The Canadian **Donation and Transplantation** Research Program

Programme de recherche en **don et transplantation** du Canada

CDTRP Patient, Family and Donor Partnership Platform

Terms of Reference

Version: March 31, 2022

1. Background

The CDTRP vision is that Canada fulfills every donation opportunity and realizes the full potential of transplantation as a cure for many chronic diseases and blood cancers. The CDTRP supports research, training and knowledge transfer, and catalyzes collaborations across disciplines, stakeholders and researchers nationwide and internationally to advance research in donation and transplantation and promote equity and diversity in these fields.

The CDTRP recognizes the central importance of engaging those with the experience of living with or caring for an individual with a solid organ or hematopoietic stem cell transplant as well as families of organ donors and living organ donors in all aspects of the Program and will ensure that committees, working groups and projects within CDTRP have meaningfully-engaged patient, family and donor representation.

2. Definitions

Donor: Living donors and acknowledged deceased donors.

Family: Family members of patients or deceased donors.

Patient: An individual with personal experience of a health issue or sometimes used in other (non-CDTRP) contexts as 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. The CDTRP includes family members and donors in this definition; termed 'PFD engagement'. (see PFD definition)

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 are considered to be members of the research team, and like other research team members they bring their unique expertise.[2] The CDTRP includes family members and donors in this definition; termed 'PFD Partner'. (see PFD definition)

PFD: Patient/Family/Donor. This term was coined by the CDTRP to be more inclusive of the various individuals participating in the PFD Partnership Platform, rather than 'patient'.

PFDPP: Patient, Family and Donor Partnership Platform

3. Creation of the Patient, Family and Donor Partnership Platform (PFDPP)

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

Within this framework, the CDTRP has created the Patient, Family and Donor Partnership Platform (PFDPP), which will review and report on its mandate to the Executive Council on an annual basis. This platform brings together the researchers of the CDTRP in partnership with PFD Theme co-leads and PFD Partners involved in the various research projects/studies of the CDTRP. The PFDPP is co-led by a PFD Partner and a researcher (both of whom also sit on the Executive Council). This platform is responsible for the deployment of the PFD Partnership strategy within the CDTRP, including the development of training tools, the evaluation of the impacts of PFD partnership, as well as the facilitation of interactions between researchers and PFD Partners as outlined in the mandate.

4. PFDPP Mandate

The CDTRP has established the PFDPP with the mandate to:

- Align the network's priorities and activities to ensure that the network remains broadly relevant to the needs of patients, donors and their families
- Ensure that core principles of partnership with citizens in health research remain the principals that define and regulate the network's goals, objectives, projects and activities
- Contribute proactively to the design and implementation of the PFD engagement strategy
- Assist and support research teams, project leaders and PFD Partners to provide seamless integration within the project
- Suggest and help identify, interview and validate PFD Partners to participate in CDTRP funded projects and main activities, where appropriate
- Provide at least one representative on the Executive Council and various committees or working groups of the CDTRP (as required)

[2] Karazivan, P., Dumez, V., Flora, L., Pomey, M. P., Del Grande, C., Ghadiri, D. P., ... & Lebel, P. (2015). The patient-as-partner approach in health care: a conceptual framework for a necessary transition. Academic Medicine, 90(4), 437-441.

- Play an active and positive role as knowledge dissemination conduits both to public audiences and from public/PFD stakeholders to the CDTRP
- Revise CDTRP appropriate metrics and indicators that are useful in measuring and reporting on PFD partnership
- Report on the performance of the CDTRP toward achieving the goals and impacts stated in the CDTRP's strategic plan about PFD engagement
- Advise the Executive Council on any changes to strategy, policies and/or programs designed to improve the network's PFD engagement

5. Composition of the PFDPP

The membership of the PFDPP must reflect the interests, philosophy and strategic direction of the various stakeholders involved in the CDTRP network. Members of the PFDPP will come from across Canada and comprise a diversity of patients and family members who have the experience of living with or caring for an individual with a solid organ or hematopoietic stem cell transplant as well as families of organ donors and living organ donors. It shall be co-led by a PFD Partner and a researcher. Additional members may be added to the platform as needed. A detailed description of PFD member roles and responsibilities is outlined in Appendix A.

6. Reporting Structure

The PFDPP is accountable to the Executive Council and will operate under these terms of reference.

7. Term of the PFDPP co-leads

The PFDPP will be co-led by one (1) PFD Partner and one (1) researcher that will serve for a term of 5 years. Any changes to terms of membership must be approved by the platform co-leads and the CDTRP Executive Council.

8. Remuneration

Members of the PFDPP are eligible for remuneration and reimbursement for their services as per the CDTRP's PFDPP 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 CDTRP. Remuneration for participation in individual research projects will be the responsibility of the principal investigator but may be paid centrally by CDTRP if agreed upon in advance.

9. Revision

These Terms of Reference for the PFDPP are to be reviewed and can be amended on an annual basis.

Appendix A

PFDPP Member Roles in the CDTRP

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

1. Code of Conduct

The CDTRP is committed to providing a professional, friendly, safe, and inclusive environment for its members regardless of gender, sexual orientation, disability, race, or any other characteristic of a person's identity. The CDTRP is committed to providing a collaborative and learning environment that allows full participation from all members.

All CDTRP members will act with personal and professional integrity to ensure positive interactions and successful collaboration. At all times, members will treat others with respect and dignity.

Discrimination, harassment, and other unacceptable behaviour will not be tolerated.

All members, including investigators, trainees, and patient, family, and donor partners, are responsible for adhering to this policy during CDTRP **meetings, events, and public discourse (including social media platforms).**

Example of unacceptable behaviour includes, but is not limited to:

- Intimidating, harassing, abusive, discriminatory, or demeaning speech or actions.
- Inappropriate verbal or written comments or images
- Racial, ethnic, gender or religious slurs and/or jokes
- Inappropriate use of nudity and/or sexual images
- Inappropriate disruption of presentations either verbally or in the chatbox

Consequences of unacceptable behaviour include, but are not limited to:

- Immediate removal from meeting or event without warning
- Restrictions from attending and participating at future CDTRP meetings and events
- Termination of CDTRP membership

Should a member express views that may be harmful to the CDTRP network, other members, and do not reflect the values outlined in our code of conduct, CDTRP will discuss the matter with the individual and determine what, if any consequences, will be issued.

2. Confidentiality

All information provided by or collected from patients, caregivers, family members, and/or living organ donors (personal, medical information, and related to an individual's experience with a disease) for the purposes of the platform activities will be treated as confidential.

All information shared with the PFDPP, including CDTRP-managed conference calls, notes from conference calls, private CDTRP meetings or workshops is of strict confidentiality and not to be shared. Information regarding projects that the PFDPP is assisting with is not to be shared with media or on social media as this information is sensitive and sharing it may jeopardize the research project or initiative within the CDTRP.

Declaration of conflict of interest
PFD Partners must avoid placing themselves in a situation where they may have to choose between their personal interests and the interests of the CDTRP. Every PFD Partner has an obligation to disclose to the PFDPP any potential or apparent conflict of interest.

Definition: A conflict of interest may arise when activities or situations place an individual or organization in the presence of interests (personal, institutional or otherwise) that conflict with the interests inherent in the duties and responsibilities associated with his or her status or function.
Ref: Declaration interest, Université de Montreal

3. Role of PFD Partner

a) PFD Partners are free to accept or refuse to participate in activities related to the CDTRP based on availability, interests, and individual state of health.
b) PFD Partners are subject to a formal assessment to be conducted by the PFDPP prior to inclusion into the CDTRP as a PFD Partner.
c) The PFDPP Leads reserve the right to suggest training for the PFD Partners prior to being included in the CDTRP and/or research project.
d) Upon accepting to be a part of a research team, the PFD Partner will closely interact with all research team members and actively participate in the research team by attending teleconferences, webinars, virtual meetings and/or face-to-face meetings of the study.
e) PFD Partners might review protocols, consent forms, publications, and other study documents prior to their finalization or as discussed with research leads.
f) PFD Partners will participate in the assessment of the impact of the CDTRP PFDPP strategy.
g) PFD Partners will inform the CDTRP PFDPP of their network activities, including research projects, committees, grant proposals and events by entering these activities in the PFDPP activity tracker: https://forms.gle/Y1MmB2twBoH6SigaA or other approved mechanism.
h) PFD Partners are strongly advised to be involved in **NO MORE** than two (2) research projects at a time.

4. Role of PFD Theme Co-Lead

In addition to the roles outlined for PFD Partners, PFD Theme Co-Leads will have additional responsibilities:

a) Each PFD Theme Co-Lead will actively participate with the Theme Lead and Co-Lead to make strategic decisions and determine the priorities and future directions for the Theme.
b) Each PFD Theme Co-Lead will inform monthly, the CDTRP PFDPP and Theme Manager, of their CDTRP network activities and involvement in activities such as research projects, committees, grant proposals and events by entering these activities in the PFDPP activity tracker: https://forms.gle/Y1MmB2twBoH6SigaA or other approved mechanism.
c) Each PFD Theme Co-Lead will take part in virtual meetings, webinars and teleconferences specifically designed for CDTRP PFD Theme Co-Leads and PFD Partners.
d) Each PFD Theme Co-Lead will show leadership in sharing living experience in research projects and CDTRP activities and support other PFD Partners as needed.
e) The term of a CDTRP PFD Theme Co-Lead will be three (3) years with a one (1) year transition as a past theme leader to support and mentor the new PFD Theme Co-Lead.
f) The three (3) year term is to begin when the PFD Theme Co-Lead accepts the position.
g) All PFD Theme Co-Leads are in no way obligated to remain for the duration of the three years. The position of PFD Theme Co-Lead may be renounced before the three years have ended.
h) All PFD Theme Co-Leads who have renounced their position are invited to continue as PFD Partners for the CDTRP and Platform.
i) The PFD Theme Co-lead is accountable to the CDTRP and will report to the CDTRP Theme Lead, Co-Lead and the PFDPP.
j) PFD Theme Co-Leads are strongly advised to be involved in **NO MORE** than one (1) research project at a time.

5. Media Relations

PFDs 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 CDTRP.

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

All project(s) details in which the PFD is involved in shall be considered as 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 CNTRP or CDTRP 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 CDTRP, including PFDs, are of the own volition of the individual, and not of the responsibility of the CDTRP.

Appendix B

PFDPP Remuneration and Travel Reimbursement Policy

1. PFDPP Remuneration Policy

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

PFD Theme Co-Leads:
The CDTRP will remunerate the activities of each PFD Theme Co-Lead at a rate of $50 per hour. Remunerated activities must be approved or based on a CDTRP invitation (from a Theme Manager or the PFDPP). The maximum remuneration for each PFD Theme Co-Lead is $1500 per year.

PFD Partners:
The CDTRP will remunerate the activities of each PFD Partner at a rate of $50 per hour. Remunerated activities must be approved or based on a CDTRP invitation (from a Theme Manager or the PFDPP). The maximum remuneration is $1500 per year, per PFD Partner.

Activities to be remunerated by the CDTRP/PFDPP:

- Theme Calls as a co-lead or speaker in a designated Theme
- Invited consultation
- Collaboration/Partnership Calls
- CDTRP Annual Meeting
- Other Activities/Conferences/Committees as a representative of the CDTRP
- PFDPP and PFD Co-Lead Strategic Calls

Activities that are not remunerated by the CDTRP/PFDPP:

- Theme Calls as an observer in a non-designated Theme
- Other activities/Conferences while not representing the CDTRP
- Reviewer for a grant application
- Training sessions or calls
- Webinars
- All activities involving individual projects that have invited you as a PFD representative (unless otherwise agreed upon)

For any activity approved by the CDTRP and PFDPP involving an entire day of participation, the maximum billing per PFD Partner or Theme Co-Lead is $250 per day.

Any remuneration related to an activity involving the CDTRP must be approved by the PFDPP prior to the involvement of the PFD Partner or Theme Co-Lead. Remuneration will apply if the PFD Partner or Theme Co-Lead was specifically invited to participate by the CDTRP or PFDPP.

New PFD Partner Remuneration Set-Up:

- Complete and sign the form 'Patient, Family and Donor Partner Information and Signature' that will be used to create your file as a PFD Partner at the Centre hospitalier de l'Université de Montréal (CHUM). (See page 9 of this document).
- Have this form signed by the CDTRP Theme Lead or their designate (i.e. Theme Manager).

Register for Direct Deposit Payment by sending the complete form, along with a voided cheque, to the PFDPP Administrator (Fabian Ballesteros, fabian.ballesteros.chum@ssss.gouv.qc.ca).

Activity Remuneration Procedure:

The PFDPP Administrator will send a prepared invoice on a quarterly basis (every 3 months) for the PFD Partner's review and approval. A template for this invoice can be found on page 10 of this document. Once approved within the stipulated deadline, remuneration will be sent according to the PFDs preferred method of payment (direct deposit or cheque).

2. CDTRP Travel Reimbursement Policy

This document outlines the terms and procedure for reimbursement of travel expenses for PFD Partners or other CDTRP Members. Travel expenses incurred by PFD Partners to attend approved CDTRP activities will be reimbursed upon presentation of proof of payment and proof of travel. Claimants are asked to pay for their expenses initially and will be reimbursed after submitting their receipts to the identified Claim Officer. Expenses need to be pre-approved by the CDTRP, otherwise the claimant might have to assume the costs themselves.

FLIGHT/TRAIN/BUS:

Please book the lowest economy fare possible. Alternatively, for flights only, 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 (i.e. 'From home to airport')
2. Public transit is a favourable economical option. Receipt should show date and amount paid.
3. Driving your own vehicle - you can claim mileage ($0.50/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)

TRAVEL CLAIM:

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

- Keep ALL original receipts from your travels (boarding passes, taxi, parking receipts, etc.)
- After travel is complete, organize the receipts by categories and SCAN them to the Claim Officer (and keep your originals in a safe place). If you don't have access to a scanner, cell phone pictures are a good alternative, otherwise please set up a time to call the Claim Officer and fill out the claim form together
- The Claim Officer will generate a claim form based on the scanned information and email it to you
- You will sign and then mail the claim form together with all your original, organized receipts to the CDTRP Scientific Director's office (address will be provided)
- The claim will be signed by the Scientific Director and then submitted to the funding institute
- After all queries have been answered (if any), the funding institute will send a cheque to your home.

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Patient, Family and Donor Partner Information and Signature

CHUM

Formulaire de création / modification fournisseur

■ **Création** ☐ **Modification**

Identification du fournisseur / Personal information

Nom/Name :	
Adresse postal/Address :	
Ville et province/City and province :	
Code postal/Postal code :	NAS/SIN :
Numéro de TPS :	Numéro de TVQ :
Adresse de paiement (si différente)/Payment address (if different)	
Ville et province City and province :	
Code postal/ Postal code :	
Devise de facturation :	
Personne-ressource à la comptabilité :	
No de téléphone/Telephone number :	Courriel/Email :
Termes de paiement (escompte, net 30 jours)	
Nom du représentant/Representant :	Courriel/Email :
No de téléphone/Telephone number :	

Le numéro d'assurance-sociale est obligatoire pour les particuliers | The Social Insurance Number is obligatory for individuals.

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Inscription paiement par dépôt direct / Modalité de transmission du relevé des paiements
Registration for Direct Deposit Payment / Payment receipts transmission

☐ Par courrier électronique/ By email	

Identification de l'institution financière / Financial Institution information

Nom de la banque ou de la caisse/Institution name :	
Adresse/Address :	
Ville et province/City and province :	Code postal/Postal Code :
No d'institution/Institution number :	No de transit ou de succursale/Transit number :
Folio ou No de compte de banque/Account number :	

Patient partner authorization
I hereby authorize the CHUM to deposit the sums due to the account specified on the enclosed VOID cheque:

_____ _____ _____

Printed Name Signature Date

Important : Vous devez joindre un spécimen de chèque avec la mention « ANNULÉ » | Please attach a cheque marked « VOID »

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 accepted the terms and conditions set out in the Patient Compensation Policy of the CDTRP.

_____ _____

Patient Partner signature Date

_____ _____

CDTRP representative signature Date

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CDTRP Patient, Family and Donor Partner Invoice

Date	
Invoice number	
Code GRM PFD Partner	3112318

PFD Partner information

Name	
Address	
Date of birth (dd/mm/yyyy)	

Invoiced at:

CRCHUM
Attn: Dre Marie-Chantal Fortin
900 St-Denis, R12-454.2
Montréal, Qc, H2X 0A9

Theme or Study:		
Activity Description	**Hours x Rate**	**Amount**
1.		
2.		
3.		
4.		
5.		
	TOTAL	