

Terms of Reference South West LHIN Patient and Family Advisory Committee

Background

The South West Local Health Integration Network (LHIN) has long recognized that listening to the patients¹ and their families can lead to improvements within the health care system. In order to improve health outcomes and experiences, patients and families across Ontario must be engaged and empowered to shape care delivery. This committee reflects the LHIN's commitment to partnering and listening to patients and families to ensure that changes in the health care system reflect the needs of those it serves.

The South West LHIN has adopted the [Health Quality Ontario's framework on provincial patient engagement](#) to guide the patient engagement strategy for the South West LHIN. Please see Appendix A for South West LHIN *Guiding Principles 'Our Moral Compass'* and *Principles for Partnering in Patient Engagement*.

Mandate (*How will they do their work?*)

The South West LHIN's Patient and Family Advisory Committee will improve care and service delivery by shaping the LHIN's programs, services and initiatives. Committee members collaborate with the LHIN based on the patient, caregiver and family experience providing a community pulse that reflects the experience of all people living in the LHIN region. Please see Appendix B for further information regarding committee members' roles.

The LHIN Patient and Family Advisory Committee will apply their learning, collective experience and insights to:

- identify opportunities to incorporate the patient's perspective in order to better integrate care across the region and across the health care system.
- support effective patient engagement within the LHIN.
- recommend strategies and practical ideas for improving standards of care, improving LHIN policy, and sharing best practices with other LHINs and the health care system as a whole, whenever possible.
- link and collaborate with other patient and family advisory groups within the LHIN and across the province, when appropriate.

When executing its mandate, the Patient and Family Advisory Committee will adhere to the following principles.

¹ The term "patient" is used to refer to a broad spectrum of people who interact and intersect with the health system-including primary care patients, residents of long-term care homes, clients of mental health and addiction or community support services, or recipients of home or community care. In some instances, it can also refer to caregivers, who are generally unpaid and are close to the patient and acting on their behalf, such as a parent, a child, a spouse, a friend or a neighbour. The term "patient" is used to encapsulate all of these individuals and communities for the sake of brevity and clarity, and its use is not meant to devalue the unique experiences of each of the individuals that access health care in Ontario.

1. The committee will make every effort to provide informed advice on LHIN policy and program initiatives taking into account local population health issues and health equity when making its recommendations.
2. The LHIN will incorporate the committee's advice. Final decisions will remain with LHIN staff, Board of Directors and LHIN CEO.
3. The committee will adopt best practices identified in the LHIN Community Engagement Guidelines and the provincial Patient Engagement Framework.
4. The committee does not have a fiscal mandate.

Accountability and Reporting Relationship (*Who are they accountable to?*)

The South West LHIN's Patient and Family Advisory Committee will provide regular updates and report annually on its work plans, activities and progress to the LHIN Board of Directors through the LHIN CEO.

Membership

The Patient and Family Advisory Committee will consist of up to 10-15 members.

Members will be selected and recruited in such a manner to ensure diversity that is reflective of the LHIN's population makeup, including age, geographic distribution, gender, cultural diversity, socio-economic status and experience with the health system.

Specifically, membership will include:

- two Patient, Family or Caregiver Partners from each sub-region in the LHIN where members will have cross-membership at the LHIN's Sub-Region Integration Tables.
- two patient or family advisors / representatives from quality improvement projects in the LHIN that are large scale and cross-sector (e.g. Health Links, Hospice Palliative Care, etc.).
- a member from provincial patient advisory council(s).
- South West LHIN Senior Leaders including LHIN CEO, Vice President Strategy, System Design and Integration and Vice President, Home and Community Care.

Appointment term

Members shall be appointed for a term of up to 2-3 years. Members may be re-appointed for an additional term at the LHIN CEO's discretion. Members that miss three consecutive meetings without sending regrets will be approached by a Co-Chair regarding their continued involvement. Members may withdraw at any time and by any means (e.g. written or verbal).

There are circumstances where a committee member may need to leave the committee before the end of his / her term. Please see Appendix C for further details regarding the process for resigning or dismissal from the committee prior to the end of a term.

Responsibilities

The role of a Patient, Family or Caregiver Partner is to share his or her knowledge, experiences, and perspectives in order to recognize that patients, caregivers and the public must have a role in making important local health planning decisions.

The committee may seek input from a wider group of subject-matter experts. Members will have links to the Sub-region Integration Tables and the Health System Renewal Advisory Committee through

cross-membership. Advice and information will be shared among these groups.

The Director, Quality and the Patient Engagement Lead will act as primary LHIN staff support and will be key resources to planning and supporting the committee.

Election of Co-Chairs

Two Patient, Family or Caregiver Partners will act as Co-Chairs of the committee. The Co-Chairs will be selected by the committee for a period of 2-3 years. LHIN staff will support the Co-Chairs and assist with committee facilitation, as appropriate.

Meetings

The committee will be engaged regularly throughout the year to collaborate on LHIN policy and program issues. At least 50 percent of members must be present for quorum.

Meeting frequency

Meetings will take place twice each year or at the call of the Co-Chairs. Meetings will be held in person, with consideration for teleconference or other electronic method available as needed. (The committee's records are subject to the *Freedom of Information and Policy Act* and are governed by South West LHIN's Records Retention Policy).

Ethical Framework and Conflict of Interest

Please see Appendix D for further information on committee member requirements.

Reimbursement

Please see Appendix E for the reimbursement policy.

Establishment of Subcommittees/Working Groups

The committee may establish time-limited working groups to provide reports and recommendations to the committee on specific issues or specific priorities set by the committee. If interested, members can also get involved in other LHIN engagement activities.

Decision-making

Group recommendations / advice will be made by consensus using the Consensus Model for Decision-Making. Please see Appendix F for detailed information on the Consensus Model. Consensus is defined as group-decision making where members develop and agree to support a decision based on the information available, viewpoints presented, and discussions related to that decision.

Amendments to Terms of Reference

These Terms of Reference will be reviewed after one year, and every two years thereafter and may be amended by the LHIN CEO.

Appendix A – Guiding Principles

Guiding Principles – ‘Our Moral Compass’

(Developed by the Executive Advisory Group November 2016)

The work and decisions of the Patient and Family Advisory Committee will be grounded by the following guiding principles:

- person and caregiver centred
- equitable and aligned to what specific populations need
- integrated across sectors and systems
- borderless access to care
- trust and respect among partners
- transparency
- sustainability

The **overall aim of the** Patient and Family Advisory Committee is to improve:

- health and wellness behaviours,
- patient experience and health outcomes,
- value for money.

Principles for partnering in patient engagement

(Developed by the South West LHIN Quality Advisory Group – February 2016)

Value statement:

Effective partnerships between patients, caregivers and families, members of the public, healthcare professionals and organizations will adhere to the following principles.

1. Be founded on common understandings and non-judgement
2. Honour, respect and leverage the differences among partners
3. Foster meaningful change by creating safe spaces that establish value
4. Effectively share and build-upon engagement initiatives without “reinventing the wheel”
5. Encourage knowledge sharing and demonstrate a willingness to learn from our peers
6. Honour the time and contributions of all partners
7. Include mutual knowledge sharing and exchange for the benefit of all partners
8. Be accountable to all stakeholders, especially patients, caregivers and families involved
9. Be driven by patient, caregiver and family experiences and satisfaction
10. Measure progress by what has been demonstrated, not by what has been promised

Appendix B - Roles and Responsibilities

The Role of the Committee Member

The role of the committee members is to provide advice to the LHIN based on the patient, caregiver and family experience that is meaningful to all people living in the LHIN region. This will involve:

- representing patients and / or families effectively when engaging with all health system partners, including community members
- reviewing and providing feedback on LHIN documents, proposals, and plans.
- doing their utmost to attend each meeting of the LHIN's Patient and Family Advisory Committee (either in person or by teleconference / videoconference).
- being prepared to be active participants in each meeting (e.g., all meeting materials should be read prior to each meeting).
- providing constructive advice, and managing diverse and differing opinions with respect
- identifying opportunities for improvements in the planning and delivery of services.
- participating in initiatives where the patient's voice can inform improvements outside of the Patient and Family Advisory Committee.
- seeking input from, and relaying information to the LHIN's sub-region integration tables and/or the Health System Renewal Advisory Committee as well as respective community partners
- acting in accordance with the internal policies of the organization and relevant legislation, including the Ontario Occupational Health and Safety Act and the Accessibility for Ontarians with Disabilities Act; and
- approving this Terms of Reference in collaboration with the LHIN staff as needed.

The Role of the Co-Chairs

In addition to the committee member's responsibilities outlined above, the Co-Chairs will also be responsible for:

- liaising between the committee and the LHIN's board/CEO.
- encouraging participation and active involvement of all members.
- providing constructive advice, and managing diverse and differing opinions with respect
- leading and facilitating committee meetings (for people both attending in-person, online or via telephone).
- attending external meetings on behalf of the committee and at the request of the LHIN's CEO.
- setting the agenda for each meeting in consultation with the LHIN Staff
- assisting in the evaluation of the PFAC on an annual basis.
- guiding LHIN staff in-between meetings; and
- recruiting and orientating new committee members (in collaboration with the LHIN staff who support the committee).

The Role of LHIN Staff

LHIN staff will:

- provide secretariat support which may include, but is not limited to, logistics and coordination, organization of meetings, project management of committee activities, orientation, research and analysis, report writing and translation, and performance measurement and evaluation.
- respond to committee feedback and advice.

- facilitate discussions with the LHIN CEO, Board of Directors, LHIN staff and others.
- prepare meeting agendas in consultation with the committee Co-Chairs.
- prepare briefing notes about agenda items and ensuring that they are clearly written and crafted with the perspective of what would be important to patients and family advisors.
- answer questions about policies / issues answered in a respectful, helpful, and prompt manner.
- support the Co-Chairs and existing committee members with the recruitment and orientation of new members; and
- collaborate with the Co-Chairs, identifying appropriate topics for engaging the committee and developing appropriate meeting agendas and activities to elicit meaningful input.

Appendix C – Resigning / Dismissal from the Committee before the End of a Term

There are circumstances where a committee member may need to leave the committee before the end of his / her term. The following is the protocol for leaving the committee

RESIGNATION:

Committee members who elect to resign from their position are requested to provide thirty days written notification of their decision to the Co-Chairs.

The Co-Chairs will then notify LHIN staff, including LHIN CEO, VP, Strategy, System Design and Integration, and VP, Home and Community Care, Director, Quality and Patient Engagement Lead, of the resignation.

DISMISSAL:

Where a member has not fulfilled his / her role as per the Terms of Reference, the committee (via the Co-Chairs) may wish to inform the LHIN CEO of the committee's concerns.

- The LHIN CEO will use the information provided by the Co-Chairs and the committee to inform his / her decision on whether or not to end the member's appointment.
- As a guiding principle, and before informing the LHIN CEO, the committee Co-Chairs will reach out to the member in question to understand the reason(s) for his / her not fulfilling the role of committee member in an attempt to mitigate / resolve the issue.
- The committee will document this outreach process, and the member's response, for the LHIN CEO's consideration.
- If members are unable to fulfill their role and/or engage in behaviour that materially undermines the integrity of the LHIN; work of the committee; or committee terms of reference; they may be requested by the LHIN CEO to resign from the committee.

Appendix D – Ethical Framework and Conflict of Interest

Ethical Framework and Conflict of Interest

Committee members are required to fulfill the duties of their appointment in a professional, ethical and competent manner and avoid any real or perceived conflict of interest. Committee members have an obligation to declare a personal or pecuniary interest that could raise a conflict of interest concern at the earliest opportunity to the Chair(s). Each member has an ongoing obligation to disclose any actual, potential or perceived conflict of interest arising at any point during a member's term of appointment in regard to any matter under discussion by the committee or related to the committee's mandate.

Appendix E – Reimbursement

Patient/Family Partners and Co-Chairs are eligible for reimbursement of pre-approved expenses incurred regarding travel, meals, accommodations, and child/elder care as per the Travel, Meal and Hospitality Expenses Directive, as applicable to the LHIN's expenses policy. The Directive may be amended from time to time. The LHIN is not responsible for any travel, meals, accommodation, or child/elder care expenses incurred by the committee members that are not pre-approved in writing by the LHIN and charged in accordance with the Directive.

Appendix F – Consensus Model for Decision Making

The simplest and most basic definition of consensus is, '**general agreement about something**' (Soanes, C. and Hawker, S., ed., The Compact Oxford English Dictionary of Current English. 3rd ed. Oxford University Press, 2005.)

In this approach, people are not simply for or against a decision, but have the option to situate themselves on a scale that lets them express their individual opinion more clearly. This model is usually used with a round, so that everyone in the meeting is given the opportunity to state where they are according to the following six levels:

1. Full support
2. Acceptable
3. Support with reservations
4. I am not thrilled with it, but I can live with it and will not block it
5. Need more information or more discussion
6. Cannot support it and cannot accept it

If everyone is at level #1, 2, 3, or 4, then by definition, consensus has been reached.

If someone is at level 2, 3 or 4, they have the option of explaining their reservations. These can be addressed by the meeting, if the group wishes. This is not absolutely necessary for achieving consensus if everyone is already at 4 or higher, but it usually improves the recommendation or suggestions being discussed.

If someone is at level 5, they have the obligation to explain what information or discussion they require from the group.

If someone is at level 6, it is important for them to try and offer a solution that can accommodate their needs and the needs of the rest of the group.

In addressing someone's reservation, it is important to:

- a) ask everyone for possible solutions (the person expressing the concern and the rest of the group have the responsibility to find solutions)
- b) ask people to suggest improvements or alternatives that meet the objectives of the entire group.

IDENTIFYING CONSENSUS

Consensus is a relative term. There are varying levels of agreement with decisions, as indicated in the table below. Levels 1 through 5 all constitute consensus. Only Level 6 lacks consensus.

Level	Position	Feelings and Behaviour		
1	Agree strongly	"I really like it!"	"I'll advocate for it publicly whether or not it's adopted"	"I'll actively support its implementation"
2	Agree	"I like it"	"I'll advocate for it publicly"	"I'll support its implementation"
3	Agree with some reservations	"I can live with it"	"I'll support it publicly and privately even with my reservations"	"I'll participate in its implementation"
4	Disagree, but willing to go along with majority	"I don't like it. I'm willing to go along with it, but I want my disagreement acknowledged"	"I'll support it publicly and privately when asked"	"I won't work against its implementation"
5	Disagree, and won't be involved in implementation	"I really don't like it, but I'm willing to go along with it because I don't want to stop others"	"I'll not oppose it publicly or privately"	"I will not be involved in its implementation, but won't sabotage it"
6	Opposed, and will work to block	"I hate it and will work to block it!"	"I'll advocate against it publicly if adopted"	"I'll work to sabotage it"