

Patients Collaborating with Teams (PaCT)



Patient Representative Goals and Role

Goals

Patient representatives:

- Have a voice in all stages of the initiative.
- Are supported and prepared for each engagement, and have full opportunity to contribute as part of any team, working group or committee.

How will we know if the goals are met?

Patient Representatives report that they feel prepared and supported for each engagement. Patient Representatives have their voices heard in meetings and in the initiative deliverables. Goals for the initiative are patient centred and reflect patient representative input. There is patient representation on each committee and working group.

Role of Patient Representatives

The role is an advisory one and Patient Representatives are volunteering to inform all processes, rather than advocate for a particular interest, patient or group. The PaCT Patient Representatives provide guidance and contribute to the success of the PaCT objectives. They do this by participating in internal planning processes and external communication processes.

a) General (from AHS role description)

- Have a personal patient or family health service related experience
- Be willing and able to share insights and personal health experiences and act to bring the patient and family voice to consultations
- Be willing to listen and to contribute ideas, feedback and input with the goal of strengthening health care services
- Share perspectives, experiences and both positive/negative feedback in a respectful manner
- Be involved in the spirit of volunteerism, to enhance patient and family centered care
- Be aware of personal limitations/boundaries and seek support if required
- Maintain confidentiality in all forms of communications (verbal, paper and electronic)
- Have regular access to email
- Attend meetings as agreed; if unable to attend, provide advanced notice to designated TOP contact(s)
- Review meeting materials in advance and complete all required preparations
- Be accountable for any commitments made for additional work.

b) Internal Planning

- Be engaged and participate in PaCT Steering Committee planning about all aspects of the initiative*
- Be engaged and participate in PaCT working groups
- Advise PaCT on planning and implementation processes for identified strategies

- Build PaCT strategies and tactics to gather and apply patient specific stories

* As with most committee member roles, the Patient Representative cannot speak on behalf of the committee but can speak about the work the committee is doing. Likewise, the Patient Representatives cannot make commitments to stakeholders on behalf of the committee but can bring community observations and concerns to the committee.

c) External communication

- Be a spokesperson, promoter, ambassador and champion for the PaCT messages
- Connect directly with other patient groups and provide relevant PaCT information
- Ask advice from other patient groups on how PaCT can strengthen the patient engagement approach
- Bring a patient voice to PaCT committee meetings, working groups and other relevant engagements
- Bring forward opportunities to share PaCT information with groups that can expand our reach.

d) Partnership Opportunities

Patient Representatives may come to PaCT with current affiliations to partner organizations. There will also be potential opportunities to partner with, and present to, other organizations and groups with a common interest in patient representation and involvement. Patient Representatives for PaCT could potentially present to, partner with, and work with other groups such as:

- IMAGINE group - citizen engagement
- Health Quality Council of Alberta Patient and Family Safety Advisory Group
- Patient Engagement Resource Group (AHS SCN patient representative group)
- AHS Patient and Family Engagement Group, including the Zone level patient advisory councils
- AMA Alberta Patients Group
- PCN patient advisory groups

Participation

- Time commitment – Patient Representatives will be asked to participate on the Steering Committee and consult with PaCT planners on other activities to negotiate participation

Supports and Resources

PaCT will support Patient Representatives to fulfil their role in the following ways, as well as by other ways brought forward through requests and consultations:

- Orientation to the PaCT initiative
- Preparation for and follow-up after Steering Committee meetings
- An identified Toward Optimized Practice contact(s)
- Guiding documents
- Ad Hoc consultation