



**Patient Partners in Research:
Guidelines for Engagement and Developing Terms of Reference**

Introduction

The CanVECTOR network aims to plan and lead research to improve the quality of care provided to patients affected by venous thromboembolism (VTE) and those at risk of VTE. Collaboration with patients is essential to better understand what is relevant, important and acceptable from the *patient* perspective. As such, we seek to involve Patient Partners as co-builders with researchers throughout the research process. The details of this collaboration for individual CanVECTOR studies will be determined together by the involved researchers and Patient Partners.

The *CanVECTOR Patient Partners in Research: Terms of Reference* document serves as a tool to formalize and record this information, including logistics, roles, expectations, and procedures to follow in case of conflict. Collaboration, inclusiveness, mutual respect and recognizing the value of experiential knowledge are guiding principles for this discussion, as well as for ongoing work together.

General Responsibilities of Researchers

- Confidentiality – respect the privacy of patient partners and maintain confidentiality
- Integrity – interact with patient partners with candour and honesty and a commitment to keep promises
- Recognition – publicly recognize the patient partner’s contributions
- Support (financial) – cover costs or reimburse patient partners for expenses incurred to participate on the research team (e.g. parking, travel, meals)
- Support (information) – provide project-specific resources to patient partners to support their learning and involvement, to better enable them to be contributors to the research process
- Communication – at minimum, involve patients by providing timely updates on the project’s status and progress; use plain language; gather and consider patient partner feedback. In face-to-face meetings and teleconferences, listen and endeavor to understand the patient partner’s perspective and suggestions
- Mutual respect – acknowledge and value the opinions and contributions of each team member; use constructive debate and communication when discussing disagreements

General Responsibilities of Patient Partners

- Confidentiality – respect the privacy of the research team and maintain confidentiality about the research study
- Integrity – interact with research team with candour and honesty and a commitment to keep promises
- Communication – in face-to-face meetings and teleconferences, listen and endeavor to understand research team members’ perspectives and suggestions
- Commitment – review the scope of the project and expected commitments outlined at start of partnership; if unable to honour commitments, contact the study team via the main contact



person identified in the *Terms of Reference* immediately, or as soon as it is possible. The patient partner may ask questions or request clarification, request changes to the expected commitments, or resign from the commitment to the project altogether.

- Mutual respect – acknowledge and value the opinions and contributions of each team member, using constructive debate and communication when discussing disagreements

Commitment to Patient Partnership

Developing written *Terms of Reference* (ToR) for patient partnerships in research provides a starting point for a dialogue about expectations. The ToR are intended to clarify the expectations of the patient partner and the research team.

CanVECTOR encourages:

- Engagement of patient partners during the early stages of study development
- Discussion and documentation of *Terms of Reference* as early as possible in the research process
- Annual review and update (as required) of *Terms of Reference* for multi-year studies

Patient Partners in Research: Terms of Reference

- The Principal Investigator or delegate is responsible for completing the ToR document, with opportunity for input from the involved patient partner.
- If more than one patient partner is assigned to a single study, one ToR form may be used if both patient partners will have the same roles and terms of participation. If patient partners have different roles or terms of participation, completion of separate documents is appropriate.
- The completed ToR document is to be signed by the patient partner and principal investigator. If this is not feasible, it is okay to have an email communication showing that the final document was reviewed and accepted.
- A copy of the final ToR is to be provided to the patient partner and sent to CanVECTOR's Patient Partners platform.

Communication

At the start of the partnership, CanVECTOR encourages agreement on:

- Preferred methods of communication for both patient partners and the research team
- Preferred frequency of communication
- A primary contact person on the study team for patient partners to reach
- Reasonable expectations concerning response times

Recognition and Acknowledgement

CanVECTOR encourages public and formal recognition of patient partner contributions, considering:

- The privacy of patient partners is to be respected; individual patient partners must agree to any public recognition
- Grant applications – patient partners may be recognized by listing them as collaborators or co-applicants (eligibility for these roles are established by individual granting agencies)
- Publications (research paper, poster, abstract) – patient partners may be recognized by naming them as authors, if their contributions meet established authorship criteria ([ICMJE recommendations](#)). Alternatively, patient partner contributions may be listed in the Acknowledgement Section of the paper, poster or abstract



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- If CanVECTOR's patient partners or the Patient Partners platform have been involved in the study, the CanVECTOR network must be acknowledged, per [acknowledgement policy](#)
- The Clinical Investigators Group (CIG) study list will include the names of active patient partners for each study
- When a research study is profiled on CanVECTOR's website, newsletter, or other network communication, patient partners will be included in any list of the research team members

Patient Partner Roles

Patient partner roles and participation will vary from study to study. It can range from low levels of engagement where patients receive information but do not actively contribute, to very high levels of engagement where an empowered patient partner is responsible for leading an aspect of the study (e.g. developing a communication plan to share study results with the community).

- CanVECTOR encourages active patient engagement. This includes jointly agreeing how the patient partner's involvement will best fit the needs of the team and the interests and abilities of the patient partner.
- Examples of patient roles in research can be found here: <https://cihr-irsc.gc.ca/e/51910.html>
- A model showing different Levels of patient and researcher engagement in health research is found here: see Figure 1 <https://pediatrics.aappublications.org/content/140/3/e20164127.long>

Reimbursement and Compensation

A new CanVECTOR policy on compensation of patient partners is being developed. Please refer to this document for guidance.

Resources for Patients

1. CanVECTOR Glossary: [Thrombosis related terms](#) and [General research terms](#)
2. CIHR Glossary of Funding-Related Terms: <http://www.cihr-irsc.gc.ca/e/34190.html>
3. Thrombosis Canada - Patient & Family Information (summaries on various clinical topics): <https://thrombosiscanada.ca/resourcepage/patient-family-information/>

References for Researchers (and interested patient partners)

1. CIHR Ethics Guidance for Developing Research Partnerships with Patients: <https://cihr-irsc.gc.ca/e/51910.html>
2. Vandall-Walker V. Patient-researcher engagement in health research: active, mutually beneficial, co-creation. In: *Proceedings from the 12th Annual Covenant Health Research Day*; February 7, 2017; Edmonton, Canada.
See model – adapted in Figure 1:
<https://pediatrics.aappublications.org/content/140/3/e20164127.long> In Amirav I, Vandall-Walker V, Rasiah J, Saunders L. Patient and Researcher Engagement in Health Research: A Parent's Perspective. *Pediatrics*. 2017 Sep;140(3).
3. NHS Trust and University of Sheffield. Patient and Public Involvement for Researchers: <https://www.sheffieldclinicalresearch.org/for-researchers/ppi-for-researchers/>
4. UK Standards for Public Involvement: <https://sites.google.com/nihr.ac.uk/pi-standards/standards> [published November 2019]