Canadian Venous Thromboembolism Research Network

Guidelines for Matching CanVECTOR Patient Partners with Projects and Studies

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.

CanVECTOR Patient Partners are patients or their family members or caregivers who have lived experience with VTE. As research partners they are directly involved as members of the research or project team. Patient Partners are different than consenting research participants; they may or may not have experience as research participants. Patient Partners are selected following a screening process to determine their suitability and readiness for the Patient Partner role. All Patient Partners are trained and supported by the network and some may complete additional training such as the SPOR Masterclass.

Requesting a Patient Partner

All requests for patient partnership for projects are to be made formally through CanVECTOR by completing this form and sending it to info@canvector.ca

We ask researchers not to personally invite Patient Partners to join their research team and partner for new projects. Please follow the request process described above, even if you have an existing relationship with a Patient Partner.

Timelines

Whenever possible, CanVECTOR encourages engagement of Patient Partners during the early stages of study development. In order to do this, the following guidance about timelines is important. With sufficient time, there are numerous ways that Patient Partners can contribute to a grant application. For example, reviewing, editing or writing the lay summary or sections of the protocol/proposal, providing a letter of support, or attending planning meetings with the research team.
For grant applications, a minimum of 4 weeks is required if you wish to be matched with a Patient Partner. This allows for administrative review of your request, and sending information about the study to Patient Partners, with sufficient time for Patient Partners to review the study summary and project details and indicate their interest. It also may provide an opportunity for the Patient Partner to meet the principal investigator to have an initial discussion about the project and expectations.

If timelines are too short to match a CanVECTOR Patient Partner to a study before a grant deadline, the process can be started and the final matching will be completed when the grant is successful. If CanVECTOR is providing a letter of support for the application, the letter will indicate that a Patient Partner has been requested and the matching process has been initiated.

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Pavilion H, Room H-452
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Ottawa, Ontario, Canada K1H 8L6

Matching Process

1. The co-leads of CanVECTOR's Patient Partners platform will review the submitted Request Form and Lay Summary and may ask for clarification or additional information from the investigator.
2. The Request Form and Lay Summary will be circulated by email to all CanVECTOR Patient Partners who will be invited to indicate their interest in partnering for the project. Patient Partners will be given a minimum of 5 days to respond after the materials were sent.
3. The Platform co-leads will review all responses and consider the best match for the study (one or two Patient Partners).
4. A member of CanVECTOR's administrative team will communicate with the Patient Partners and the investigator once a match has been made.

Many factors are considered when matching Patient Partners to studies or projects. The following are some of these.

- **Partnership experience**: Patient Partner and investigator experience with Patient Partnership.
- **Availability**: The study's time requirements and the Patient Partner's capacity, taking into consideration commitments and responsibilities that are both related and unrelated to the network.
- **Lived experience**: Generally, it is not necessary, nor should it be expected that the Patient Partner will have personal experience that aligns exactly with the research topic. Patient partners are trained to broadly consider patient interests, including those that are outside of their own experiences.
- **Interest:** often Patient Partners will be most interested in volunteering to partner with projects that they can relate to in some way (age, gender, personal experience with VTE diagnosis, treatment, symptoms, etc.).
- **Relationships**: previous positive or negative relationships or experiences with research partnership.
- **Skills / Knowledge**: in addition to lived experience with VTE, Patient Partners have varied personal and professional skills that may be well suited to the requirements of a particular study.
- **Opportunities**: the platform aims to be equitable and allow all Patient Partners the chance to join research teams.

Additional Resources

Resources for patient engagement can be found on the CanVECTOR website.

The network has developed Guidelines for developing *Terms of Reference* (ToR) for patient partnerships in research which provides a starting point for a dialogue about expectations. A ToR template is also available. The guidelines outline the **general responsibilities of Researchers and Patient Partners.**

Please refer to CanVECTOR policies for guidance on Patient Partner compensation and reimbursement.