Nipissing Wellness Ontario Health Team

# Patient, Family, Caregiver Council Partnership and Engagement Strategy

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## 1) Introduction:

The 2019 Ontario Health Teams: Guidance for Health Care Providers and Organizations sets out that Ontario Health Teams will uphold the principles of patient partnership, community engagement, and system co-design. The Nipissing Wellness Ontario Health Team (NW OHT) will be driven based on the needs of patients and communities within its defined boundaries. The NW OHT will meaningfully engage and partner with patients, families, caregivers, and communities, in unified, caring healthcare and social services centred around families and caregivers, through the Patient, Family Caregiver Council (PFCC), based on a robust patient partnership model and community engagement strategy.

To advance this foundational building block, the NW OHT has created a Patient, Family and Caregiver Partnership and Engagement Strategy as a priority activity in their early formation.

A Patient, Family and Caregiver Partnership and Engagement Strategy for the NW OHT is intended to ensure that partnership, co-design and engagement with patients, families and caregivers are at the core of the NW OHT; these are not just activities that the NW OHT conducts, but the ethos of its foundation. The Patient, Family and Caregiver Partnership and Engagement Strategy will set out overarching principles that will guide the appropriate inclusion of these essential partners in all work of the NW OHT. It is expected that the Patient, Family and Caregiver Partnership and Engagement Strategy will be an ongoing demonstration of the NW OHT's commitment to patient, family and caregiver partnership, not just a one-time perfunctory exercise.

The purpose of this document is to provide a guiding and living framework for the NW OHT Patient, Family, Caregiver Council as it establishes a Patient, Family and Caregiver Partnership and Engagement Strategy. In response to needs identified by OHTs, this document will profile leading practices, provide links to respected resources, and set out a streamlined validation and confirmation process.

## What is the role of the NW OHT PFCC?

The Patient Family Caregiver Council (PFCC) will serve as a forum for dialogue among community members and health care partners, providing counsel, input, feedback and advice to the Nipissing Wellness Ontario Health Team (NW OHT) on issues and perspectives related to the following:

- Health system integration
- Healthcare access and service delivery improvements
- Care coordination/navigation of care transitions across the system
- Information sharing across providers, sectors and geographies
- The mobilization of technology and innovation

The members of NW OHT PFCC will contribute as collaborative team members addressing critical issues that will lead to improved health outcomes of our population and health system outcomes. Being an active member of the PFCC is an opportunity to make a difference in the coordination and delivery of healthcare.

# 2) Patient, Family and Caregiver Partnership and Engagement Strategy:

The Patient, Family and Caregiver Partnership and Engagement Strategy incorporates four foundational elements listed below. The inclusion of these elements will support a consistent focus and approach.

#### Element # 1: Strategic Goal

The Nipissing Wellness Ontario Health Team (NW OHT) will engage patients, families and caregivers in all aspects of our communities OHT health system co-design. By disseminating patient, family and caregiver representatives throughout our OHT councils, working groups and leadership structures, we will effectively acknowledge and learn from the lived experiences of our PFCC, and our community members (PFCCCom), and will strive to create a more efficient, and effective health system within our community.

Our decision making will be informed by health care users' lived experiences and will be grounded in the foundational Quadruple Aim Framework which aims to improve patient experience, clinical experience, lower costs and yield better health outcomes.

The rich and essential feedback from our patients, families, and caregivers, will inform decision making, facilitate enhanced engagement with caregivers and care organizations and streamline processes to allow our patients to avoid unnecessary barriers, confusion or duplication of services throughout their care journey.

The guiding Principles of Engagement, including Partnership, Learning, Empowerment, Transparency, Responsiveness and Respect will be woven into the fabric and functioning of our PFCC. Through these Principles of Engagement, a higher quality of care and services will be built and accessible to those who need it most, helping to preserve health and wellness in our community and avoid disruptions or delays in care when it is needed.

By establishing an intentional commitment and structure to engage, not only the members of NW OHT PFCC, but also other patients, families and caregivers in our community; our OHT will be well positioned to effectively implement strategies and improvements across the local health care system that are both informed by, and tailored to, the needs of our patients families and caregivers.

1) PFCC representatives will be present and active on all councils/working

groups.

2) Engagement with the broader Patient, Family and Caregiver Community (PFCCom) will be ongoing via Town Halls, and other community events. PFC interaction via survey accessible through NW OHT website.

#### Element # 2: Guiding Principles

## PURPOSE:

To work in collaboration with the NW OHT through a shared vision of giving a strong voice to the patient, family, caregiver partnership in determining the outlook for a seamless model of delivery of services.

#### Partnership and Co-design:

- enhancing patient, family and caregiver engagement through inclusive collaboration in the redesigning of a seamless system in the delivery of care.
- aligning ongoing work plans with the mandate created by the OHT in partnership with patient, family, caregiver
- identifying existing models of care, for the purpose of reshaping a delivery model that is inclusive and benefits all patients, families and caregivers regardless of boundary, culture etc.
- enabling early identification of patient needs and easy access to the delivery of care.

#### Leveraging existing Networks, Partnerships, Resources and Services:

• Identifying what already exists to create an integrated care model by networking with existing community resources and building a framework where patient, family and caregivers have constant input in shaping a sustainable model of care.

## Transparency:

- ensuring consistent messaging and updates to the public.
- ensuring healthcare professionals and organizations are honest and forthcoming about their apprehensions, limitations, and knowledge gaps when it comes to engaging with patients, families and caregivers.

#### Motivating and preserving towards a common purpose with shared outcomes:

- identifying and defining the existing gaps in the delivery of service to patient, family, caregiver and making recommendations in equitable service distribution and resource allocation.
- breaking down silos and collectively respecting what we are trying to achieve together. Promoting consistent involvement among members over time. Measuring our success against shared performance and outcomes.

#### Committing to diversity, equity and inclusivity:

 advocating and recognizing the uniqueness of the geography of the area as well as the diverse cultural groups and the required care within the community settings.

#### Providing access to connected-up care:

 Removing barriers to accessing health and social services across our catchment communities and addressing the needs of all our Northern Ontario residents.
Making sure that people do not fall through the cracks - working as one team to enable people to navigate services and get the help they need, when they need it.

#### **Element # 3: Engagement Domains and Approaches**

#### Program and Service Design

Engaging patients in the domain of organizational program and service design means health organizations initiate engagement activities that invite patient and caregiver input for the purpose of improving specific health programs, services, or other organizationwide projects such as quality and safety improvement initiatives. It's often a specific health care unit, program, project team or working group within the organization that undertakes patient engagement in this domain.

**Example**: As we work to co-design a desired future state care model for our OHT Year 1 population; our frail seniors, we will utilize the experiences of our PFCC members, and larger PFCCom, to help identify critical system issues and gaps. These lived experiences will help inform future system design and help to ensure we design a regional solution that meets the needs of the people we serve. Our new NW OHT care model for our frail seniors will be co-designed by our population, for our population.

Engaging patients is an important way for organizations to develop new programs and services, and to determine whether existing programs or services are meeting the needs of the patient and caregiver populations they serve. Engagement with patients is an iterative process, helping to generate new ideas that harness patient experiences, concerns and dissatisfaction, and identify possible improvements.

#### Personal Care and Health Decisions

Engaging in the domain of personal care and health decisions means health care professionals partner with patients and their caregivers in processes of shared decision-making and care.

**Example**: There is no "one size fits all " approach to ensure patient engagement is addressed in meaningful and integrated ways. The same approach may look and feel different depending on the health sector, setting, and region, and may produce varying results. The key to integrated and successful patient engagement is matching the right approach, to the right situation, at the right time - and often using more than one approach to achieve the intended goal. The following concepts will be shared across member organizations, with the goal of developing an overall organizational culture where health decisions and personal care choices are the result of a collaborative discussion between involved stakeholders.

Share - This includes the ways health organizations provide information that is easy for patients and their caregivers to get, understand, and act upon, to support personal care decisions, as well as to support engagement about a program, service, policy or decision.

Consult - This includes the ways health professionals, organizations and system planners get feedback from patients and their caregivers on a health issue, policy or decision that needs to be made.

Deliberate - This includes the ways patients and their caregivers are engaged to discuss a health issue, policy, or decision, and begin to explore solutions with healthcare professionals.

Collaborate - This includes patients and their caregivers, health professionals, planners, and organizations finding and applying solutions together to address health issues, create policy or make decisions.

#### Policy, Strategy, and System Level Discussions

NW OHT and its members work together with patients, families and caregivers to enable system-level changes, by engaging in broad domains of policy and strategy. This includes driving more accountable health priorities, plans and policies by embedding patient, family and caregiver partners within collaborative decision-making structures. NW OHT will be able to foster a culture of system co-design that is more likely to be long-standing and effective.

**Example**: Some ways the NW OHT will do this is by having 2-3 PFCC representatives on each working group and at the Collaborative Council, having a vote at the decision making table. Additionally, our PFCC members and the larger PFCCom, will be consulted during our strategic planning session, ensuring that our patients have a voice in designing the direction of the OHT over the next few years.

#### Element #4 Enablers:

The following are key enablers that will facilitate meaningful patient, family and caregiver partnership and co-design within the NW OHT:

A Culture of Continuous Quality Improvement – Co-creating a culture of trusting relationships that exemplifies unified, caring healthcare and social services centred around patients, families and caregivers and focused on wellness. Through active engagement, the PFCC will collaboratively represent the lived experience and be the voice of patients/families/caregivers in the co-development, co-design and implementation of the scope of the Nipissing Wellness Ontario Health Team work: High Quality Health Care that is safe, effective, efficient, patient-centred, timely and equitable. An ongoing commitment from NW OHT partners / members to come together in shared purpose using the experiences, perspectives and needs of patients, families and caregivers and in collaboration with the NW OHT PFCC to identify and implement continuous improvement aligned with the community's priorities within its defined boundaries. Our OHT is demonstrating an early and intentional commitment to best practice through registration in Cohort 2 of the RNAO BPSO program.

#### The Power of CO

Collaborating is how the NW OHT including PFCC membership will ensure that perspectives inform shared decision-making. Engaging a diverse representation of the population as members of the NW OHT PFCC with a range of lived experience navigating the health system in Nipissing. That the important advocacy work of the PFCC is promoted and continual recruitment is actively encouraged. That the role of PFCC member and the responsibility of engagement in this capacity is described as:

- Collaborative Decision Making and Voting
- Dignity and Respect/Engagement
- Sharing Information, Patient and Family driving the process
- Participation in Collaborative Council and Working Groups

#### **Refocusing with a Lens on Environmental Considerations**

As programs, approaches, structures and strategies are being co-considered, a mindful review of the following environmental conditions will be used as a framework to Repeat, Rethink, and Remove practices in order to align with PFCC values and expectations. These considerations describe how the patients, families and caregivers across our northern region expect coordinated health care to feel and they will be woven into HOW every aspect of NW OHT functions:

- In keeping with person-centred care, we begin by asking the patient, family, caregiver, "How can we help you?"
- Care is flexible and responsive Why this for this person, at this time, in this way?

- Building trusting relationships is central to all interactions and encounters
- Transparency and communication are the conditions that build trust
- Innovative approaches are explored to move us forward collectively
- Intergenerational partnerships are valued, encouraged, promoted and codeveloped
- **The Patient Declaration of Values for Ontario** is the framework referenced for quality of services: (statements adapted from the PDV for Ontario)
  - We expect Respect and Dignity for all.
  - Empathy and Compassion are at the heart of health care.
  - Accountability is key.
  - Transparency invites feedback and ensures quality of care.
  - Together we expect Equity for all and Engagement in all levels of care across Ontario.

#### **Ongoing Orientation, Education and Communication**

Providing patients, families and caregivers with ongoing professional learning, support, tools, and resources to enable them to meaningfully contribute in their role as partners/co-designers/advisors. An ongoing commitment to creating an environment for PFCC members and all who engage from the Patient, Family, Caregiver community (PFCCCom), to thrive. These conditions include thoughtful consideration to onboarding new members into existing structures, the use of inclusive/non-exclusionary language, creating respectful environments for patients, families and caregivers to share their lived/living experiences, and ensuring they feel their role on the PFC council and/or their contributions and ideas at any time are heard and valued.

#### Commitment to Diversity, Inclusivity, Health Equity and Cultural Competence

Engaging patients, families and caregivers through the lens of health equity across the communities of Nipissing means health care professionals, planners, and organizations have a responsibility to engage with – and respond to – the unique needs of our Indigenous population, Francophone population, dementia community, the long term care community, mental health and addictions community, survivors of gender-based violence, the LGBTQ2 community and other racialized or vulnerable patients, families and caregivers who have long been disadvantaged by the health system. It is the work of the NW OHT, including the PFCC to include and highlight voices of a diverse range of populations to inform the shared path forward. Engagement strategies may include soliciting feedback from town halls, focus groups, collection of data from surveys, etc. to determine how best to meet the needs of the people of Nipissing. An ever-evolving inventory of learning opportunities will be offered in response to needs identified (e.g., Indigenous Cultural Safety Training)

#### **Minimizing Barriers**

How can we serve you? We appreciate and need your voice! PFCC involvement will serve as a forum for dialogue among community members and healthcare partners where counsel is shared on NW OHT for issues and perspectives related to health system integration, healthcare access and service delivery improvements, care coordination/navigation of care transitions across the system, information sharing

across providers, sectors and geographies, and the mobilization of technology and innovation. Addressing these critical issues will lead to improved health outcomes of our population and health system outcomes as well. It is through engaging the broader community that residents, families and caregivers will recognize their opportunity to contribute to making a difference in the coordination and delivery of healthcare across Nipissing. The NW OHT PFCC will acknowledge and address barriers to participation including financial and logistical (i.e. time and length of meetings) by continually soliciting feedback and input when arranging meetings or offering diverse platforms for communication. With the leadership/guidance of the member, inclusive strategies and technological approaches will be explored to minimize any chronic/systemic barriers (including and not exclusive to race and disability). Any and all barriers to participation will be addressed by the PFCC through other enablers such as education, resources, training, technology support, etc.

#### **Skillset Matching**

Ensuring that the right patient, family and caregiver members are sought for the diverse spectrum of work (i.e. offering a menu of options for levels of engagement) that can occur within the NW OHT. Council members with specific lived experience, knowledge, and facilitator skill sets will be better positioned to contribute meaningfully when matched with the appropriate role or capacity.

#### Rigorous Research and Evaluation

Focusing on accountability, efficiency and financial sustainability, it is the continual goal of the NWOHT PFCC to evaluate the process, outputs, and impacts of engagement activities to demonstrate value and build a case for new, improved and sustainable ways of partnering with patients, families, and caregivers. The shared and collaborative goal and purpose of NW OHT and PFCC is the following:

Achieving the Quadruple Aim

- Improved Patient Experience
- Improved Population Health
- Improved Efficiency
- Improved Provider Wellbeing

## 3) Developing, Validating and Confirming the OHT Patient, Family and Caregiver Partnership and Engagement Strategy (PES)

The Nipissing Wellness Ontario Health Team Patient Family Caregiver Council engaged 4 PFCC members alongside 3 Collaborative Council members including the perspective of a Clinician and the NW OHT Executive Lead in the shared co-design of a locally-developed Partnership and Engagement Strategy. It is informed by those with experience navigating the health care system in our district, as well as those who have worked in health care within it. These combined perspectives take into account the patients, families, caregivers and community partners that we serve and represent. Through this trusting, collaborative and transparent process, all voices were considered and perspectives could be challenged respectfully to ensure it was representative of those across our district and along the lifespan. The planning and work of the NW OHT has been informed by membership through the PFCC which is embedded in Collaborative Council (the decision-making body), as well as representation by at least two members of PFCC on each Working Group and Task Group. The PES has been endorsed by the Collaborative Council as a guiding document.

The PES will be posted on our NW OHT public-facing website to communicate our purpose, encourage others to share their experiences, and engage others in the opportunity and responsibilities of the NW OHT PFCC as they see and hear their value in a co-designed system.

## 4) Reflecting Back and Co-planning Forward

We will use reflective question prompts like the examples below, to guide the ongoing process. This iterative process will enable the NW OHT to recognize leading conditions and emerging practices that are contributing to a shift to a co-designed system in health care.

- a) Is there a dedicated resource or staff to lead patient, family and caregiver activities within the OHT (including leading engagement efforts)?
- b) Are patients, families and caregivers continually integrated into working and decision-making structures, including as co-chairs?
- c) Is more than one patient, family or caregiver partner included in working structures (preferably three, at least two)?
- d) Is training and orientation assessed and evaluated to ensure that patients, families and caregivers feel comfortable, well supported and prepared to provide counsel?
- e) Is long-term, sustainable patient, family and caregiver partnership supported through mentorship, to also assist in smooth and effective onboarding?
- f) Is patient, family and caregiver partnership and co-design being maintained through challenging or unpredictable times?
- g) Is there a concerted effort continuously invested to bring a diversity of patient, family and caregiver voices to the table, including those from Indigenous, Black or other racialized minorities, Francophone communities and other vulnerable sectors?

## 5) Summary:

Transformation of health care in Ontario OHTs, and in the Nipissing Well Ontario Health Team, will be driven by the needs of patients, families and caregivers. The development of the Patient, Family and Caregiver Partnership and Engagement Strategy by the NW OHT will be an integral step to advancing a patient-centred health system. As the NW OHT develops its strategies, the team will incorporate opportunities for engagement at all stages, recognize and address barriers to equitable participation, and use co-design methodology to guide planning.

As the NW OHT and its PFCC matures, these strategies will lay the foundation for patients to be partners in designing, implementing and evaluating strategies, policies, programs, and services within the NW OHT to meet the unique needs of the local populations within the NW OHT's boundaries Quadruple Aim Framework. The NW OHT should understand this exercise as the beginning of a process that will evolve over time and should commit to renewing their strategy on a regular basis.

## 6) References:

- Government of Ontario. (n.d.) Ontario Health Teams: Guidance for Health Care Providers and Organizations. Retrieved March 12, 2021, from https://health.gov.on.ca/en/pro/programs/connectedcare/oht/docs/guidance\_doc\_ en.pdf
- Health Quality Ontario. (n.d.) Ontario's Patient Engagement Framework: Creating a strong culture of patient engagement to support high quality health care. Retrieved March 12, 2021, from https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagementframework-en.pdf