

Canadian Cancer Clinical Trial Network (3CTN): Patient and Public Involvement (PPI) Reference Tool

Background:

Throughout the global health research sector, there is growing support to include the patient and caregiver perspective in designing research studies and setting the research agenda. Due to this growing support, the Canadian Cancer Clinical Trials Network (3CTN) is committed to including the “patient’s voice”, also known as Patient and Public Involvement (PPI), in all aspects of the Network.

PPI has the potential to help 3CTN achieve its main objectives in the following ways:

- Increase the number of adults and children enrolling in academic clinical trials
- Increase the number of centres offering academic clinical trials across the country
- Improve the efficiency and effectiveness of the management of clinical trials to complete trials in a timely manner
- Streamline processes such as training of trial personnel, ethics review and specimen collection and storage nationally
- Demonstrate the positive impacts of this work on the Canadian health system

PPI Tools:

Due to the potential positive impact of PPI on 3CTN activities, the 3CTN Coordinating Centre (CC) and the 3CTN Lay Representative Advisory Committee (LRAC) have created and compiled a number of resources and tools to help sites implement local PPI roles and activities. Two notable resources that may be useful for sites are:

1. The 3CTN Guide to PPI
2. The Framework of Community Representation on Health Research Committees

Taken as individual documents, either will be a beneficial resource for site-level staff that are interested in learning more about PPI or interested in starting to incorporate PPI roles/activities locally. To help sites navigate both documents and the tools they provide, the following table cross-references the 3CTN PPI Guide with the Framework article.

PPI Example Role - The “Ask Me” Ambassador:

To aid sites that would like to implement a PPI role, 3CTN and the LRAC have devised the “Ask Me” Ambassador role that can be used in concert with the “Ask Me” clinical trial public education and awareness campaign. The details of this role can be found in the table below and associated documents listed in the table.

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Name of Task	The Framework*	The Guide*	Ask Me Ambassador
Identify need for PPI role/activities	C - Calibre A - Accountability P - Partnership T - Trust U - Understanding R - Respect E - Empathy	Chapter 4: The Role of the Lay Representative	<u>Need:</u> <ul style="list-style-type: none"> • Site interested in leveraging PPI to help with trial recruitment/enrollment • Easy and concrete way to include PPI at sites that may find PPI implementation challenging. <u>Activity:</u> <ul style="list-style-type: none"> • Ask Me Ambassador role can use Ask Me campaign materials and act as a clinical trial advocate at local site activities/events
Develop Philosophy/Goals of Committee/Role	<ul style="list-style-type: none"> • First: Clearly define the purpose of the committee/group; • Second: decide on individual roles or the particular skill sets required to fulfill this purpose 	Chapter 4: The Role of the Lay Representative <ul style="list-style-type: none"> • Page 19: PPI at Network Centres 	<u>Philosophy:</u> <ul style="list-style-type: none"> • It is beneficial to use “Peer Mentoring” between patients/families that have been involved in a trial and patients/families considering clinical trial participation. • Patients considering trials may find it less intimidating to speak to “Lay” individuals as their entry point into learning about trials. <u>Goals for the Ambassador role:</u> <ul style="list-style-type: none"> • Provide an easy and accessible way for potential trial patients to start to learn about clinical trials and help patients find further information (websites etc). • Aid 3CTN site staff with goal of increasing patient awareness of clinical trials as a treatment option (and therefore, possibly increase site accrual)

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Role creation	Potential Roles: <ul style="list-style-type: none"> • Protocol Review • Clinical Trial Advocacy • Patient Recruitment initiatives • Peer Mentors (ex-trial patients) 	Chapter 4: The Role of the Lay Representative <ul style="list-style-type: none"> • Page 16: PPI at All Network Levels 	Please see Ask Me Ambassador Job Description <i>(link TBD – email info@3ctn.ca for more information)</i>
Lay Rep Recruitment	<ul style="list-style-type: none"> • Start with a description of the ‘community’ the Lay Rep will represent; • Designate a committee/group member to conduct the recruitment; • See main article for specific recommendations on where to post the “Job Advertisement”. 	Chapter 5: Maximizing PPI Impact <ul style="list-style-type: none"> • Page 26: Creating the Lay Rep Job Description Appendix 3: Template Job Description Appendix 4: Example Job Advertisement	Please see Ask Me Ambassador Job Advertisement <i>(link TBD – email info@3ctn.ca for more information)</i>
Lay Rep Interviews	<ul style="list-style-type: none"> • Key to this step: Lay Reps are been ‘mapped’ to the right partnership; • Once selected, it may be prudent to offer the Lay Rep a ‘trial period’ to ensure the right fit for the particular role. 	Chapter 5: Maximizing PPI Impact <ul style="list-style-type: none"> • Page 28: Introducing the Candidate to the Role of the Lay Rep Appendix 5: Potential Interview Questions	Please see Ask Me Ambassador Example Interview Questions <i>(link TBD – email info@3ctn.ca for more information)</i>
Identify Educational Needs for new Lay Reps	Assess what type of education is needed, some examples include: <ul style="list-style-type: none"> • Targeting reading based on knowledge gaps • Assign a mentor • Introductory meeting with Chair 	Chapter 5: Maximizing PPI Impact <ul style="list-style-type: none"> • Page 29: Educating the Lay Rep • Page 24: Links and Further Reading 	Training to be identified and conducted locally based on candidate Ambassador’s background/needs

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Name of Task	The Framework*	The Guide*	Ask Me Ambassador
Provide support and education	Initial education could include: <ul style="list-style-type: none"> • Expectations of the Committee • Other members • Tutorials or online reading Note: Initial/onboarding training is the first step, but updating the Lay Rep's training on a regular basis is important.	Chapter 6: Training	Training to be identified and conducted locally based on candidate Ambassador's background/needs
Ongoing Committee function/activities	<ul style="list-style-type: none"> • Committee/group to function as required • At this point, potential to evaluate that all required perspectives are represented 	Chapter 5: Maximizing PPI Impact <ul style="list-style-type: none"> • Page 32: During the Committee Meeting 	Ongoing role as defined by the Job Description
Formal Evaluation	<ul style="list-style-type: none"> • There should be a planned Committee/group evaluation (ex: annually) • Based on the evaluation, practical feedback should be given to Committee/group on the whole 	Chapter 5: Maximizing PPI Impact <ul style="list-style-type: none"> • Page 33: If You Have Concerns about a Contribution from a Lay Rep • Page 33: When a Lay Rep Leaves the Committee 	Training to be identified and conducted locally based on candidate Ambassador's background/needs

*both documents can be found at: <http://3ctn.ca/page/patient-public>