



TIPS FOR PATIENT AND COMMUNITY ENGAGEMENT AND PARTICIPATION IN PCN GOVERNANCE AND PROGRAM DEVELOPMENT

What is Community Engagement?

Community engagement involves people working together to create solutions by setting priorities, planning operations and projects, and solving problems that affect them, their families and their communities. It invites people to participate in decision-making.

The International Association for Public Participation (IAP2) views public participation as any process that involves the public in problem solving or decision making and uses public input to make sustainable decisionsⁱ.

Meaningful Community Engagement:

- Is an ongoing practice, embedded in the way we work
- Is approached from a position of good faith and respect
- Requires willingness from all participants
- Involves stakeholders in planning participation activities
- Gives people the information they need for meaningful participation
- Encourages genuine conversations
- Creates a shared understanding
- Balances ideas and solutions
- Provides reasonable opportunities to influence decisions
- Builds trust and relationships
- Informs decision-making through an understanding of participants' values, interests and priorities

What is Patient and Family Engagement?

Patient and family engagement in primary care is one of the key components of Patient and Family Centred Care, which is defined as an approach to the planning, delivery and evaluation of health care that is grounded in mutual beneficial partnerships among health care providers, patients and familiesⁱⁱ. Patient engagement occurs when patients and families **meaningfully and actively collaborate** with health professionals in the design, delivery and evaluation of health services.

Who are Patient, Family and Community Representatives and/ or Advisors?

Meaningful engagement with patients and communities requires involvement of individuals and groups as determined by the community's and PCN's needs and opportunities. Within the context of PCN organizations, patient, family and community representatives and or advisors may consist of:

- Patient and family members who have experiences with the PCN practice
- Community representatives and or advisors categorized by geographic (neighborhoods within PCNs), non-geographic (based on age, gender, ethnicity, users with similar needs), and general public
- External operational and quality improvement organizations / teams

What do Patient, Family and Community Representatives bring to the table?

- They volunteer their time to provide the perspectives of patients, families and communities in planning, development, implementation and evaluation of programs and decisions that affect their care.
- They can participate on PCN boards, teams, working groups, committees, and task forces; review and provide feedback on PCN materials; share personal stories at meetings, conferences and education sessions.
- Patient, family and community participation may be one-time, ad hoc, or ongoing.

Meaningful patient, family and community engagement and participation in PCN business models means a wide variety of activities undertaken by the organization to ensure that those who are affected by decisions have a right to be involved in the decision-making process.

Why Engage Patients, Families and Communities?

Meaningful patient and community participation and involvement in a PCN has many benefits:

- Supports patient-centred medical/ health home concepts
- Creates better patient experiences and health outcomes, through empowering individuals, families and local communities to be involved in “what matters to them”
- Creates opportunities for shared understanding of issues, opportunities and decision making
- Increases empathy for understanding the health and wellness journeys of others
- Enables PCNs and communities to collaboratively decide (when appropriate) how care should be planned and provided to meet the values and needs of individuals, families and communities
- Patient, family and community representatives/ board members can contribute specific knowledge and skills that are relevant to the population and could also provide diverse perspectives, leading to more innovative ideas, better decisions and planning; more effective communication and more time efficient planning processes

Representation of patients, families and community members in PCN boards and teams has the potential to improve the governance, accountability and sustainability of the organization.

Spectrum of Engagement: What is Right for Your PCN?

Recognizing the variations in PCN’s maturity and resources, the purpose and scope of patient, family and community engagement will need to vary as no single approach will meet all the needs. The level of engagement should be determined according to the topic, capacity of PCN and the community, time available, and the ability for participants to influence decisions that is right for their purpose and available resources.

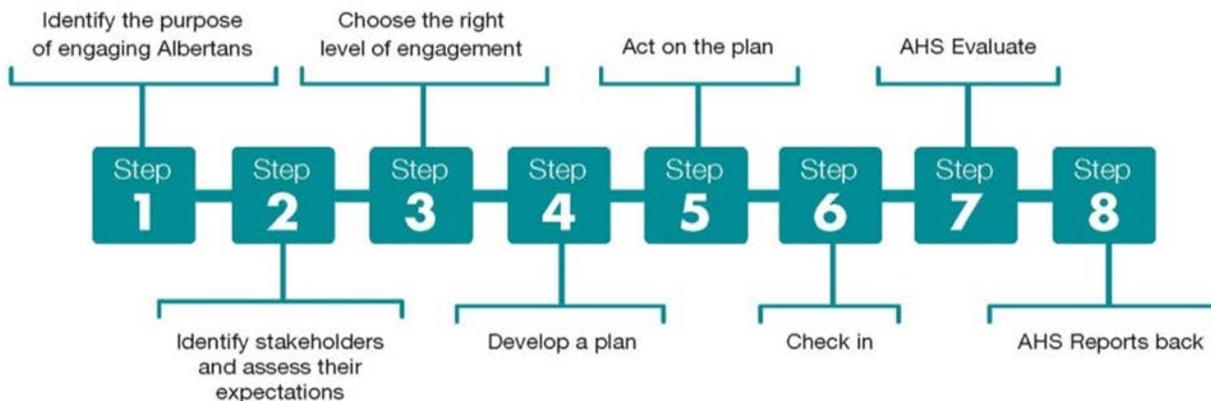
The International Association of Public Participation (IAP2) Spectrum of Engagement outlines the five levels of engagement and how they translate to action. Although the goal for all PCNs should be to move public engagement further down the spectrum towards a more two-way communication, sometimes the right level of engagement might be at the 'inform' or 'involve' levels. It is recommended that 'inform' should be done at all levels at the same time, depending on stakeholder group.

Increasing Level of Impact					
Level of Engagement	Inform	Consult	Involve	Collaborate	Empower
What it means	Give people the information they need to understand the situation.	Get feedback from people. We need to listen before making our decision	Work with people to understand their views and concerns.	Work with people to identify alternatives and solutions.	Participants make the final decision.
How do we do it	Help people understand the issues, alternatives and solutions.	Use feedback to analyze issues and alternatives that add to the decision-making process.	Work together to clarify issues and to design the decision-making process. Identify solutions and evaluate them.	Collaborate with people to analyze issues, and to identify alternatives and solutions.	Participants control parts of the decision-making process.

Adapted from the International Association of Public Participation (IAP2)

How Can PCNs Meaningfully Engage with the Patients, Families and Communities?

Successful patient, family and community engagement consists of 8 stepsⁱⁱⁱ. Using these steps to guide the process will support PCNs in achieving their patient, family and community participation goals.



Step 1: Identify the Purpose of Engagement with Patients, Families and Communities

It is essential to understand the purpose of your PCN's engagement with patients, families and communities. For example:

- Patient and or community representatives/ advisors on PCN Board
- Conducting Community Needs Assessment
- Getting patient, family and community feedback/ input in specific areas

It is also important to define the scope and level of participation to select the appropriate method of engagement. A Community Engagement Assessment Tool may be used to determine your purpose and scope (see IAP2: www.iap2.org).

Step 2: Identify Stakeholders and Assess their Expectations

In selecting your participants, consider:

- Who will be most impacted by, or interested in the outcome of your decisions?
- Use your PCN's panel/ community assessment to understand priority communities and perspectives.
- Identify ***what is important to your patients, families and communities***: what are their values and greatest concerns?
- What can participants bring to the table to support your PCN?
- Identify any impacted groups that may be hard to reach to ensure inclusive participation.

Step 3: Choose the Right Level of Engagement

Not every issue requires the same level of engagement and participation. There will be different types and levels of appropriate engagement, sometimes concurrently, depending on the situation. In determining the right level, consider these factors:

- Assess readiness of your PCN and leadership and the resources that will be needed.
- Assess the degree to which patients, families and communities consider the issue important.
- Use the IAP2 Spectrum of Engagement to understand and decide on the right level of engagement.

Step 4: Develop an Engagement Plan

Meaningful patient, family and community engagement needs time to be planned effectively:

- Gaining an appropriate level of commitment from PCN leadership/ governance is one of the most important steps in planning engagement.
 - Confirm the benefits of patient, family and community participation in your PCN.

- Seek your PCN governance support/ buy-in and inform and involve members in engagement plans and decisions.
- Based on the information you have gathered in previous steps, develop a clear PCN engagement plan. Following are the critical elements of an engagement plan:
 - An effective engagement process needs a formal engagement team. Identify champions and resources in your PCN. The engagement planning team can be the same staff who will implement the process.
 - Clearly defined PCN engagement goals, objectives and desired outcomes: what your PCN intends to accomplish.
 - What do stakeholders expect to gain from the engagement? What is their level of interest?
 - Develop a list of budget and resources required for the engagement, including staff time and tangible and intangible compensation for participants.
 - Create a realistic timeline for each engagement step and decide on key dates and practical logistics (venues, visual aids, catering, etc.).
 - If aiming for public board member or patient/ family representatives in your PCN, determine the length of terms and develop a list of required/ desired competencies.
 - Use appropriate patient, family and community engagement tools and methods to fit the purpose of engagement (Appendix 1).
 - Develop a communication strategy and plan for the overall engagement process and for each step (participant information needs, appropriate communication tools, key messages).

Step 5: Implement the Engagement Plan

Meaningful engagement is a journey and an iterative process. It may be some time before you put the engagement plan into action. Implement your PCN's engagement process when your PCN is ready.

Step 6: Checkpoint

Schedule checkpoints to ensure the objectives of patient, family and community participation are met by both the participants and your PCN: What is working/ not working? Are the engagement objectives being met?

Step 7: Evaluation

It is important to evaluate the overall engagement process, each step and implementation to learn what worked well and what could be improved for the next time. It is critical to know if patients, families and communities were satisfied with the engagement process and outcomes. Evaluation will also help to spread successful public/ community engagement and participation models.

Step 8: Report Back

It is a critical step to communicate back to the participants and the PCN Governance Board and committee. The PCN is accountable to let participants know how their participation impacted the process and decisions made as well as the overall impact on patient care and providers.

Suggested Community Assessment and Patient Engagement Resources

International Association for Public Participation, Planning for Effective Public Participation
www.iap2.org
https://c.mcdn.com/sites/www.iap2.org/resouve/resmgr/imported/06_planninStudentManual.pdf

Institute for Patient and Family Centred Care
<http://www.ipfcc.org/advance/topics/engagement-strategies-and-definitions.pdf>

Community Engagement for PCNs -Alberta Medical Association, 2015
<http://pcnevolution.ca/SiteCollectionDocuments/Toolkit/AMA%20PCN%20Advisory%20Council%20Guidebook.pdf>

AHS Patient Engagement Toolkit
<http://www.albertahealthservices.ca/assets/info/pf/pe/if-pf-pe-engage-toolkit.pdf>

ⁱ International Association for Public Participation, Planning for Effective Public Participation
www.iap2.org

ⁱⁱ Community Engagement for PCNs -Alberta Medical Association, 2015
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Appendix 1 – AHS Patient Engagement ‘Wheel of Possibilities’

