



PAN Annual Report 2022-2023

A message from PAN's Board of Directors

July 2023

PAN'S BOARD OF DIRECTORS

Chair - Alies Maybee, Toronto, ON

Secretary - Amy Ma, Montréal, QC

Annette McKinnon, Toronto, ON

Donna Rubenstein, Bedford, NS

Maxime Lê, Ottawa, ON

Ramona Bonwick, Winnipeg, MB

Sandra Holdsworth, Gravenhurst, ON

Susan Palijan, Guelph, ON

Click [here](#) to read the board members' individual biographies.

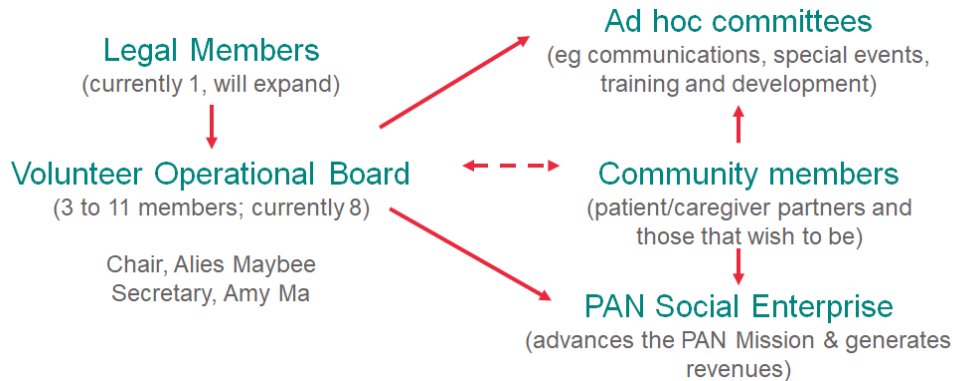


On behalf of PAN, we welcome the addition of Susan Palijan and Ramona Bonwick to its Board of Directors in 2022-2023.

The role of the Board is to set strategy, determine priorities, and operationalize the strategy. The Board also creates and amends the By-Laws which must be approved by the Legal Members. It acts as an operational board often seen in the early stages or smaller organizations.



Board members are volunteers and not paid. With the growth in our activities, we needed to expand our Board, and have amended our Bylaws to go from a maximum of 7 Board Members or Directors to a maximum of 11.



As PAN grows, so too does its operational needs. In order to better streamline membership requests, respond and track inquiries and manage the day-to-day business of the organization, the Board has chosen to hire a part-time administrator, Marion Knutson, who has lived experience as a patient and caregiver partner as well as a wealth of administrative experience. Marion began with PAN at the start of 2023 and has been instrumental in keeping PAN’s affairs in order and provide the capacity to expand our membership and activities.

AN OVERVIEW OF WHERE PAN IS TODAY

From our launch in 2017, we continue to focus on our two main objectives.

Our two main objectives continue to be:

1. To support and build capacity of patient and caregiver partners working towards better healthcare experiences and outcomes for patients, caregivers and workers in healthcare.
2. To mobilize our experiences in patient and caregiver partnership to ensure that applying the wisdom gained from the lived experience of patients, caregivers and families becomes the norm for all aspects of healthcare.

Over time, how we worked towards those objectives has matured and changed as you will see from the projects we were, are, and will be involved in this year, detailed below.

Our maturity as an organization has also prompted us to embark on new strategy work to further grow our community, which we detail later in this report.

To learn more about PAN and its origins and how we work, go to the [About Us](#) section of the website.



PAN’s financials for fiscal year 2022

We were able to finance the rollout of the new Community site in 2022 and have set aside monies for updates. We are also now in a position to support a part-time administrator as of January 2023.

Balance Sheet 2022		<p>This reflects payments to PAN for work we are doing. Much of this will be paid out to patient/caregiver partners on the PAN projects.</p>
Assets	\$88,325	
Total Liabilities and Equity	\$88,325	
Profit & Loss 2022		<p>The balance goes to support our on-going operations.</p>
Gross Profit	\$ 63,517	
Total Expenses	<u>\$ 52,045</u>	
Net Income 2022	\$ 11,472	

ACTIVITIES

THE PAN COMMUNITY SITE 2.0

Community Site 2.0 officially launched in the Fall of 2022 with

- a separate opportunity listing where PAN Community members and those outside PAN can list opportunities for engagement
- the Forum for discussion with the old discussions carried over
- a Dashboard for updates and announcements
- other pages with resources and information about PAN projects

Expect to hear about updates soon as we will add improvements as well as fix any glitches. In the meantime, keep engaging and making those connections!

We appreciate your patience as we deal with any technical difficulties. We plan for further enhancements for Fall of 2023.

If you are still experiencing any issues with the Community Site, e-mail hello@patientadvisors.ca with your issue and we will get back to you.

CONVERSATIONS, WEBINARS AND COURSES

Our webinars and PAN Parle member discussions were more plentiful this past year and we hope to continue to add thoughtful, informative webinars and discussions going forward.

Our webinars feature a presentation with time for questions; our PAN Parle sessions are more informal discussions around a topic.



Throughout 2022, and early 2023 PAN hosted two “PAN Parle” sessions. Thank you to Community members for your passionate participation!

- ✓ October 2022– **Book Club: “Ducks in a Row”** with Sue Robins
- ✓ November 2022 – **Film: “Falling Through the Cracks - Greg’s Story”** with Terri Price (Greg’s Wings)

The webinars we held were:

- ✓ February 2023 – **Canadian Patient Partner Survey** Results with Julia Abelson and **Mary Anne Levasseur** – Feb/23
- ✓ **AI in Healthcare** with the Vector Institute – Apr/23
- ✓ Learning Together Evaluation Framework for Patient and Public Engagement (PPE) in Research with Audrey L’Espérance and **Mary Anne Levasseur**: – May/23

And announcing our first ever PAN-created education workshop!

The workshop, **Foundations of Patient Partnering**, will be piloted soon. Please help us refine it by participating. This workshop is meant to cover the core items we need to be aware of and comfortable with as patient/caregiver partners. We could not cover everything in one workshop so we also have a list of additional modules we hope to tackle.



PAN WORKING GROUPS

Last summer for the first time, PAN initiated three working groups. These arose in some cases from Forum discussions on our Community site, in others from earlier webinars and in others were appeals for interest from the Board.

Digital Health WG

The group developed a question list (resource) for patient/caregiver partners involved in a digital health project. This is posted on the Community site as a resource.

Safety and Ethics WG

This group is developing a question list for patient/caregiver partners in the early days of a project or committee as conversation starters. Stay tuned for this resource which is planned to have links to additional resources!

Compensation WG

This group is reviewing gaps and opportunities to support patient/caregiver partners in this emerging area. It is considering where PAN can collaborate and have optimal impact.



PAN PROJECTS AND PARTNERSHIPS

PAN makes an impact through our partnerships by harnessing the experience, knowledge and incredible talent in our PAN Community.

Below you will find a list of the various projects PAN is involved in and partnerships the organization has built. Further information is available on our Community site.

Over the last three plus years, PAN has been involved in two research projects which came to a close this Spring.

Research Project: The Strategy for Patient-Oriented Research (SPOR) Patient and Public Engagement Evaluation Framework

This project was led by Dr. Antoine Boivin, Alexandre Grégoire, Audrey L’Espérance and Dr. Marie-Pascale Pomey out of the Centre of Excellence on Partnership with Patients and the Public (CEPPP), Montreal with PAN co-leads: Carolyn Canfield and Mary Anne Levasseur. The goal was to develop a national adaptable framework for the evaluation of patient and public engagement (PPE) in research which was launched this Spring as the [Learning Together : Evaluation framework for Patient and Public Engagement \(PPE\) in research.](#)



PAN was deeply involved in the decision-making through our leads resulting in this framework which represents a unique approach as can be seen in the above diagram. It also establishes patient/caregiver partners right from the planning stage on.

It is being widely accepted and adopted and should become the national standard for evaluation of PPE in research.



To learn more click on the link and also go to the PAN May 2023 webinar with Audrey L’Esperance and Mary Anne Levasseur found under Learning Resources on the Community site.

Research Project: Examining Patient Partner Roles in the Canadian Health System

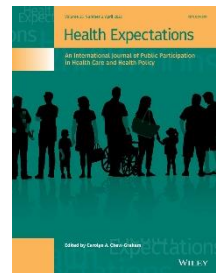
This was the [first ever in depth look at our patient/caregiver partner community in Canada.](#)

This project was led by Dr. Julia Abelson and Dr. Meredith Vanstone with PAN co-leads: Mary Anne Levasseur and Carolyn Canfield.

The goal was to gain an in-depth understanding of the patient partner role as an emerging resource to the Canadian health system.

The following reports have been published ... so far!

[The impact of COVID-19 on patient engagement in the health system: Results from a Pan- Canadian survey of patient, family and caregiver partners](#)



This was a look at how the activities and experiences of patient, family and caregiver partners, as a large group across a variety of settings within the health system, changed due to the substantial health system shifts catalysed by the pandemic.

[Understanding patient partnership in health systems: lessons from the Canadian patient partner survey](#)



This is an examination of the sociodemographic characteristics, activities, motivations, experiences, skills and challenges of patient partners working across multiple health system settings in Canada. Over 600 of us filled in the survey that took about 37 minutes to complete!

Now we have hard data about who of us are involved, it is clear we need to find ways to bring the voices of our diverse and rural communities to the work to improve healthcare.



Partnership: Centre for Digital Health Evaluation (CDHE) - since 2019

We would like to pay tribute to Women’s College Hospital (WCH) in Toronto. Their research arm, WCH Institute for Health System Solutions and Virtual Care or WIHV, houses the CDHE. They have participated in co-designing the innovative approach to patient engagement that supports the PAN-CDHE partnership.



<https://cdhe.wchwihv.ca/>

There are two innovations: that PAN provides the patient engagement function to the CDHE, and the creation of Peer Groups.

The group of about 20 patient/caregiver partners who are the partners on the evaluation projects come together once a month to share experiences in digital health and in engagement. The group supports and learns from each other... and comes up with new ideas to present to the CDHE. For example, PAN influenced the making public of the evaluation reports.

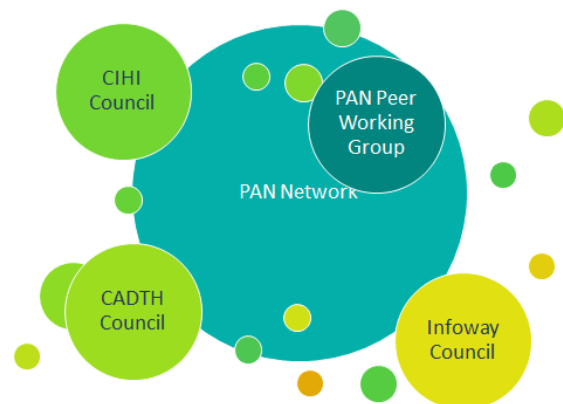
Some of the projects completed this year reflect a wide range of digital health topics:

- ✓ internet-based Cognitive Behavioural Therapy (iCBT)
- ✓ Patient Digital Identity, Access and Authorization (PDIAA)
- ✓ Breaking Free Online (BFO)
- ✓ AI Screening for Retinopathy in Patients with Diabetes
- ✓ Virtual Care Scorecard
- ✓ Evidence 2 Practice (E2P)
- ✓ Clinical Information Systems Maturity Model (CISMM)
- ✓ Remote Patient Monitoring (RPM)
- ✓ Regional Security Operations Centres (RSOCs)

With many thanks to the intrepid PAN-CDHE Peer Group!

Partnership: Canadian Network for Digital Health Evaluation (CNDHE)

Through the CDHE, PAN also partnered with the national network, CNDHE, to provide patient/caregiver partners from the PAN-CDHE Peer Group for the projects funded nationally on secure messaging and equity case studies. PAN also did a workshop on patient engagement for the Symposium for partners and interested stakeholders.



So far, three have been completed: Asynchronous messaging across 5 provinces ; Asynchronous Care Model Analysis and Equitable Virtualization of Primary Care.

Together with the CDHE team, PAN will continue to explore additional opportunities to work together.



New Partnership: CIHR – SPOR Refresh Strategy Advisory Council

First ever request for a PAN representative as opposed to an individual patient/caregiver partner

The Canadian Institutes of Health Research (CIHR) requested that PAN provide a PAN representative to their Strategy for Patient Oriented Research (SPOR) Refresh Strategy Advisory Council. We are delighted to be involved in this important initiative that is looking at how patient-oriented health research can mature.



We have not only provided Diana Ermel as our Representative, but we have created a small PAN-CIHR Council of very seasoned patient/caregiver partners in various aspects of research to support and advise her as well. This has just started and is planned to go for two years. During that time, the PAN-CIHR Council may reach out to the Community for input. In the meantime, feel free to pop your thoughts and ideas into the Forum discussions as that will add to the advice going forward.

STRATEGIC PLAN

Since the Spring of 2023, the Board has been in the process of developing a three-year strategic plan. The PAN survey of last year and the discussions within our working groups and webinars have formed the primary input to the plan. While it is not yet complete, we would like to share those aspects that are with you.

Mission

The mission of the PAN community is to:

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**



Strategic pillars

To transform our mission and values into action, we have developed four strategic pillars with goals.

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

Next steps

Our next steps are to identify the actions PAN needs to take under each pillar to move towards the goal. Then we will set priorities and scope based on our resources. As we identify actions, there will be plenty of room for the PAN Community to participate so expect us to reach out with opportunities for involvement.

In the meantime, if you have any feedback, please feel free to share on the Forum or send us an email at hello@patientadvisors.ca.

LAST WORDS

As we move into this year, we all can and must continue to participate in local improvements. At the same time, we are operating in health systems in crisis. There are big changes being talked about – team-based care, funding models different from fee-for-service, changes to scopes of practice, data access and sharing, and new technologies like remote monitoring. We, as patient and caregiver partners will need to be prepared to understand and support the changes we feel are needed. PAN will do its part to help us all learn.

We are excited for what the future holds for PAN and for all of us. Times of crisis are also times of great opportunity for change. Let's seize the day!

Thank you for taking the time to read through this annual report and please continue to let us know what you are thinking about and doing.

