PaCT
Patients Collaborating with Teams

IDEAS TO SUPPORT PATIENT REPRESENTATIVES TO PaCT IMPROVEMENT TEAMS

This resource is for patients, family members and/or caregivers who have been asked to engage and partner with primary care clinics or Primary Care Networks to be a part of the development of Patients Collaborating with Teams (PaCT). It will also help the PCN when including a patient representative in planning new services or approaches.

PaCT Patient Representative Goals

Patients and patient advocates should have a voice in all stages of the initiative. Patient representatives should be supported and prepared for each engagement, and have full opportunity to contribute as part of any team, working group or committee.

Role of PCN PaCT Patient Representatives

Because of the perspective of patients, each brings unique value to PaCT work. Each is an expert in his/her own right, and will contribute fully from that position.

The patient representative will provide guidance and contribute to the success of the PCN PaCT objectives. This is accomplished by being an equal partner in the work, and participating in development, internal planning, and implementation processes as appropriate.

A short list of ways for patient representatives to be effective in the role:

- Be honest with your perspective and opinions about the topics, subjects, and situations
- Be available, and honor commitments
- Be open-minded
- Ask questions, and expect to answer questions from others about your perspective*
- Accept your role
- Speak from your own experience and be willing to take on another perspective to gain understanding
- Contribute to the vision of success as well as the progress toward it
- Get comfortable educating others about your perspective
- Be a willing partner to staff, clinicians, and other patients and family members, including helping to set goals for the role
- Be a willing partner with your key PCN contact(s)
- Take responsibility for learning
- Tell your own story, or be clear that you are telling someone else's if that is the case
- Plan for the points you want to make, and work at making them clear for others
- Offer suggestions for how things could be improved if they didn't go well
- Ask for help and use the supports available to you

- Take risks
- Practice self-care, and if you've over committed, share some responsibilities and take a break if needed
- Appreciate that you don't speak for all patients and that other patients will have different experiences and different perspectives.

List adapted from, *Tips for How to be an Effective Patient or Family Advisor: A Beginning List*, Institute for Patient and Family-Centered Care, 2010

*Your questions will help everyone learn. If you do not understand something, ask questions to help with understanding. If something does not seem right, lead with your questions to help clarify, or to address the issues that could stop things from moving forward. It can be intimidating to answer questions from health care "experts", but understanding that your wisdom and expertise as a patient, family member, or caregiver is required for the best result.

Some tips for the PCN that may help with engaging patient representatives:

- When recruiting a patient representative, think about the experiences and/or expertise that you are looking for. Sometimes those with specific experiences are limited in their ability to provide innovative input; other times, a patient with a particular experience may be of most value to your planning team. Be open to anyone interested in participating regardless of specific experience.
- Name one individual for the patient representatives to connect with and provide phone/email addresses.
- Plan to have telephone (or other) conversations before and after the full team meetings between the person named above and the patient representative to help explain new processes, terminology and hear feedback from their perspective.
- Advise other members of the PCN about the patient representative(s) and what their function is so that the patient representative position is fully understood and utilized by everyone.
- Provide a list of common terms (and all the acronyms we use!) and plan to review this with the patient representatives.

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Appendix: Common Acronyms/Terms used in PaCT discussions

ASaP The Alberta Screening and Prevention Initiative (an improvement for primary care practices in screening healthy people for common conditions like high blood pressure or cancer)

CCM Chronic Care Model (an internationally recognized model for considering all aspects that impact managing chronic care); there is also an expanded one that considers more of the social or community aspects of chronic conditions (ECCM); also called the Wagner Model

CDM Chronic Disease Management: some of these also have acronyms

- **COPD** – Chronic Obstructive Pulmonary Disease
- **CV and CVR** – Cardiovascular (disease) and Cardiovascular Risk
- **DM** – Diabetes Mellitus

CPG Clinical Practice Guideline: a way of collecting all the medical evidence and communicating it to physicians so they know how to best diagnose, treat and manage clinical conditions; sometimes a broader term "Clinical Decision Supports" is used

CTA University of Alberta Primary Care Research called Cognitive Task Analysis

EBM Evidence Based Medicine

EMR Electronic Medical Records; the computerized chart in the physician's office

IAs Improvement Advisors; TOP/AMA staff who work with PCNs to support clinical improvements

IFs Improvement Facilitators; staff hired by Primary Care Networks to support clinical improvements

PAM Patient Activation Measure

Panel a defined list of patients who are considered active with each physician – includes identification (of the patients), management (to keep the list up to date) and management (like in chronic disease)

PHC Primary Health Care; PC – Primary Care

PMH Patient's Medical Home; an internationally recognized model for promoting comprehensive care in response to the public's needs – now widely adopted in Alberta Family Physician practices

QI Quality Improvement

SCN Strategic Clinical Network: groups within Alberta Health Services that focus on specific illnesses or conditions and provide clinical leadership

03.04J a billing code that family physicians sometime use when planning care for patients with certain chronic diseases

Organizations involved

PCNs Primary Care Networks – groups of family physicians who work together and with AHS to make improvements; funded by Alberta government; 42 in the province with the majority of family physicians belonging to one

AHS Alberta Health Services – the province wide organization responsible for community services and hospital/long term care, population health (not responsible for private physician practices)

AMA Alberta Medical Association – 3 specific programs: TOP – Toward Optimized Practice (clinical improvements); PMP – Practice Management Program (business improvements); PCN PMO –Primary Care Networks Program Management Office (specific support to PCNs)

HQCA Health Quality Council of Alberta - gathers and analyzes information, monitors the healthcare system, and collaborates with **Alberta Health, Alberta** Health Services and others to help in making improvements to quality and patient safety.