Patient Partners in Research: 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. CanVECTOR encourages discussion and documentation of *Terms of Reference* as early as possible in the research process.

This 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.

Please refer to the *CanVECTOR Patient Partners in Research: Guidelines for Engagement and Developing Terms of Reference* document for a summary of **General Responsibilities of Researchers** and **General Responsibilities of Patient Partners.**

Differences of opinion are inevitable on any team. Researchers and patient partners are encouraged to openly discuss expectations and concerns on an ongoing basis.

In case of unresolved questions or conflicts within the team, CanVECTOR's Patient Partners platform is available to provide support.

CanVECTOR's Patient Partners Platform	
Lisa Duffett, Platform co-lead **Email:** lduffett@toh.ca	Carol West, Platform co-lead **Email:** info@canvector.ca

Study Information	
Research study title	
Funder	
Expected duration of the study	
Study Description	

Research Team Information	
Patient Partner name	
Preferred method of contact	
Patient Partner contact information (only preferred/acceptable methods)	
Patient Partner name	
Preferred method of contact	
Patient Partner contact information (only preferred/acceptable methods)	
Principal Investigator Name	
Preferred method of contact	
Principal Investigator contact information (all acceptable methods)	
Other team member – name and role (e.g. project coordinator, admin assistant)	
Preferred method of contact	
Team member contact information (all acceptable methods)	
Primary contact for patient partners	

Study Stage or Task	Role
Scientific Steering Committee	
Determination of research question	
Grant preparation	
Protocol preparation	
Development of study materials and procedures	
Data collection	
Safety oversight	
Analysis of results	
Dissemination of results	
Publication	
Additional Description of Patient Partner role	

Logistics / Expectations	
Email progress updates	
Meeting frequency	
Meeting location	
Travel requirements	
Email response time	
Minimum frequency of communication from PI or delegate	
Preferences for meetings (scheduling considerations – time of day, day of the week, etc.)	

Supports and Recognition	
Accommodations needed for health conditions	
Lay summaries/ glossary of terms and acronyms, study-specific background information	
Financial compensation	
Recognition and celebration of contributions	

Additional comments:

Approved by

Name _____

Signature _____

Date _____

Principal Investigator

Name _____

Signature _____

Date _____

Patient Partner

Name _____

Signature _____

Date _____

Patient Partner