



## PAN Manifesto

**PAN is the next generation of patient and family involvement.**

**We believe that harnessing the collective power of patients and families will transform healthcare.**

The Patient Advisors Network (PAN) is a community of people from across Canada who welcome individuals committed to improving healthcare for the good of all. Together, we can create a greater, collective impact.

### Objectives

We collaborate with healthcare providers, researchers, administrators, and policy makers to realize the following objectives:

1. To mobilize our experience in patient and family partnership to ensure that applying the wisdom gained from the lived experience of patients and families becomes the norm for all aspects of healthcare.
2. To support and build capacity among people working towards better healthcare experiences and outcomes, both for users and workers in healthcare.
3. To model accountable, open governance for a peer community that safeguards the authenticity of the patient and family voice and its sustainability as a community.

### Methods

We have chosen to come together to:

#### CONNECT, LEARN, & BUILD CAPACITY

- To learn from each other, develop our capacity and our community, and provide support to each other in this work.
- To contribute out of our experience how best to partner with healthcare professionals to deliver truly patient-centred care that supports families.

#### IMPORTANT NOTES:

1. We define *patients* as individuals with personal physical or mental health experience with any aspect of the healthcare system in Canada. This includes individuals who might be called *clients* or *residents*, depending upon the healthcare context they are in.
2. We define *family* as family members or friends identified by the patient as their family. *Family* includes parents of children with mental or physical health issues. *Family* also includes children of parents with mental or physical health issues that limit their capacity to manage on their own.
3. We do not advise patients.

### WORK COLLECTIVELY

- To use education, consulting, research, and publishing to enable healthcare to better partner with patients and families.
- To tackle issues we can't deal with as individuals but can as a community.
- To see and act on opportunities to improve healthcare that we can't do on our own but can as a community.

### TO BUILD A NETWORK OF RELATIONSHIPS AND INFORMATION

- To be a source of connected, informed advisors to meet the growing demand across all domains of healthcare.
- To enhance our ability as individuals to appreciate the full complexity of the healthcare system, its many issues, and the diversity of patient concerns.
- To respect, reflect, and learn from the diversity of Canadian health experience.

## Why is the time right for PAN?

We are at a tipping point:

- Patient and family involvement has been building momentum: it is now recognized and often mandated.
- Patients and families are taking new, unprecedented roles in healthcare—a trend that is growing.
- There is a largely untapped and unrealized opportunity for harnessing the collective experience of patient and family advisors across the country.

And we are at a sticking point:

- Patients and families as advisors are disconnected from each other, functioning within isolated healthcare silos.
- Advisors are organization-based, so their relationships are with their organizations, not with each other.
- Patient and family engagement expertise is not usually shared across silos.

## Who We Are

As advisors, we are independent patients and family members trying to improve healthcare, each in our unique way and in collaboration with a variety of partners. We have a deep interest in healthcare and want to use our experience and understanding of Canadian healthcare systems to improve the experience and outcomes of care.



Individually, we are involved in one or more of the following ways:

- We are patient and family advisors (PFAs) in hospitals and on hospital advisory councils, including acute care, children's, and mental health facilities.
- We are on family and residents councils and participate as volunteers in long-term care facilities (LTCs).
- We advise and collaborate with health authorities, quality councils, healthcare associations, professional colleges, and academic institutions.
- We are members of boards and patient and family associations.
- We are involved with digital health initiatives, technology device development, and other innovations.
- We help set research priorities, evaluate research papers, partner on research teams, and conduct peer research.
- We teach and mentor students in the healthcare professions.
- We participate in focus groups, advisory councils, and other bodies to inform policy decisions, both for healthcare organizations and for our local provincial/territorial ministries of health.
- We blog, tweet, and write articles; we speak at conferences, on panels, to patient and family groups, and in the media. Some of us are thought leaders.

### TYPES OF ADVISORS

While we have all had experience with the healthcare system, we recognize that there are different types of advisors:

#### SINGLE LENS

Advisors who have the outsider's experience of the healthcare system have a single lens through which to view their experience. They include:

- Those who have experienced care as a patient but have never worked as a healthcare professional
- Those who have provided care as a family member but have never worked as a healthcare professional

#### DUAL LENS

Advisors who have the insider's experience of the healthcare system have a dual lens through which to view their experience. They include:

- Those who have experienced care as a patient and who also are working or have worked in healthcare
- Those who have provided care as a family member and who also are working or have worked in healthcare



### PATIENT PERSPECTIVE

Advisors who have or have had an illness or injury and received care from the healthcare system have a user's experience of the system.

### FAMILY PERSPECTIVE

Advisors who care for or have cared for a loved one have an (often unacknowledged) view of the healthcare system built on their struggles to provide and get care for their patient.

We believe each of these lenses and perspectives bring value.

We also believe that our partners' choice of type of advisor should be an informed decision, based on respect for and understanding of the unique value of each lens and perspective.

## Guiding Principles

These qualities characterize how our group functions as a collective and the way in which we conduct our work.

1. Inclusive and welcoming openness.
2. Respectful communication that honours listening as much as speaking.
3. Respect for the diversity of roles patients can and do play and for the diversity of healthcare experience and concerns.
4. Recognition of patients as experts with unique knowledge of the healthcare system and of patient advisors as knowledgeable partners in healthcare.
5. A holistic view of health in the broadest sense of well-being, including physical and mental health, the social determinants of health, and spiritual care for patients.
6. Autonomy and independence from any other organization.
7. Collaborative operating style with other organizations.

