

Patient Partner Terms of Reference

— Outline of Key Elements

This document provides an outline for a Patient Partner Terms of Reference for patient partner engagement in a research project. A Terms of Reference co-developed with patient partners is an important tool to clarify roles and responsibilities, keep team members accountable and help the team work towards their mutual vision for the project. The Terms of Reference should be initially drafted by the researcher and finalized in close collaboration with all patient partners.

Project:	Title and brief description of research project, including expectation of what it will accomplish, preliminary plan for knowledge translation and overall timeline.
Timeline & Key Milestones:	Summarize key stages, deliverables of the full research project, and the stages and component(s) in which patient partners will be engaged.
Patient Partner Roles & Responsibilities:	Activities and deliverables, nature of interactions (i.e., attend team meetings vs bilateral engagement), anticipated time commitment per week/month.
Researcher Role & Responsibilities:	How the researcher will engage patient partners to support their roles and responsibilities, schedule meetings in consideration of patient partner availability, provide adequate notice for meeting dates, adequate time to review documents, review and update Terms of Reference as appropriate etc.
Guiding Principles:	Conditions to ensure optimal engagement i.e., clear communication, mutual respect, inclusivity, trust, joint decision-making, etc.
Meetings & Communication:	Specifics re use of shared drive(s), document distribution, emails, scheduling and notification timelines for in-person or virtual meetings, responsibility for drafting and distributing meeting agendas and minutes, planned location of meetings, meeting frequency and times.
Researchers:	Names and contact information for lead researcher(s), organization(s) and position(s), and research team contact for patient partner(s).
Patient Partner(s):	Names and contact information.
Recognition:	Commitment to patient partners re: named in or co-authorship of publications and/or presentations, other mutually agreed to recognition.

Compensation: Anticipated financial compensation \$ amount for planned # of hours/meetings/other, timeline/dates or project milestones for payment(s), form of payment (may vary between patient partners), provision for additional contributions beyond estimated hours and scope (i.e., to be compensated separately). Ensure alignment with TRANSFORM HF/ TRCHR Appreciation Policy. See sample Compensation Payments Schedule below.*

Expense Reimbursement: Administrative contact, eligible expenses and amounts, pre-approval and approval steps, documentation required.

*** Sample Patient Partner Compensation Payment Schedule:**

Milestone/Anticipated Timing	Patient Partner Tasks e.g.	Hours e.g.	Payment e.g.
#1 Grant Application Timing: Fall 2025	Review & comment on draft research study proposal, attend virtual meeting	4	\$XXX
#2 Information Materials Timing: Winter 2026	Co-develop ethics application, consent forms and information materials to recruit study participants	10	\$XXX
#3 Team Meetings Winter 2026-Spring 2027	Monthly team meeting to check on progress, review findings, determine next steps	16	\$XXX
#4 Report Research Study Findings	Review & comment on draft journal article and conference poster	10	\$XXX
#5 Knowledge Translation	Optional activity(s): co-present at conference Note: patient partner role and compensation to be agreed for each KT activity	TBD	TBD