

CHF Alliance Patient Engagement and Empowerment Platform Terms of Reference



1. Background

The Canadian Heart Function Alliance (CHF Alliance) Network brings the top Canadian researchers and clinical experts in heart failure (HF) together with patients, caregivers, Indigenous Elders and Knowledge Keepers, government, policymakers, knowledge users, not-for-profit organizations, health care providers, academic institutions, and industry partners to improve the prediction, prevention, diagnosis, and management of HF. The Alliance's priorities are patient-driven and span the lifecycle. It includes innovative research projects within an integrated program and leverages clinical expertise, industry partnerships, and access to large cohorts. The Alliance activities will support the development of platforms to foster digital health, pragmatic clinical trials, artificial intelligence (AI) and advanced data analytics, training, patient engagement and knowledge mobilization that will sustain research and develop the next generation of HF researchers across Canada.

The CHF Alliance recognizes the central importance of engaging those with lived and living experience of HF, including patient partners, caregivers, and other knowledge users. By adopting Patient-Oriented Research (POR) principles, practices, and methods, the CHF Alliance Patient Engagement and Empower Platform will spearhead and support initiatives that accelerate scientific discovery on the role and impact of patients in research and in their own HF care.

2. Definitions

Family: Family members, significant others, and meaningful personal connections of patients

Patient/Person with Lived Experience (PWLE): An individual with personal experience of a health issue contexts. Patient is considered an overarching term that includes informal caregivers, such as family and friends.

Patient Engagement: Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context, patient-oriented research may also engage people who bring the collective voice of specific, affected communities.

Patient-Oriented Research: A continuum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.¹

¹ Canadian Institutes of Health Research. (2014). Strategy for Patient-Oriented Research – Patient Engagement Framework. Retrieved from <http://www.cihr-irsc.gc.ca/e/48413.html#a4>.

Patients as Partners: Patients who are meaningfully engaged in the research team, and like other research team members, contribute unique expertise and experiential knowledge.

Knowledge Holder: Indigenous persons who are engaged in identifying, maintaining, protecting, reclaiming, and supporting culturally grounded knowledge traditions and practices. This is a special and important role within Indigenous communities.

3. Creation of the Patient Engagement and Empowerment Platform

The CHF Alliance Executive Council holds the overall responsibility for the governance and management of the CHF Alliance and must act in accordance with the program guidelines and relevant Funding Agreements. The Executive Council is the highest decision-making body and serves to provide a framework for CHF Alliance operations.

The CHF Alliance has created the Patient Engagement and Empowerment Platform, which will review and report on its mandate to the Executive Council on an annual basis. This platform brings together the researchers of the network in partnership with patients, along with theme co-leads and partners involved in the various research projects/studies of the CHF Alliance. The Patient Engagement and Empowerment Platform is co-led by a patient partner and researcher, both of whom also sit on the Executive Council. This platform is responsible for the deployment of the Patient Partnership strategy within the CHF Alliance.

4. Platform Mandate

The CHF Alliance Patient Engagement and Empowerment Platform has established the mandate to:

- Align the network's priorities and activities to ensure that the network remains broadly relevant to the needs of patients and those around them;
- Ensure that core principles of partnership with patients and citizens in health research remain the principles that define and regulate the network's goals, objectives, projects, and activities;
- Contribute proactively to the design and implementation of the Patient Partnership Strategy;
- Assist and support research teams, project leaders, and partners to provide seamless integration of patient partners within the Alliance projects;
- Suggest and help identify, interview, and validate patient partners to participate in CHF Alliance-funded projects and main activities, where appropriate;
- Provide at least two representatives on the Executive Council and other leadership committees;
- Play an active and positive role as knowledge mobilization conduits both to public audiences and diverse stakeholders;

- Develop, implement, and evaluate appropriate metrics and indicators that are useful in measuring and reporting on partnership outcomes and impacts in the CHF Alliance;
- Report on the performance of the CHF Alliance toward achieving the goals and impacts stated in the CHF Alliance’s strategic plan and Patient Engagement and Empowerment Platform plan;
- Advise the Executive Council on any changes to strategy, policies and/or programs designed to improve the network’s engagement of patients and caregivers;

5. Composition of the Patient Engagement and Empowerment Platform

The membership of the Patient Engagement and Empowerment Platform must reflect the interests, philosophy, and strategic direction of the various stakeholders involved in the network. Members of the platforms will come from across Canada and comprise a diversity of patients, caregivers, and/or family members who have the experience of living with or caring for an individual with HF. It shall be co-led by a patient and scientific lead. Additional members may be added to the platform as needed. A detailed description of member roles and responsibilities is outlined in Appendix A.

6. Reporting Structure

The Patient Engagement and Empowerment Platform is accountable to the CHF Alliance Executive Council and will operate under these terms of reference.

7. Term of the Patient Engagement and Empowerment Platform co-leads

The Patient Engagement and Empowerment Platform will be co-led by one patient partner and one researcher that will serve for a term of five years. Any changes to terms of membership must be approved by the platform co-leads and the CHF Alliance Executive Council.

8. Remuneration

Members of the Patient Engagement and Empowerment Platform are eligible for remuneration and reimbursement for their services as per the CHF Alliance Patient platform Remuneration and Reimbursement Policy (Appendix B) and will be reimbursed for actual and reasonable expenses necessarily incurred by the member to participate in pre-authorized activities led by the CHF Alliance.

9. Revision

These Terms of Reference for the Patient Engagement and Empowerment Platform are to be reviewed and can be amended on an annual basis.

Appendix A

Patient Engagement and Empowerment Platform Member Roles in the CHF Alliance

These descriptions outline the roles, responsibilities, and expectations of partners participating as active members in the CHF Alliance. These descriptions are not restrictive and other roles could be defined depending on individual research projects or studies.

1. Confidentiality

All information provided by, or collected from, patients, caregivers, and/or knowledge users for the purposes of the platform activities will be treated as confidential and access to this information will be restricted to members only.

All information shared with the Patient Engagement and Empowerment Platform, including CHF Alliance conference calls, notes from conference calls, private CHF Alliance meetings, or workshops is of strict confidentiality and not to be shared without the express agreement of the CHF Alliance Platform Leads or CHF Alliance Executive Council. Information regarding projects that the Patient Engagement and Empowerment Platform are assisting with is not to be shared with media or on social media without express permission, as this information is sensitive and may jeopardize the research project or initiative within the CHF Alliance.

2. Role of platform partners

- A. Platform partners are free to choose to participate in activities related to the CHF Alliance based on availability, interests, and individual state of health;
- B. Patient partners may be asked to participate in assessments related to their alignment and interest in research activities prior to inclusion into the CHF Alliance and/or Alliance activities. This will be conducted by the Patient Engagement and Empowerment Platform prior to inclusion into the CHF Alliance;
- C. The Patient Engagement and Empowerment Platform Leads reserve the right to suggest training for partners prior to being included in the CHF Alliance and/or research project;
- D. Upon accepting to be a part of a research team, the patient partner will closely interact with all research team members and actively participate in the research team teleconferences, webinars, and/or face-to-face meetings of the research study;
- E. Patient partners may be expected to review protocols, consent forms, publications, and other study documents prior to their finalization or as discussed with research leads.
- F. Platform partners will inform the CHF Alliance Patient Engagement and Empowerment Platform of their network activities, including research projects, committees, grant proposals and events by liaising with Platform Leads or staff;
- G. Patient partners **are strongly advised to be involved in NO MORE than two (2) research projects at a time.**

3. Role of Patient Engagement and Empowerment Platform Theme Co-Leads

In addition to the roles outlined for platform partners, the Patient Engagement and Empowerment Platform Co-Leads will have additional responsibilities:

- A. Each Co-Lead will actively participate in all Platform activities, including leading and contributing to strategic decisions and determining the priorities and future directions for the Theme;
- B. Each Co-Lead will provide regular updates to the Patient Engagement and Empowerment Platform and CHF Alliance Executive Council of their CHF Alliance network activities and involvement in activities, such as research projects, committees, grant proposals and events;
- C. Each Co-Lead will take part in Platform webinars and meetings;
- D. Each Co-Lead will demonstrate active expertise and leadership in sharing living experience in research projects and CHF Alliance activities and support other patient partners as needed;
- E. The term of a Theme Co-Lead will be five years, with a one-year transition as a past theme leader to support and mentor the new Co-Leads.
- F. The five (5) year term is to begin when the Co-Lead accepts the position;
- G. All Patient Co-Leads are in no way obligated to remain for the duration of the five years. The position of Co-Lead may be renounced before the five years have ended;
- H. All Co-Leads who have renounced their position are invited to continue as patient partners for the Patient Engagement and Empowerment Platform;
- I. Patient Co-Leads **are strongly advised to be involved in NO MORE than one research project at a time.**

4. Media Relations

Patients may be asked to give interviews to media or social media for topics regarding their areas of expertise. A member who approaches media and social media independently is considered to do so as an individual and not a representative of the CHF Alliance.

All internal matters that are of CHF Alliance intellectual property shall be considered confidential and not be shared to media or social media. CHF Alliance intellectual property includes details shared on conference calls, workshops, training, or any other event.

All project(s) details in which a patient partner is involved shall be considered confidential and not be shared on media or social media, unless otherwise authorized in writing by the principal investigator.

All official social media platforms under the CHF Alliance nomenclature will be used to post or share significant information to the research community. Other social media initiatives that are started by members of the CHF Alliance, including patient partners, are of the own volition of the individual, and not of the responsibility of the CHF Alliance.

Appendix B

CHFA Patient Engagement and Empowerment Platform Remuneration and Travel Reimbursement Policy

1. Patient Engagement and Empowerment Platform Remuneration Policy

This remuneration policy covers various activities in connection with the CHF Alliance *only* (i.e., meetings, teleconferences, committee participation, or any other event). The remuneration details below do not include remuneration in research projects, in which patient partners may be involved. Unless otherwise agreed upon by the CHF Alliance, it is the responsibility of the project's principal investigator to allocate remuneration for the Partner's involvement based on a mutual understanding of the Partner's obligations to the project and the principal investigator's needs.

Theme Co-Leads

The CHF Alliance will remunerate agreed activities of the Patient Co-Lead through a stipend negotiated between the Platform Lead and CHF Alliance Principal Investigator Co-Leads. Special remuneration rates may be negotiated. Remunerated activities must be approved or based on a CHF Alliance invitation. Alternative remuneration may be negotiated but must be in accordance with allowable expenses.

Patient Partners

The CHF Alliance will remunerate the activities of each patient partner at a rate of \$50 per hour. Special remuneration rates may be negotiated. Remunerated activities must be approved or based on a CHF Alliance invitation (from a Theme Manager or the Patient Engagement and Empowerment Platform). Alternative remuneration may be negotiated but must be in accordance with allowable expenses.

Activities to be remunerated by the CHF Alliance/ Patient Engagement and Empowerment Platform:

- Theme Calls as a co-lead or speaker in a designated Theme
- Reviewer for a grant application
- Collaboration/Partnership Calls/Invited Consultation
- Annual Meeting
- Other Activities/Conferences/Committees as a representative of the CHFA
- Patient Engagement and Empowerment Platform Co-Lead Strategic Initiatives

Activities that are not remunerated by the CHF Alliance:

- Theme Calls as an observer in a non-designated Theme
- Other activities/Conferences while not representing the CHF Alliance
- Training sessions or calls
- Webinars or platform update meetings

- All activities involving individual projects that have invited you as a patient representative (unless otherwise agreed upon)

For any activity approved by the CHF Alliance involving an entire day of participation, the maximum billing per patient partner or Theme Co-Lead is \$400 per day.

Any remuneration related to an activity involving the CHF Alliance must be approved by the Patient Engagement and Empowerment Platform prior to the involvement of the patient partner or Theme Co-Lead. Remuneration will apply if the patient partner or Theme Co-Lead was specifically invited to participate by the CHF Alliance.

New Patient Partner Remuneration Set-Up

- Complete and sign the form 'Patient Partner Information and Signature' that will be used to create your file at the Montreal Heart Institute. (See page 8 of this document).
- Have this form signed by the CHF Alliance Theme or Platform Lead or their designate (e.g., Theme Manager).

Register for Direct Deposit Payment by sending the complete form, along with a voided cheque, to the **Patient Engagement and Empowerment Platform** Engagement Coordinator.

Activity Remuneration Procedure

The Patient Engagement and Empowerment Platform Engagement Coordinator will send a prepared invoice on a quarterly basis (every three months) for the patient partner's review for participation in a CHF Alliance activity for the patient's review and approval. A template for this invoice can be found on page 9 of this document.

As for Travel Expenses Claim for the expenses incurred in connection with the event, you don't have to wait until the next quarterly (3 months), you can submit your expenses claim right after the event. You can SCAN all the receipt to the Engagement Coordinator (and keep the originals in a safe place). If you don't have access to a scanner, please set up a time to call the Engagement Coordinator who will give you the information you need to submit your claim by regular mail. A template for the Travel Expenses Claim can be found on page 10 of this document.

Once approved within the stipulated deadline, the invoice and/or the Travel Expenses Claim will be submitted to the Montreal Heart Institute and remuneration will be sent according to the Patients preferred method of payment (direct deposit or cheque).

Patient Partner Information and Signature Form

All personal information collected as part of your involvement in CHF Alliance activities will be kept strictly confidential to the extent permitted by law. Only authorized CHF Alliance individuals, or a delegated person, will have access to this information in whole or in part.

PFD Partner identification

Name		
Address		
Phone	Home:	Mobile:
SSN (xxx xxx xxx)		
E-mail		

Information related to source deductions

By signing this form, I understand that no tax withholding or contribution is supported. I understand that it is my responsibility to properly report this income on my tax return.

In witness whereof, the parties certify that they have read, understood, and accept the terms and conditions set out in the Patient Engagement and Empowerment Platform Remuneration Policy of the CHF Alliance.

Patient Partner	Signature	Date
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CHF Alliance representative	Signature	Date
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Registration for Direct Deposit Payment

Patient Partner authorization

I hereby authorize the Montreal Heart Institute to deposit the sums due to the account specified on the enclosed VOID cheque:

Printed Name	Signature	Date
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** Please attach a cheque marked "VOID"

INVOICE

Date:	
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Invoice Number:	
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Patient Engagement and Empowerment Platform Partner Identification	
Name	
Full Address	
Phone:	
Email:	
SSN*	

*Can be provided directly to Montreal Heart Institution upon finalized paperwork if preferred.

INVOICE TO:

CHF Alliance
 Montreal Heart Institute
 5000 Belanger Street
 Montréal, Quebec, Canada – H1T 1C8
 CHF Alliance Contact: maryse.desjardins@icm-mhi.org

Theme or Study:				
Activity Description	Date	Rate/Hour	Hours	AMOUNT
1.				
2.				
3.				
4.				

Approved by Patient: _____

Date: _____

Approved by Engagement Coordinator: _____ Date: _____

TRAVEL EXPENSES CLAIM

Surname	Given Name	Phone
Address	Province	Postal Code

The following expenses were incurred in connection with :

Date	DETAILS	Transportation	Accommodation	Meals	Other expenses
	Mode of transportation (Plane, Train, Automobile*, Taxi)				
TOTAL					

REQUISITION DIRECT DEPOSIT : or CHEQUE

_____ Signature (Claimant)	_____ Date	TOTAL CLAIMED \$
_____ Signature (CHF Alliance Platform Lead or equivalent)	_____ Date	

*\$0.59/ km will be allocated

2. CHF Alliance Travel Reimbursement Policy

This document outlines the terms and procedure for reimbursement of travel expenses for patient partners or other CHF Alliance Members. Travel expenses incurred by patient partners to attend approved CHF Alliance activities will be reimbursed upon presentation of proof of payment and proof of travel. Where possible, claimants are asked to pay for their expenses initially and will be reimbursed after submitting their receipts to the Engagement Coordinator. Should this not be possible, please contact the Engagement Coordinator. Expenses need to be pre-approved by the CHF Alliance, otherwise the claimant might have to assume the costs themselves. Payment timelines can vary and are at the discretion of the Montreal Heart Institute.

FLIGHT/TRAIN/BUS:

Please book the lowest economy fare possible. Alternatively, for flights or train, the Claim Officer can book and pay for these directly. You will need to submit your original boarding passes, along with an itinerary/receipt that indicates the price (including details on taxes), fare class and the proof of payment. The cost for one piece of checked baggage is an eligible expense (receipt required).

GROUND TRANSPORTATION:

Transportation to/from the airport or train/bus station, or directly to a meeting via personal vehicle, are eligible expenses for the claim.

1. Taxi receipts must clearly show the date and amount paid. Please indicate what the trip was for (e.g., 'From home to airport')
2. Public transit is a favourable economic option. Receipt should show date and amount paid
3. Driving your own vehicle - you can claim mileage (\$0.59/km) up to 800km total roundtrip
4. Parking expenses will also be covered with the presentation of a valid receipt.

ACCOMMODATIONS:

Please obtain a detailed receipt showing the dates stayed and the amount paid, including taxes. Alternatively, for hotel accommodation, the claim officer can book and pay for these directly.

TRAVEL CLAIM:

The Engagement Coordinator will assist with all travel claims. Here is a general overview of the process:

1. Keep **ALL** original receipts from your travels (boarding passes, taxi, parking receipts, etc.)
2. After travel is complete, organize the receipts by categories and SCAN them to the Engagement Coordinator (and keep your originals in a safe place). If you don't have access to a scanner, please set up a time to call the Engagement Coordinator who will give you the information you need to submit your claim by regular mail.
3. For charges on your credit card, a receipt if not enough, be sure to submit proof of your expenses on your credit card statement.
4. The Engagement Coordinator will generate a claim form based on the scanned information and email it to you for approval and signature.
5. The claim will be signed by a CHF Alliance Platform Lead or equivalent, and then submitted to the Montreal Heart Institute.
6. After all queries have been answered (if any), the Montreal Heart Institute will issue the reimbursement by direct deposit or cheque. Please allow three or more weeks for payment.