



PAN Annual Report 2021-2022

A message from PAN's Board of Directors

August 2022

PAN'S BOARD OF DIRECTORS

Chair - Alies Maybee, Toronto, ON

Secretary - Amy Ma, Montréal, QC

Annette McKinnon, Toronto, ON

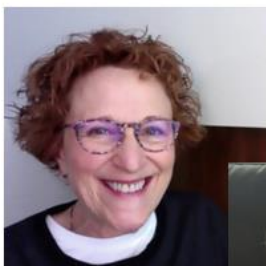
Donna Rubenstein, Bedford, NS

Maxime Lê, Ottawa, ON

Sandra Holdsworth, Gravenhurst, ON

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

PAN Board



Donna
Rubenstein



Alies Maybee



Max Lê



Annette McKinnon



Amy Ma



Sandra Holdsworth



AN OVERVIEW OF PAN

Patient partners include those who have received health services or cared for those who have and are committed to improving healthcare as patient partners and advisors for the good of all across Canada.

PAN is our community.

SOME HISTORY

In early 2016, a group of patient and caregiver advisors as we were then called from across Canada were looking for an independent community of patient advisors where patient advisors could get to know each other, exchange ideas, and learn from one another.

Unsatisfied after having looked nationally and internationally, the twelve founding members started to talk about creating a group where patient partners as we now call ourselves could get to know each other, exchange ideas, support and learn from one another - and be part of a community.

We created PAN's [Manifesto](#) to explain what we are, what we are about, and why we should exist. Shortly after that we launched our initial public website in French and English and our PAN Community site in January of 2017. We grew our Community by word of mouth.



PAN'S OBJECTIVES

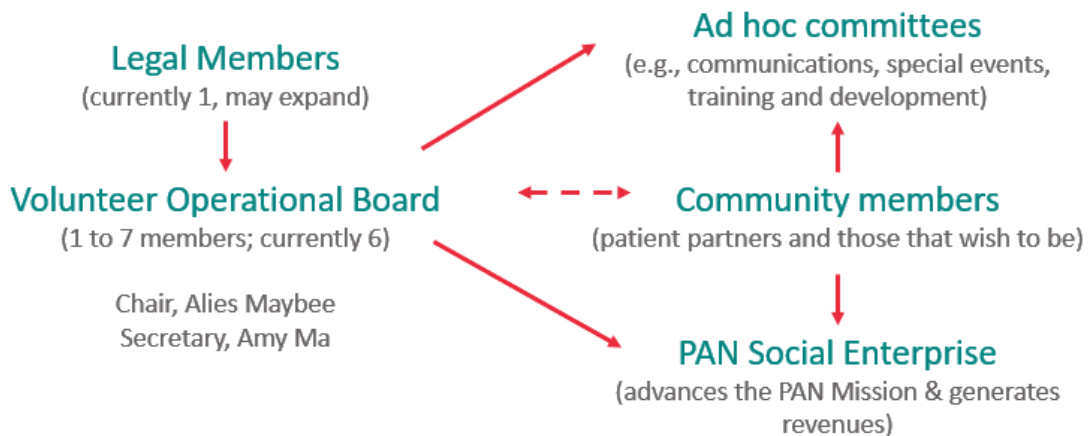
We have two main objectives:

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



HOW PAN WORKS

PAN is incorporated as a non-profit organization



As an incorporated non-profit organization, PAN has a Board with a minimum of one and maximum of seven Directors.

- Currently, we have 6 Directors with room for one more
- All our Board members are patient partners and members of our Community. We will be posting an expression of interest for Directors soon.

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. Currently, PAN has no staff support. In the Fall of 2022, the Board hopes to hire a part-time admin and staff person to allow PAN to grow and support members.



PAN AS A NON-PROFIT AND A SOCIAL ENTERPRISE

- As a not-for-profit corporation, PAN's profits must be used to further the goals of the PAN rather than to pay dividends
- PAN is a non-soliciting corporation and currently does not receive grant funding from public sources
- Typically, social enterprise non-profit organizations like PAN operate businesses to generate revenues and fulfil their missions. In PAN's case, we provide services to research teams and healthcare organizations to further our second objective.
- The revenues support PAN's ability to provide our network infrastructure, our capacity-building offerings and compensates the contributing patient partners.
- PAN contracts for work with partners that fit our goals and our values as set out in the Manifesto. This enables us to remain independent of any healthcare organization or government. It has also enabled us to launch PAN without charging fees so that there are no barriers to belonging. While we may consider charging a nominal annual fee in future, we will always ensure that no one is left out because of finances.
- Some of the projects we are partnered on also offer opportunities to help participating members build their capacity.
- When PAN members participate on these projects, they have the choice to receive compensation or to donate their compensation to PAN. Thank you to all who are generous enough to support the organization!



PAN'S FINANCIALS FOR FISCAL YEAR 2021**Balance Sheet 2021**

Assets	\$31,438
Total Liabilities and Equity	\$31,438

***NOTES**

This includes what we owe to develop our new community site. Therefore, this shows as a negative amount.

Profit & Loss 2021

Gross Profit	\$ 8,172
Total Expenses	<u>\$24,414</u>
Net Income 2021	-\$16,241*

This amount has been covered by incoming revenues already paid in 2022 and will be paid out by the Fall when the work is completed.

Note from the Board:

Do not be alarmed by the negative number. PAN is in healthy financial status. Have questions pertaining to our finances? Contact us at: hello@patientadvisors.ca .



MAJOR ACTIVITIES

PAN 2.0. AND THE PAN COMMUNITY SITE 2.0

In January of 2022, we launched our new public website after having collected PAN member feedback in the fall of 2021.

Though our launch site served its purpose, this newer one will have the ability to integrate our new Community site as well, allowing PAN members to stick to one familiar interface instead of multiple windows.

PAN members have proven to be very active on the Community site: from 2021-2022, there have been over 95+ postings on the Community site, ranging from expressions of interests in project participation / webinars / courses / research projects, and more.

The new and improved private Community site is planned to launch in the early Fall of 2022. Expect to hear updates soon. In the meantime, keep engaging and making those connections!

CONVERSATIONS, WEBINARS AND COURSES

Throughout 2021 and the start of 2022, PAN hosted two “PAN Parle” sessions, where PAN members come together to talk about a given topic.

- Feb 2021 – Impact of COVID-19 on our lives
- April 2021 – Caregivers and Caregiving: Sharing our Experiences

PAN also hosted three webinars featuring guest speakers with lots of participation:

- Nov 2021 – David Gilbert : The Rise of Patient Leadership
- March 2022 – Dawn Richards: Patient Compensation
- June 2022 – Dawn Richards : Clinical Trials

Additionally, following David Gilbert’s webinar, David facilitated a four week program, *Foundations of Patient Leadership* from February to March of 2022.

Based on discussions that occurred in the program, a grassroots group came together to explore ideas that were generated in the course. There was more interest in the course than PAN could sponsor at that time so PAN is considering having David return to offer a second session later this year or early next year.



PAN MEMBER SURVEY RESULTS

In December of 2021, PAN sent around a member survey with the goal of understanding members' experience of PAN's work to date, and gathering suggestions for future activities. What follows below is a brief summary of what we heard from this survey. To access the complete results, visit PAN's Community site.

Overall, we heard from 48 PAN members or approximately 20% of the Community, 44% of which were PAN members for 5+ years, 46% were PAN members between 3-5 years, and 10% had been PAN members for less than 3 years.

PAN members were generally pleased with PAN's current direction and also provided valuable feedback on the path forward. PAN members' ranked their satisfaction with the organization as follows:

- 87% were moderately to completely satisfied
- 10% were slightly satisfied
- 3% were unsatisfied

Some of PAN's strengths, as identified by its community members, were that:

- PAN is a national, independent, peer community led by and for Patient Partners
- PAN members have broad based experience representing diverse areas of healthcare
- PAN is a non-partisan (neutral / non lobby) organization providing space for many views
- PAN's community offers guidance and support to members at all stages of their journey

Some of PAN's areas of improvement, as identified by its community members, could be that:

- PAN share more about its mandate, accomplishments and plans going forward
- PAN share more about Board membership and opportunities for members to be more involved
- PAN expand frequency of learning and exchange of ideas events
- PAN conduct more outreach to community groups and other patient networks
- PAN builds a more user-friendly website

Thank you to everyone that took some time to respond to our survey. The feedback we received and what we heard is being integrated in PAN's 2022-2023 plans.



PAN PROJECTS AND PARTNERSHIPS

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 private Community site, and when the new community site launches later this year, there will be more details about the PAN projects.

RESEARCH PROJECT: EXAMINING PATIENT PARTNER ROLES IN THE CANADIAN HEALTH SYSTEM

Principal investigators: Dr. Julia Abelson, Dr. Meredith Vanstone

PAN co-leads: Mary Anne Levasseur and Carolyn Canfield

Project Aim: To gain an in-depth understanding of the patient partner role as an emerging resource to the Canadian health system as follows:

- Map and explore the community of patient partners/advisors across Canada
- Assess prospects for role to contribute to health system decision-making & policy
- Identify challenges and how these might be addressed

RESEARCH PROJECT: THE STRATEGY FOR PATIENT-ORIENTED RESEARCH (SPOR) PATIENT AND PUBLIC ENGAGEMENT EVALUATION FRAMEWORK

Principal investigators: Dr. Antoine Boivin, Alexandre Grégoire, Audrey L'Espérance and Dr. Marie-Pascale Pomey

PAN Co-leads: Carolyn Canfield and Mary Anne Levasseur

Project Aim: To develop a national adaptable framework for the evaluation of patient and public engagement (PPE) in research. This project has two complementary goals:

- Building consensus within the Canadian community on the core evaluation criteria, process indicators and impact indicators of PPE in research
- Develop guidelines to implement the evaluation framework and adapt it to different contexts

PARTNERSHIP: THE CENTRE FOR DIGITAL HEALTH EVALUATION (CDHE) OUT OF WOMEN'S COLLEGE HOSPITAL

PAN co-leads: Munira Ratansi, Amy Ma, Tayaba Khan

Activities: PAN co-designed and manages patient engagement for the CDHE

- PAN co-designed the patient engagement framework for the CDHE in 2017
- PAN has a group of patient partners (PAN members) working on digital health evaluations that comes together monthly



With the CDHE, PAN has completed or is working on the following projects:

Completed projects	In progress / pending
<ul style="list-style-type: none"> ✓ MyChart ✓ Virtual care ✓ OMD Dashboard (for primary care docs) ✓ Virtual care in COVID ✓ Patient Digital Identity, Access and Authorization (PDIAA) 	<ul style="list-style-type: none"> • internet-based Cognitive Behavioural Therapy (iCBT) • Clinical Information Systems Maturity Model (CISMM) • Remote Patient Monitoring (RPM) • Breaking Free Online (BFO) • Regional Security Operations Centres (RSOCs)

PARTNERSHIP: CANADIAN NETWORK FOR DIGITAL HEALTH EVALUATION (CNDHE)

PAN co-leads: Kathy Borthwick, Alies Maybee

Activities: PAN has a contract to partner with the CNDHE, a national initiative including the development of a framework for digital health evaluation, developing a network of stakeholders (patient groups included) and demonstration projects (see below).

CNDHE projects:

Asynchronous messaging

- Local level evaluation of specialty care at Women’s College Hospital through the patient portal
- Multi province, including the University of California in San Francisco

Equity case studies:

- Exploring what is being done to consider health equity with virtual care for primary care in Ontario
- Will hold 1-2 focus group sessions with patient partners Sep - Nov 2022 to discuss results of the study and include patient perspectives to help interpret the study data



GETTING INVOLVED

Have some time and want to get more involved in PAN's activities? We'd love to have you.

In response to our Community members, we have established some working groups to create supports and training for our fellow patient partners.

Here are some of PAN's current opportunities:

COMPENSATION COMMITTEE:

PAN plans to continue efforts on this topic to explore how PAN can advance development of standards of practice and a broader understanding of the importance to meaningful patient partnership

COMMUNICATIONS COMMITTEE:

If you have any experience in marketing and communications, join our Communications Committee and help spread the word about the organization.

DIGITAL HEALTH COMMITTEE:

The Committee is developing guidelines and questions to ask for patient partners getting involved with digital health projects. Also, as the CNDHE identifies digital health evaluation projects across Canada, there may be opportunities to become patient partner evaluators on those projects.

OTHERS:

As discussions arise on the discussion board or forum, PAN identifies areas and issues that appear important to our Community. From these ideas, we will pursue additional working groups so stay tuned.

A reminder:

PAN is a volunteer-led organization. We do our best, and we can always use some help. Thank you to those that have invested some time and effort into PAN and thank you to members who participate in and support what we do.

If any of these opportunities interest you, please let us know at hello@patientadvisors.ca



LAST WORDS

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

We are excited for what the future holds for PAN, whether it's the launch of our new and improved Community site, more PAN Parles and webinars, or the various projects that will engage the community.

PAN members and the community have time and again proven that patient partners are resilient and can meaningfully contribute to improving our healthcare systems, making it fairer and more equitable for all Canadians from coast to coast.

This coming year will challenge all of us as we face health systems stretched to the breaking point. There will need to be bold changes as the status quo can't endure. We, as patient partners will need to be prepared to understand and support the changes we feel are needed.

