Getting Oriented

A Guide for Patient Partners Engaging in a Research Project

This guide is intended for individuals joining a research team as a person with lived experience (PWLE) or patient partner. It summarizes key questions to consider and tips to help you engage with the research team so your involvement increases the project's relevance and value to heart patients.

The Research Project: Goals, Scope and Timelines

QUESTIONS TO ASK YOURSELF

- Do I understand the purpose of this research project?
- Why is this project of interest to me?
- Do I know the project scope, current status and timeframe?*
- What are my expectations for the outcome of this project?
- What are the benefits and risks of participating?

ACTIONS TO TAKE

- Ask to review the research proposal and competition guidelines.
- Get clarity on how the research team plans to involve you.
- Consider how you would like to contribute to the project.
- Ask for the accommodations you need, e.g. if you have time, health or other limitations that may impact your participation, virtually or in person.
- If you have any potential conflicts of interest in the project, make them known; e.g., as a peer reviewer for a grant competition, you would have a conflict of interest in reviewing an application from a researcher who is also one of your doctors.

The Research Team

QUESTIONS TO ASK YOURSELF

- Who is involved in the research project, i.e., researchers, other patient partners?
- Do you know who your primary contact on the research team will be and how to reach them?*
- How does the team interact (i.e., virtual, shared drives) and meet (i.e., virtual, in-person)?*
- What technical or other support do you need to participate comfortably?

ACTIONS TO TAKE

- Plan how you will introduce yourself to the research team. Briefly describe your relevant lived experience of heart failure/disease, work/community experience and abilities, and what interests you about the project.
- Meet the principal investigator(s) and build a relationship with your research team contact, and other patient partners.
- If the team uses given names, you should too. This presents you as an equal, with equally valuable contributions.
- Tell your research contact how much notice of meetings and time to review documents you need to participate effectively.*

Know Your Role

QUESTIONS TO ASK YOURSELF

- Do you understand your role on the team and what is expected of you?
- Is the time commitment realistic for you?
- How long will you be involved in the project, i.e., weeks, months, years?

ACTIONS TO TAKE

- Review what the commitment involves and the nature of your contribution, workload and timelines.*
- Ask questions or raise concerns as they arise.
- Be prepared for calls and/or meetings by reviewing agendas and documents in advance.
- Keep your research contact informed if your schedule or health impacts your availability for work or meetings.

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Compensation

QUESTIONS TO ASK YOURSELF

- Has the research lead been clear about compensation?
- Do you understand how to claim expenses?
- Are there any tax or other concerns if you receive a T4?
- Learn more: www.ourhearthub.ca/patient-appreciation-policy/

ACTIONS TO TAKE

- Confirm that compensation for your time will be in accordance with the TRCHR PWLE Appreciation Policy and is included in the Terms of Reference.*
- Consider any implications for you of receiving an honorarium or cash gift, e.g., if it could affect disability or social support payments.
- If you have concerns, ask if other types of compensation are available, e.g., smaller disbursements.
- Ask for an administrative contact for expense reimbursement, what expenses are eligible, whether prior approval is needed, and what forms and documentation you will need to submit. *

Making a Contribution

- Focus on constructive contributions and be open to other team members' viewpoints.
- Tell your research contact what you need to feel included and safe while participating in the team. Speak up if you feel your voice isn't given the space you need.
- Share your experience while respecting others' privacy. Review the privacy protocols and raise any concerns you have.
- If sharing your story of lived experience, consider what is relevant to the project or situation, and only share what you are comfortable with.
- Let the team know if they are using acronyms you don't understand or if you need clarification of technical or medical references, or anything else being discussed.

Resources and Support

- Complete any recommended training and the confidentiality and/or privacy documentation required. *
- If you feel additional training or resources would be helpful, ask your research contact or the TRANSFORM HF/Ted Rogers Centre for Heart Research team.
- Check what the team uses for virtual meetings (i.e., Zoom, MS Teams) and to share documents. Test that you have access to the platform and ask your research contact for technical help if needed.
- Visit the research project lab and get to know the digital tools/technologies being developed or studied.

Recognition and Knowledge Translation

- Ask how your contribution will be recognized/acknowledged, e.g., co-authorship of publications, named in presentations.*
- Ask if you will be given the opportunity to participate in knowledge translation activities, such as presentations to conferences and workshops.
- Contribute to the preparation of manuscripts and presentations, e.g., writing, editing, reviewing.

* Terms of Reference

* Patient Partner Terms of Reference for the research project should be co-developed by the research contact and all patient partners, for sign-off by the PI and each patient partner.

Contact info@transformhf.ca for help or if you have any comments or concerns.