Engaging Patient Partners

A Guide for Researchers

This guide is intended for researchers engaging people with lived experience (PWLE) as patient partners on your research project. TRANSFORM HF/TRCHR researchers are expected to meaningfully engage patient partners, ideally from the earliest stages of the work. This guide summarizes key questions to consider and tips to help you identify, onboard and engage patient partners throughout the research process.

Preparing for & Recruiting Patient Partners

QUESTIONS TO ASK YOURSELF

- What contribution could a patient partner make to the project from this point forward?
- What lived experience would be relevant to the project (e.g., specific heart disease, a procedure, technology or medication; analytical or communication skills; urban/rural/isolated location; socio-economic and/or racialized group; language barriers; precarious housing)?
- How can I promote the opportunity to those key audiences?

ACTIONS TO TAKE

- Outline the roles for patient partner(s) at each stage of your project (may be roles for more than one person).* Some examples:
  - Co-principal or co-investigator (co-PI or co-I), research team member, occasional contributor or peer reviewer.
  - Co-develop/draft and/or provide input to draft research objectives, study design and methodology, grant proposals, data collection tools, interpretation of study results, production of reports and/or publications.
  - Co-design/deliver broader patient partner engagement activities, e.g., focus groups of patient partners or study participants.
  - Co-deliver knowledge translation activities.
- Budget for compensation and expense reimbursement for patient partners in the research project budget (see below).
- Identify potential patient partners and promote the opportunity. Consider posting invitations in clinics, hospitals, social support organizations, posting on social media, and reaching out to cardiac support groups (e.g., Heart Hub, HeartLinks). Connect with TRANSFORM HF team.
- Recruit more than one patient partner to bring in multiple perspectives and distribute the workload.

Orienting Patient Partners to the Project & Research Team

- Provide new patient partners with project documentation and update them on the history, current status, timeline and funding of the project.
- Introduce patient partners to the research team, including the PI.
- Provide all team members, including patient partners, with the timeline of key milestones and the role for patient partner(s) at each stage.*
- Designate a lead contact person on the research team for patient partners.*
- Share team members' contact information and create a way for patient partners to connect with the team between meetings, i.e., email, phone, team chat/channel.

- Depending on project complexity, co-create with patient partners the Terms of Reference* for patient partner(s) engagement on the project, to document roles and activities of patient partners, expected time commitment, responsibility for meeting scheduling, agendas and minutes, planned advance notice of meetings and documents for review, compensation, expense reimbursement, recognition in project reports. Update the Terms of Reference as needed over the course of the project.
- Arrange for lab or clinic visits as appropriate, so patient partners can understand the digital technology, algorithm or model of care that is being developed, validated or implemented, as well as the environment for its implementation.

Creating an Inclusive Space

QUESTIONS TO ASK YOURSELF

- Have you given time for patient partners to share their story?
- Are you using inclusive language?
- Do you and your team need to complete any training before engaging with patient partners, e.g. cultural sensitivity training?
- Are you vigilant about the use of acronyms and taking the time to make sure the patient partner(s) are able to speak and offer their perspective?

ACTIONS TO TAKE

- Take the time to establish relationships among patient partners and team members to improve communication and build trust.
- Avoid using acronyms and/or offer a glossary to patient partners and other non-experts on your team. Check in often to ensure everyone understands the discussion and terminology.
- Use first names among all team members to reduce power differentials.
- Make space in meetings for all to contribute. On meeting agendas identify information, discussion and decision items. Consider assigning a facilitator.
- Be deliberate about asking for patient partner contributions (e.g., turn to them every meeting for their input/feedback/perspective).
- Ask patient partners what they need to feel safe and included and ensure you adjust your approach accordingly. Keep in mind that patient partners decide what part of their story they are comfortable sharing. Check-in regularly.

Providing Resources and Support

QUESTIONS TO ASK YOURSELF

- Have you provided the necessary training for patient partners to effectively contribute to your research project?
- Have you explained what a conflict of interest is, confidentiality and privacy agreements, and ensured patient partners have signed the required documents?
- Have you ensured access for patient partners to the platform(s) the team uses to communicate and share documents?

ACTIONS TO TAKE

- Provide patient partners with documentation on conflict of interest (as relevant to the project), confidentiality and privacy. Offer to answer any questions they have.
- Identify options for patient partners to access training, pay the cost of training (if any) from project budget.
- Ask patient partners what lead time they need for reviewing documents and scheduling meetings.*
- Share meeting materials in advance.
- Be flexible and offer accommodations to meet the needs of each patient partner.
- Offer technical support to assist patient partners with accessing on-line platforms (e.g. Teams, Zoom) and shared drives.

Giving Recognition

- Give patient partners the opportunity to contribute to or comment on drafts of manuscripts and presentations, e.g. writing, editing, reviewing.*
- Ensure patient partners are acknowledged by name or as co-authors in research publications to which they contribute.*
- Offer opportunities for patient partners to participate in knowledge translation activities, such as webinars, workshops and conference presentations.*
- Explore other means of recognition with patient partners (i.e., ask what is meaningful to them).*

Compensation

QUESTIONS TO ASK YOURSELF

- Have you budgeted appropriately for patient compensation and expense reimbursement?
- Are you aware of your institution's rules and policies on patient partner expenses and compensation?
- Have you been clear about compensation in accordance with the TRCHR Compensation Policy?
- Learn more: www.ourhearthub.ca/patient-appreciation-policy/

ACTIONS TO TAKE

- Plan and budget for compensation of patient partners' expertise in research projects and funding/grant proposals.
- Review and ensure alignment with the TRANSFORM HF/TRCHR PWLE Appreciation Policy.*
- Share TRANSFORM HF/TRCHR PWLE Appreciation Policy with patient partners.
- Offer compensation in accordance with patient partner preference*:
  - Ask patient partners if there are any implications for them of receiving an honorarium or invoicing for services rendered, e.g., if it could affect disability or social support payments.
  - If they have concerns, work with them to determine what form of payment, timing and documentation is needed.
  - Note that gift cards are not typically viable as a form of payment given institutional limits of $25 value, which is not reflective of the value of ongoing patient partner engagement.
- Tell patient partners how to contact the administrative contact for expense reimbursement, who can tell them what expenses are eligible, whether prior approval is needed, and what forms and documentation they will need to submit.*
- Where practical, have project staff book and pay for transportation and accommodation directly, so patient partners are not out of pocket.

* 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.

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