay dedicated to transforming healthcare into a system that truly values and includes the insights of patients and caregivers.

PAN supports the practice of involving a minimum of 2 patient partners on any healthcare project. PAN has adopted this policy for internal project leadership, where we will have 2 co-leads. In addition, we implemented a co-chair model for our Board of Directors, ensuring continuity, broadening knowledge and experience, and providing shared support.

Thank you for your unwavering support and dedication to our shared mission.

Alies Maybee and Donna Rubenstein, Co-chairs

Our Board

Board of Directors

PAN is a Canadian registered not for profit . We operate with a volunteer working board of patient/caregiver partners from our member community. The role of the board is to set strategy, determine priorities, and operationalize the strategy.



Co-Chair
Donna Rubenstein
Bedford, NS



Donaldda Maclsaac
Halifax, NS



Sandy Ketler
Kelowna, BC



Secretary
Amy Ma
Montréal, QC



Mindy Tindall
Edmonton, AB



Annette McKinnon
Toronto, ON



Maxime Lê
Ottawa, ON



Co-Chair
Alies Maybee
Toronto, ON



Sandra Holdsworth
Gravenhurst, ON

About Us

The Patient Advisors Network (PAN) is a community of people who have received health services or cared for those who have and are committed to improving healthcare for the good of all across Canada.

Partnering as a patient/caregiver in healthcare can be lonely work. No matter what we call ourselves, we are often working alone or with a few others like us. PAN is a grassroots organization that was formed to provide us a community home. A place to discuss topics of interest to us; a place to learn from and support each other.

PAN is also a platform for sharing our insights both as individuals and as a collective. We are a Canadian, not-for-profit organization that is self-funded. We contract with healthcare, research and academic organizations to provide patient and caregiver insights related to healthcare and to patient engagement. When money is earned we compensate the participating patient/caregiver partners. The remaining funds are invested in operating the organization including the website and administration costs.

Mission

Support the transformation to people-centered healthcare that is inclusive for all through policy, research, service delivery and education.

Embed the passion, knowledge and lived experiences of patient/caregiver partners in healthcare through collaboration.

Values

PAN is a forward-thinking, innovative, independent, dynamic organization that drives impact and embodies the following values (in no particular order):

- ✓ Community-Driven / Member-Driven
- ✓ Collaboration – Partnerships – Cooperation
- ✓ Respect – Trust – Integrity
- ✓ Sustainability – Accountability – Transparency
- ✓ Diversity – Equity – Inclusion

Our Vision

STRATEGIC PLAN OVERVIEW 2023-2026

Patient Advisors
Network



Patient Advisors Network (PAN) Mission

1. Support the transformation to people-centered healthcare that is inclusive for all through policy, research, service delivery and education.
2. Embed the passion, knowledge and lived/**living** experiences of patient and caregiver partners (PCP) in healthcare through collaboration.

STRATEGIC PILLARS

1

PAN COMMUNITY EXPERIENCE AND ENGAGEMENT

2

PAN PROFILE AND AWARENESS

3

PARTNERSHIPS AND NETWORKS

4

ORGANIZATIONAL SUSTAINABILITY
AND STEWARDSHIP

VALUES



Community-Driven
Member-Driven



Diversity
Equity
Inclusion



Collaboration
Partnership
Cooperation



Respect
Trust
Integrity



Sustainability
Accountability
Transparency



Implementing Our Vision

In 2023, PAN created a 3-year strategic plan based on the collective feedback from our community. Our work over the past year has been guided by the goals outlined below, with focus on Pillars 1 and 3.

PILLAR 1: COMMUNITY EXPERIENCE AND ENGAGEMENT

➤ GOAL: Engaged and satisfied PAN members, with outreach to diverse patient/caregiver partner groups

PILLAR 2: PAN PROFILE AND AWARENESS

➤ GOAL: Increased awareness across established patient/caregiver partner groups, individuals, the public, key Pan-Canadian Healthcare Organizations (PCHOs), researchers, decision makers, health care providers

PILLAR 3: PARTNERSHIPS AND NETWORKS

➤ GOAL: Build and foster relationships and partnerships with key patient/caregiver partner and healthcare organizations, researchers (especially those engaged in patient/caregiver partner partnership) around furthering shared goals

PILLAR 4: ORGANIZATIONAL SUSTAINABILITY AND STEWARDSHIP

➤ GOAL: Effectiveness in governing and administrative practices

➤ GOAL: Diverse and stable funding source development

Our Year By the Numbers

345
Members
(18% increase)

56
Opportunities
Posted

310
subscribers
to our
emails

7
Webinars /
Conversation
events

241
overall
webinar
participants

95%
satisfied with
webinar
content

Global Recognition

The innovative approach that PAN has for supporting the patient/caregiving partner community has been recognized globally by its peers.

One of PAN's co-founders and co-chairs, Alies Maybee, was awarded the Made with Patients Champion Award in May 2024 at the Patient Engagement Open Forum (PEOF) conference in Bavano, Italy. She shares this global award with Abigail Simon-Hart from Nigeria.

This award recognizes Alies' contribution to creating an organization with such an innovative approach to patient engagement and her efforts in co-initiating Equity-Mobilizing Partnerships in Community (EMPACT), a diverse community table focused on health equity. Alies accepted the award on behalf of all those who have contributed to the creation and evolution of PAN.

PAN's report, "Reimagining the Research Landscape," influenced one of the concurrent sessions at this international gathering. This PEOF session used PAN's suggestions directed at funding agencies as probing ideas for discussion.

PEOF is a global gathering bringing together an unparalleled network of multicultural and multidisciplinary visionaries to shape the future of Patient Engagement. It is organized by Patient Focused Medicine (PFMD.org), the European Patients' Academy (EUPATI) and the European Patients' Forum (EPE) and started in 2019. The many patients and caregivers who attended are so like the folks in our community, committed to making health and care better through their efforts.

There is nothing quite like PEOF in North America, so being part of this global network makes sense for PAN. Join the PAN community and be part of a Canadian movement that leads from the heart.

In her acceptance speech, Alies asked us all to consider how patient engagement will need to innovate to tackle the huge impact on health from AI, climate change, and future pandemics.



Alies Maybee, PAN's co-founder and co-chair, with her 'Made with Patients' Award.

Our Projects and Partnerships

We are a Canadian, not-for-profit organization that is self-funded. We contract with healthcare, research and academic organizations to provide patient and caregiver insights related to healthcare and to patient engagement. When money is earned we compensate the participating patient/caregiver partners. The remaining funds are invested in operating the organization including the website and administration costs.

Partnership with the Centre for Digital Health Evaluation (CDHE) – Ongoing

Since 2019, PAN has been partnering with CDHE. We co-designed the patient engagement framework for them in 2017 and currently manage patient engagement for CDHE. Our team includes 25 Patient Partner Evaluators (PPE's), patient/caregiver partners from across Canada, with 15 being actively involved, while others are alumni. In 2023, we had 5 active projects and to date have completed 25. Projects range from 6 months to 2 years and cover a variety of digital health initiatives. Some examples are Patients before Paperwork, AI Scribe and Secure Messaging. For each project, there are a minimum of 2 PPE's .

We want to acknowledge Women's College Hospital (WCH) in Toronto, whose research arm, the WCH Institute for Health System Solutions and Virtual Care (WIHV), houses the CDHE. They have played a crucial role in co-designing the innovative approach to patient engagement that supports our partnership.

Two key innovations in this partnership are: PAN's provision of the patient engagement function to CDHE and the creation of Peer Groups. For example, the Patient Partners Peer Group meets monthly to share insights on experiences with projects and to discuss emerging issues in the digital health forum.

Project with the Canadian Institutes of Health Research (CIHR) – SPOR Refresh Strategy Advisory Council – New

CIHR commissioned PAN to provide a PAN representative for their Strategy for Patient-Oriented Research (SPOR) Refresh Strategy Advisory Council. In addition CIHR asked PAN to contribute insights from the unique perspective of patient/caregiver partners to their Refresh process. To achieve this, PAN surveyed the PAN Community and beyond about people's knowledge and experience of health research in December 2023 and January 2024. 262 people responded. We also held 2 focus groups with 15 members of the PAN Community to discuss future directions of research.

Our Projects and Partnerships (cont'd)

The insights of the survey and the focus group provided the basis for the PAN report “Reimagining the research landscape” published in May 2024. This illustrated report has received tremendous feedback across the patient and researcher community. It highlights some fresh perspectives from the patient community and provides a platform for further conversations.

Patient and Caregiver Hub – CAHSPR2024 Conference – New

PAN and the Canadian Association for Health Services and Policy Research (CAHSPR) co-sponsored a Patient and Caregiver Hub at the annual conference. It was a 1st partnership of its kind for PAN to provide a space for caregivers and patients to rest as well as meet and connect with each other.

In addition, the Hub piloted an innovative approach to patient partnership, as researchers were invited to meet one to one with patient/caregiver partners. This facilitated the sharing of ideas and discussions related to challenges and opportunities for advancing meaningful patient engagement in research. The feedback and experience from this pilot support building on this model for future conferences .

Looking Ahead

We are both proud and excited about the progress PAN has made over the past year. Our achievements reflect the dedication of all of you in our community, and we are enthusiastic about the opportunities for further growth that lie ahead.

We are exploring new partnership and contract opportunities, recognizing their positive impact and the strength that comes from alliances and collective efforts. We realize that the success of these opportunities builds on the foundation of a strong member community. We are committed to more opportunities to further support our patient/caregiver members.

We have heard from our community members that there is a desire for increased interaction, participation and website improvement. We understand that website updates have been slow in coming and are critical to improving members' experience of navigating our site. In response, we are actively working on making it more user-friendly and exploring additional ways to support and enhance member engagement. This is a high priority for the year ahead. To support this work, we are rolling out our biannual member survey this fall. Member feedback and insights are crucial for ensuring that we continue to support our community effectively.

We are also excited to launch a new member onboarding program, which will be an important step in welcoming and integrating new members effectively.

Education and learning remain central to our mission. We will continue to focus on our webinars and PAN conversation events, providing valuable opportunities for growth and discussion.

Looking ahead, our focus will be on strengthening community member engagement and support while continuing to pursue impactful partnerships and projects. Together, we will build on our successes and work towards a future where both our internal community and external partnerships thrive.

Visit us at: www.patientadvisors.ca
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