



Canadian Society of Vascular Medicine PAD Patients With Lived Experience Support Group

Background: The Canadian Society of Vascular Medicine is establishing a Peripheral Artery Disease (PAD) Patients With Lived Experience (PWLE) support group to develop a bidirectional dialogue between CSVM members and their constituents who are represented by patients with PAD. The evidence is clear that clinicians, educators, and researchers all learn greatly by hearing concerns expressed by groups of patients with common lived experience. We will convene a regular group of patient voices, including patients with the mildest symptoms of PAD to those with the greatest of complications. We look forward to beginning this dialogue.

Patient Journey: Engaging patients to discuss and describe their patient journey helps patients and their providers understand barriers and facilitators that exist within our healthcare system.

Patients: PWLE, including informal caregivers, will be selected to share a breadth of experience with the healthcare system, and they will have the skills and competencies to communicate this experience. Patient members may express interest to participate in the research process and design of future studies, and / or to aid providers and payers with advice on how to optimize the healthcare process.

Education and Knowledge Translation: We will seek the input of PWLE group to help us develop educational tools that clearly convey important prevention, diagnosis, and treatment messages. Sometimes when these are put together by clinicians, the key messages are too technical and become lost in translation. The PWLE group's insights during creation, prototyping and testing of knowledge translation tools will enhance their effectiveness. The PWLE group may also be engaged in the education of Vascular Medicine trainees and staff, to improve mindfulness of patient priorities in clinical practice.

Research: Health research and health service design can improve the precision and relevance of the research question and improve patient care by engaging with PWLE (Kiran T et al CMAJ 2020). We will call upon the PWLE Support Group for their input into the design, conduct, and interpretation of research studies. We will be guided by the CIHR Strategy for patient-oriented research. (https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf)

Terms of Reference:

Peripheral Artery Disease Patients With Lived Experience (PWLE) Support Group

Co-Chair (s): To be named

PWLE Members: We seek representation from the PAD patient community to include:

- Patient with new diagnosis
- Patient with severe PAD including amputation
- Patients with and without health benefits
- Patient with experience receiving in hospital care
- Patients in urban and rural environment

We will aim for diversity of representation considering age, gender, socioeconomic position, and ethnicity/race.

Term Length: 3 years

Discussion Topics: Discussion topics will be determined in collaboration with patient partners, to ensure discussions are focused on patient-identified priorities.

Topics may include:

- My healthcare journey
- What is my understanding of PAD?
- Advice to fix a broken system of care
- What I would like Healthcare professionals to know
- What I would like to know from Healthcare professionals
- In what areas do we need more research?
- In what areas should more educational materials be developed?

Knowledge Translation of PWLE Group:

- Weblog
- Facebook group

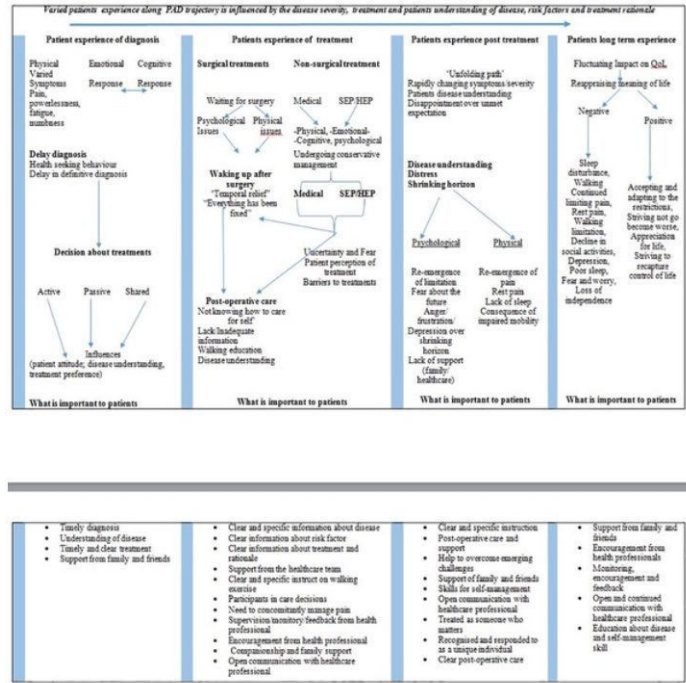
Meeting Frequency: Four Meetings per Year: 2-hour duration each.

Invitations to participate in other annual CSVM meetings, and approved research collaborations.

References:

1. The Way to My Heart. (2020). World's largest Peripheral Artery Disease Support Group. Retrieved August 16, 2022, from <https://www.thewaytoomyheart.org/>
2. Arnstein, L., Wadsworth, A.C., Yamamoto, B.A. *et al.* Patient involvement in preparing health research peer-reviewed publications or results summaries: a systematic review and evidence-based recommendations. *Res Involv Engagem* 6, 34 (2020).
<https://doi.org/10.1186/s40900-020-00190-w>
3. Abaraogu UO, Ezenwankwo EF, Dall PM, Seenan CA (2018) Living a burdensome and demanding life: A qualitative systematic review of the patients experiences of peripheral arterial disease. *PLoS ONE* 13(11): e0207456.
<https://doi.org/10.1371/journal.pone.0207456>
4. Kiran, T., Tepper, J., & Gavin, F. (2020). Working with patients to improve care. *Canadian Medical Association Journal*, 192(6), E125–E127.
<https://doi.org/10.1503/cmaj.190439>
5. https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

Fig 2. Framework synthesis of patients experiences of living with peripheral arterial disease.



Abaraogu UO, Ezenwankwo EF, Dall PM, Seenan CA (2018) Living a burdensome and demanding life: A qualitative systematic review of the patients experiences of peripheral arterial disease. PLOS ONE 13(11): e0207456. <https://doi.org/10.1371/journal.pone.0207456>