

Leading Through Governance



Patient/Caregiver Partner Experiences

June 2026

Background

Thank you to everyone who took part in our Governance & Oversight Experience Survey!

This survey was conducted to get a snapshot of patient/caregiver partner experience, knowledge and interest in governance, oversight and leadership.



PAN, the value of community

Our goal is to better understand the needs of patient/caregiver partners, and how we can support your involvement in these roles.

We are seeing an increasing number of opportunities for Patient/Caregiver Partners to contribute at governance and oversight levels. Let's make sure we're ready to step into these roles with confidence and impact.

This report shares what we heard — the highlights, key themes, and some next steps for PAN.

Acknowledgements

This report and the survey is the result of a collaborative effort of the PAN Governance Committee, led by **Donna Rubenstein**. PAN thanks each member for their expertise, experience and passion shared throughout the process.

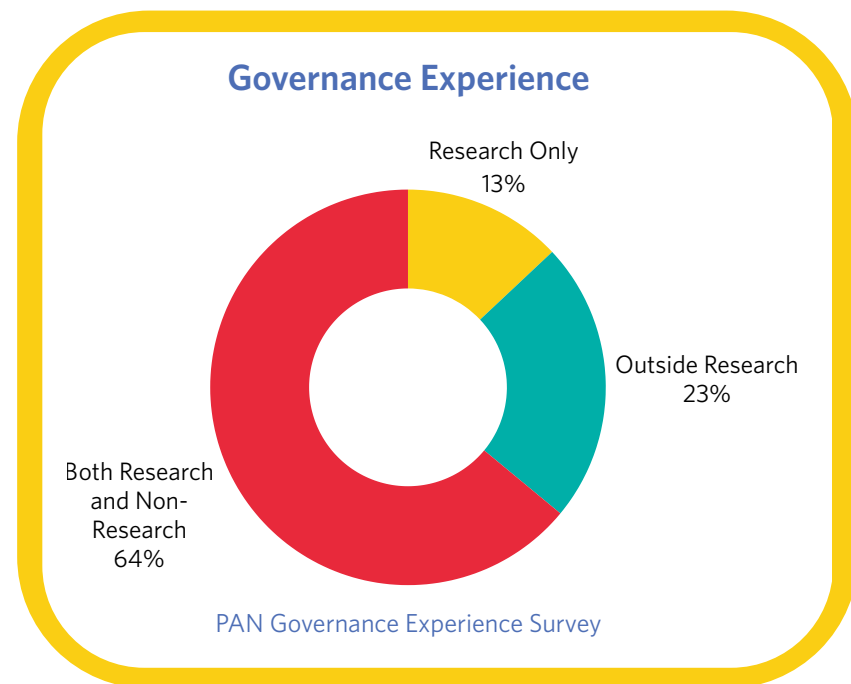
Members included:

Sandra Holdsworth, Lisa Ridgeway, Brenda Andreas and Alies Maybee.

Who Took Part

Patient/Caregiver partners who participated have a wide range of experiences.

- Respondents have served on advisory councils, boards, or governance committees.
- Most respondents (64%) have both research and non-research governance experience
- 70% Were PAN members and 30% non PAN members

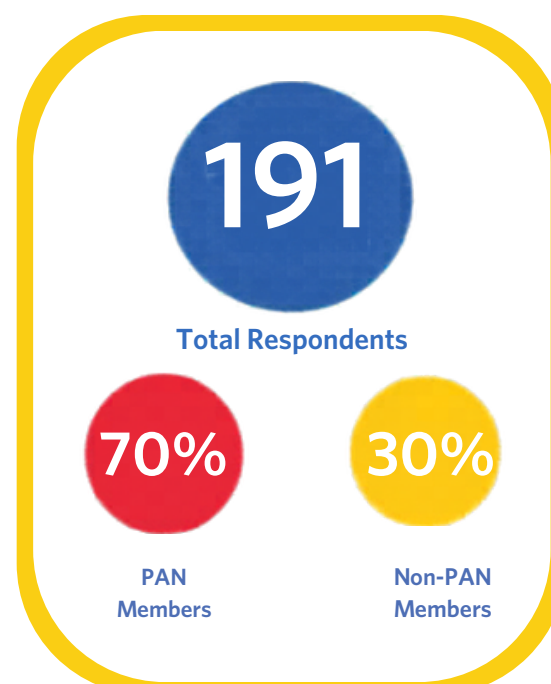


Governance experience is extensive and far reaching

Respondents have experience with a wide variety of organizational settings - public, not for profit, community and private, often serving in multiple areas.

Governance Experience of PAN Respondents

- We gathered insights from 191 respondents, consisting of patient and caregiver partners with a diverse range of governance-related experiences.
- Almost all respondents have served on an advisory council, board, or governance committee.

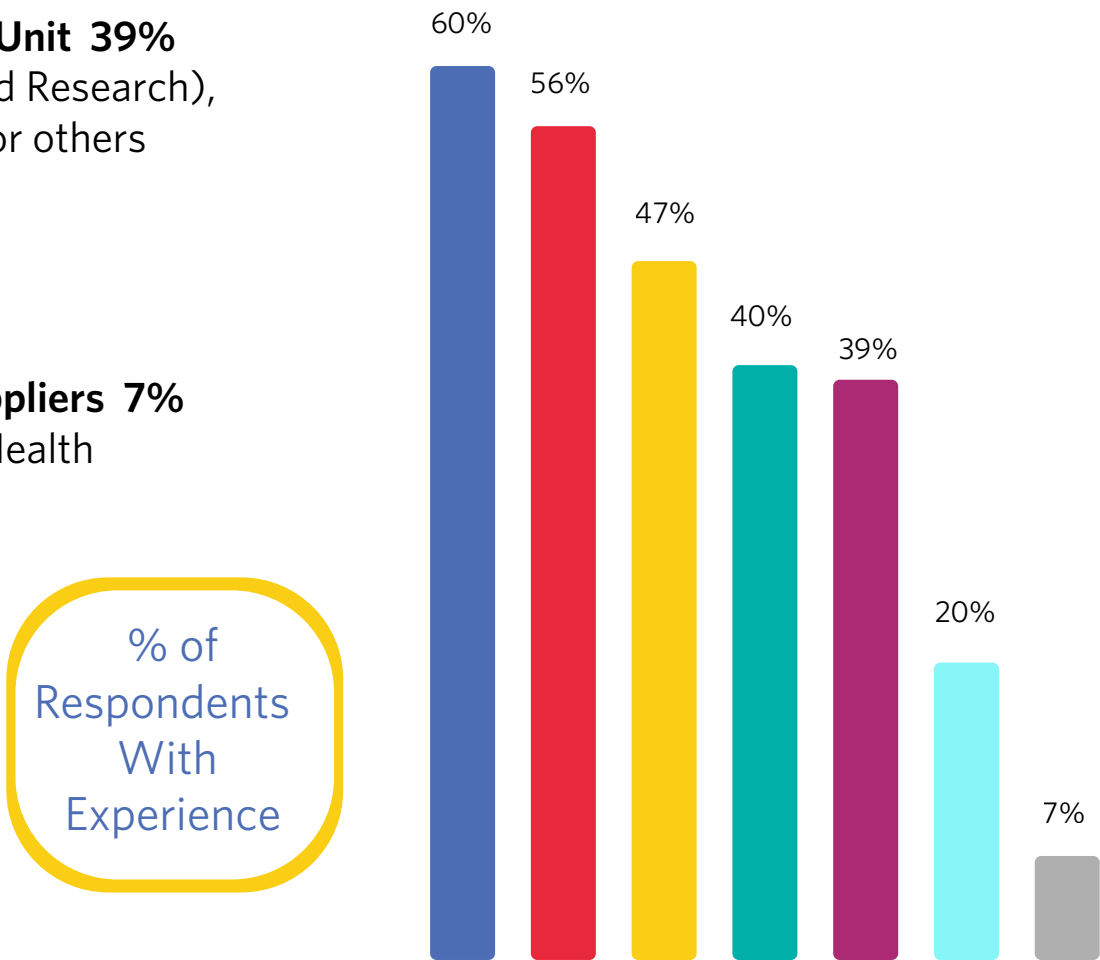


Governance Experience of PAN Respondents

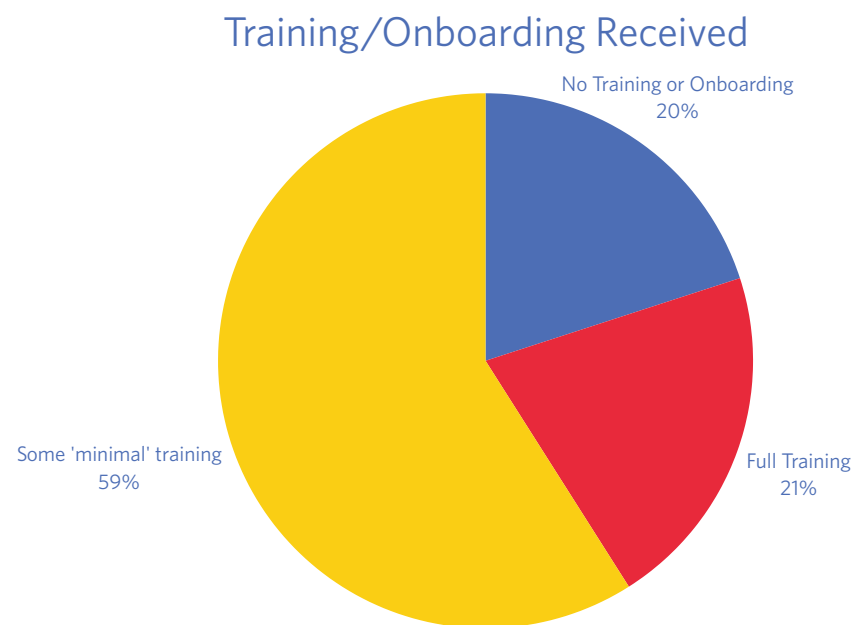
The respondents' governance experience spans both research and non-research domains, illustrating a comprehensive involvement in various organizational settings. These settings include public, not-for-profit, community, and private sectors.

Type of Committee or Board

- Not for profit or community group 60%**
(e.g. YWCA, Arthritis Society, Fibromyalgia Association Canada, children's sports, environmental group, or others)
- Provincial Health organization 56%**
(e.g. Ontario Health, Saskatchewan Health Authority, Nova Scotia Health, BC Provincial and/or Regional Health Authorities, or similar organizations)
- Health Research 47%**
(universities, academic hospitals), philanthropic organizations
- Organization supporting the health system 40%**
(e.g. CIHR, CIHR Institutes, CIHI, HEC, HSO, Canada Health Infoway Canada, Vector, or others)
- Provincial or national SPOR Unit 39%**
(Strategy for Patient Oriented Research), e.g. OSSU, MSSU, AbSPOR, or others
- Other 20%**
- Health related Vendors/Suppliers 7%**
(e.g. pharmaPharma, Telus Health or others)



TRAINING AND ONBOARDING GAPS



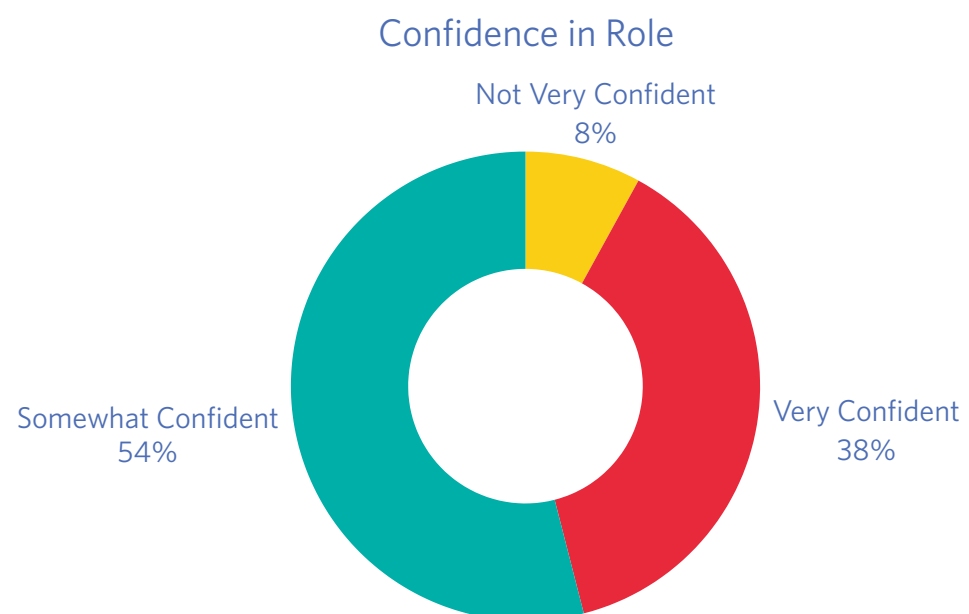
Most respondents had little or no training or onboarding when joining boards or committees.

- Only 21% received full training;
- 79% received minimal or no training.

Confidence is Strong

Most respondents (88%) feel somewhat or very confident in understanding their role and responsibilities in these roles.

- This was a surprising number given the limited training most people received.
- The comments helped explain the disconnect as many people expressed, they 'learned as they went'.



This reflects the determination and resilience of the patient/caregiver partner community.

INTEREST IN LEARNING

Most people (90%) are interested in learning more about the basics of governance, oversight and their role as committee member. Only 10% are not very interested.

THEMES WE HEARD

In the comments shared about what governance/oversight means to them, what's important and issues of concern, several themes came through:

- Understanding roles, responsibilities and accountability is key
- Importance of collaboration, respect and diverse voices at the table
- Decision making process, ethics and conflict resolution are foundational
- Tokenism persists and limits Patient/Caregiver Partner opportunity to contribute and impact the work. Mentorship is part of the solution
- Distinction between governance (strategic) and operations (tactical). Inconsistent handling of compensation
- Need for training of non-patient/caregiver partners who are on these committees/board

COMMENTS FROM PARTICIPANTS

"Training is rare - often you learn as you go."

"..committees are not platforms for personal grievances."

"Clear roles and national standards would strengthen governance."

"Patient partners need more than a token seat at the table."

"Mentorship from experienced members made all the difference."

LOOKING AHEAD

The comments shared and themes we heard in this survey aligned closely with what was learned from the PAN Refresh Survey conducted for CIHR SPOR in 2024. The learnings from that are reported in the [Reimagining the Research Landscape report](#).

The results from this governance experience survey will help PAN plan future learning opportunities and practical resources for members who want to grow their skills and confidence in governance and oversight roles.

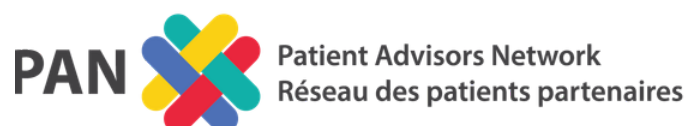


In the short term we are looking at hosting workshops throughout 2026. We will also use your feedback in discussions with organizations around ways to foster impactful partnerships with Patient/Caregiver Partners. Research reports and surveys of the past few years are clear in identifying where the gaps are.

PAN thinks it's time to level the playing field and support patient/caregiver partners to fully participate in governance roles.

Thanks again for sharing your experiences and ideas. We look forward to moving this forward.

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