



The Canadian **Donation and Transplantation** Research Program

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

TREAT-COVID NATIONAL PRIORITIZATION FORUM REPORT

Emerging COVID-19 Issues in Transplantation

DECEMBER 6, 2023



TABLE OF CONTENTS

02	STUDY SUMMARY
06	FORUM OBJECTIVES AND FORMAT
09	SUMMARY OF DISCUSSION
18	APPENDIX 1
19	APPENDIX 2

STUDY SUMMARY

Organ transplantation offers transplant recipients, families, caregivers, and support networks the best clinical treatment for organ failure. In Canada, there are approximately 40,000 people with a solid organ transplant (SOT) (1,2), with nearly 4,000 (3) more on a transplant waitlist across the 10 provincial organ procurement organizations and 29 transplant programs (4).

Despite medical advances in donation and transplantation, many transplant patients, families, and caregivers experience challenges throughout their journey. These challenges include clinical concerns related to organ survival, post-transplant infection, and short-term and long-term impacts of immunosuppression medication, mental health, and quality of life post-transplant (5). Patients, families, and caregivers also experience mental health challenges, including post-traumatic stress disorder (6), related to their journey associated with both pre-transplant and post-transplant (7,8).

The financial pressures associated with a transplant increase the complexity of the journey, as evidence suggests that the pre-and-post-transplant experience is associated with financial strain (9-12). One study exploring the experience of patients, families, and caregivers highlighted the financial burden associated with transplantation as a significant concern. Further, patients and families also identified the lack of support and resources available to them as their top priority (7).

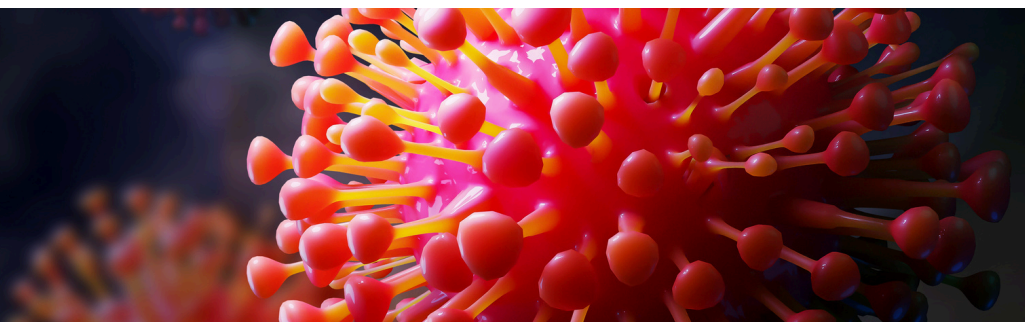
COVID-19 has increased the financial burden on many Canadians, with certain communities experiencing more significant hardships (13). However, researchers do not fully understand the financial impact of COVID-19 on transplant patients, families, and caregivers at the macro level (across the entire transplant population) and micro level (individual cases). Researchers also do not know how sociodemographic variables such as age, income, ethnicity, household family status, education, and employment influence a patient's COVID-19 and transplant experience.

STUDY SUMMARY

What is known is that navigating the transplant system is complex and difficult (14), and COVID-19 has highlighted the communication and information gap between patients and providers (15). From a clinical perspective, this gap is significant because transplant recipients are at higher risk of severe COVID-19 and have experienced higher rates of morbidity and mortality due to their immunocompromised state and underlying health conditions (16). From a mental health perspective, patients and caregivers reported that the pandemic has adversely impacted their access to their healthcare team and their mental health (17).

Transplant patients, families, caregivers, and stakeholders have prioritized COVID-19 as a significant area of study. In response, the Canadian Donation and Transplantation Research Program (CDTRP) mobilized a national, multisite research project: Addressing Critical Issues and **T**herapeutics **E**merging in **T**ransplantation in **C**COVID-19 for Transplant Recipients (TREAT-COVID) to support patient, family, and caregiver identified priorities.

The aim of TREAT-COVID is to identify effective strategies for treating COVID-19 in transplant recipients, including understanding mental health and economic impacts for patients, families, and caregivers. This will be accomplished through data collected from objectives 1 – 3.

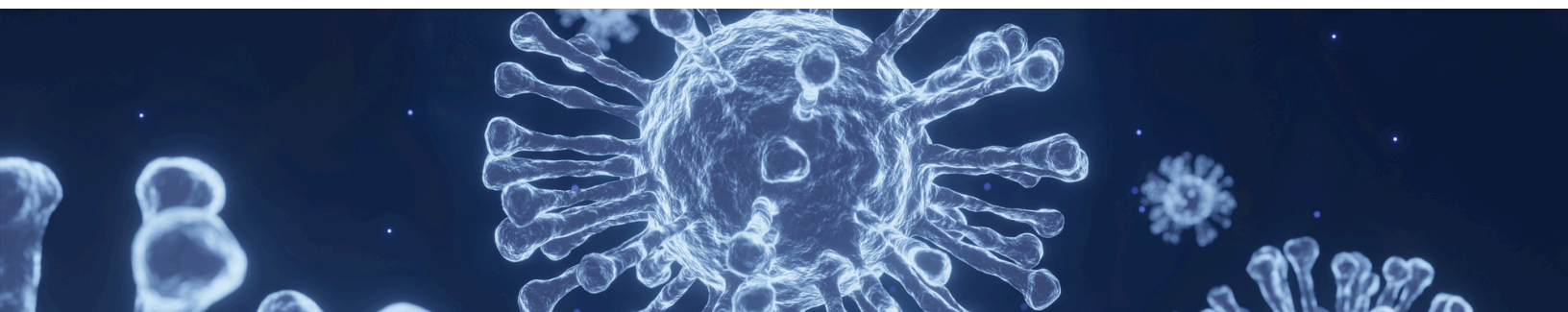


STUDY SUMMARY

Objective #1: Assess COVID-19 prophylactic/therapeutic safety and effectiveness in transplant patients: rapid response.

Led by Drs. Dima Kabbani (University of Alberta), Sarah Shalhoub (London Health Science Centre), and Catherine Burton (University of Alberta, objective #1 will be met by collecting clinical information from study participants. The variables to be collected include information on age, sex, gender, indication for transplant, co-morbidities, transplant type, immunosuppressant regimes, graft function measures, SARS-CoV-2 vaccine information, therapeutics administered, SARS-CoV-2 infection correlating to variant type, hospitalization, rejection, ICU admissions, and death.

Data will be captured through the online questionnaires will capture clinical, mental health and wellness as well as economic health information about study participants every three months. All questionnaires can be accessed through the TREAT-COVID Study Data Platform, which is accessible on any device with internet connection. If study participants do not wish or cannot use the online platform, they can speak to their study coordinators or transplant physicians regarding completing questions over the phone or through mail-in.



STUDY SUMMARY

Objective #2: Assess mental health impacts of COVID-19 on immunocompromised patients and families and develop strategies to improve well-being.

Led by Drs. Caroline Piotrowski (University of Manitoba, pediatrics) and Istvan Mucsi (University Health Network, adults), objective #2 will be met by collecting physical and emotional quality-of-life information captured through Patient-Reported Outcome Measures (PROMS). The study will also implement qualitative measures to understand the facilitators, barriers, and gaps in resources that help ease the negative impacts of COVID-19 on mental health.

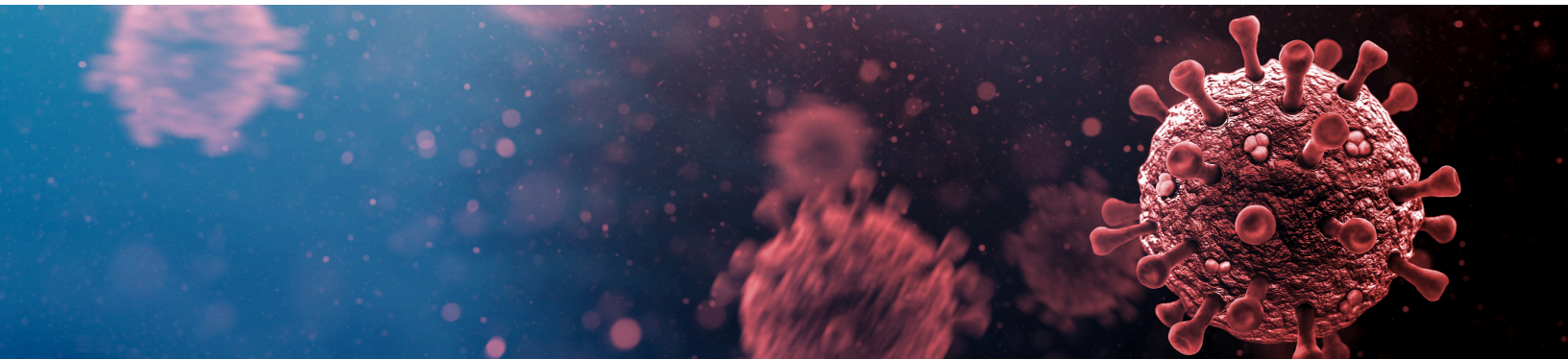


STUDY SUMMARY

Objective #3: Analyze the economic burden and value of emerging and existing pre-prophylaxis and therapeutic options for COVID-19 in transplant patients.

Led by Dr. Kednapa Thavorn (Ottawa Hospital Research Institute), objective #3 will collect information related to diversity and economic information, including the patient's caregiver age, ethno-cultural background, education, income, employment status, and urban/rural residence.

All study data will be stored and collected on the national TREAT-COVID Data Platform, developed in collaboration with the Ottawa Methods Centre. Personal health information will remain confidential and secure in accordance with ethical standards.



FORUM OBJECTIVES AND FORMAT

TREAT-COVID aims to recruit 5000 participants for this study. Participants will include adult organ and stem cell recipients, and pediatric organ transplant recipients. The study aims to recruit one family member/caregiver for each patient participant. While family/caregiver enrollment is not mandatory for adult transplant recipients, it is mandatory for pediatric participants. Family/caregiver recruitment will help reduce the impact of confounding variables (other factors that might impact the clinical, mental, and financial impact of COVID-19).

Recruitment will begin in 2024 across all sites in British Columbia, Alberta, Manitoba, Quebec, and Ontario. Patients must be followed by one of the transplant programs involved in the study (Appendix 1). Depending on where they live, participants may have several options to register for the study, including in clinic, online, and by telephone.

Early experience from our first site to begin recruitment has highlighted several and significant barriers to recruitment, including COVID-fatigue, questionnaire-related fatigue, participant, and study coordinator burden. Concerns have been raised about how best to reach the target number of participants in order to achieve the study's goals. The 2nd National Forum provided a venue to engage with stakeholders in the transplant community, including patients, families, caregivers, clinicians, trainees, and researchers, to address potential approaches to these barriers.

FORUM OBJECTIVES AND FORMAT

1. Share progress over the past year on the TREAT-COVID project.
2. Work with everyone to develop ways that best communicate to potential participants to increase patient and family recruitment.
3. Engage collaborative teams with all perspectives.
4. Continue to align the research priorities with the priorities of the transplant community and the changing healthcare landscape.

Following the formal presentation, in-person and virtual participants were split into six groups (four in-person and two virtual). The overarching goal of the breakout session was to identify strategies to overcome barriers to participation & improve recruitment of patients, families, and caregivers.

When developing their responses, participants were encouraged to consider communication strategies that (1) best identify, engage, and encourage the full spectrum of participants in the project and (2) focus on building patient and family confidence in the study, reducing complacency, and increasing convenience and access.

Each in-person group focused on a specific theme and was tasked with answering a specific question (Table 1). Both virtual groups were tasked with answering all four questions. Each group had a facilitator and notetakers and selected a member to report the main themes back to the Forum's audience.

FORUM OBJECTIVES AND FORMAT

These questions were developed by a smaller working group of TREAT-COVID’s Steering Committee: Sherrie Logan, PFD Partner (family member/caregiver to a pediatric transplant recipient); Rienk de Vries, PFD Partner (adult transplant recipient); Dr. Patricia Gongal, CDTRP Executive Director; Dr. Margherita Cameranesi, University of Manitoba, and Dr. Dima Kabbani, University of Alberta.

This Forum was hosted during CDTRP’s Annual Scientific Meeting and included patients, family, and donor partners, researchers, clinicians, trainees, and representatives of transplant-focused organizations. This broad representation of Canada’s donation and transplant community ensures input from an ample number of individuals in the affected population, bringing together diverse backgrounds and varied perspectives.

Table 1: Breakout Session Themes and Questions

Theme	Barriers to recruitment	Motivators to participate	Ways to communicate so we reach everyone	People so we leverage all our networks
Question	<p>Why would transplant recipients not enroll in this study?</p> <p>Why would family members not enroll in this study?</p> <p>Why would researchers not support recruitment?</p>	<p>Why would you, as a patient, family member, or a researcher, want to get involved in this study?</p> <p>Why would you stay involved over 2 years?</p>	<p>What are some specific communications, platforms, media, locations, or organizations that would reach recipients and families across the country?</p>	<p>Who can act as credible sources, influencers, or leaders to communicate across the country</p>

SUMMARY OF DISCUSSION

The breakout session produced 273 statements across the four priority questions identified by the working group. These statements have been reviewed and categorized thematically by CDTRP management staff and reviewed by the project's PFD partners.

See Appendix 2 for a complete list of the statements.

Barriers to Recruitment: Why would transplant recipients not enroll in this study? Why would family members not enroll in this study? Why would researchers not support recruitment?

Statements surrounding barriers to recruitment produced 74 statements. 57 focused on barriers impacting patient, family, caregiver recruitment, and 17 focused on barriers impacting researchers. These statements are categorized as follows:

- COVID fatigue (7)
- Patient approach (3)
- Lack of benefits (11)
- Mental health implications (5)
- Privacy concerns (6)
- Research study fatigue (7)
- Study Site concerns (14)
- Time commitment (11)
- Other (2)

SUMMARY OF DISCUSSION

For patients, families, and caregivers, the main barrier identified was potential research participants perceiving that TREAT-COVID lacks tangible short or long-term benefits. Statements included a feeling that patients/caregivers already feel powerless with COVID and may not see value in this research, given limited supports offered throughout the pandemic. Participants also identified a need for research questions to be meaningful, and for participation to be accessible.

Considering these findings, it is crucial for lead clinicians and research coordinators to effectively communicate the benefits of participating in TREAT-COVID to potential research participants. Since site research coordinators are responsible for communicating the project details and providing assistance, it is recommended that the project team develop guidance documents (i.e., frequently asked questions) for coordinators to confidently answer participant questions. By developing strong messaging and Standard Operating Procedures (SOPs) materials, coordinators can respond to identified barriers related to accessibility, COVID fatigue, privacy concerns, and time commitment.

An SOP document will also support lead clinicians and coordinators when approaching patients for participation. While only three statements focused on the patient approach, participants emphasized that research coordinators must be well-versed in the study's details to foster trust and partnerships with potential participants.

Forum participants identified mental health implications as a potential barrier. These statements included concerns related to the difficulty for patients to talk about their health and associated traumas. From a recruitment perspective, this also highlights a need for messaging, materials, in-person discussions and partnership development that are trauma informed, particularly for individuals and communities who have a historically difficult relationship with institutions and medical systems.

SUMMARY OF DISCUSSION

Motivators to Participate: Why would you, as a patient, family member, or researcher want to get involved in this study? Why would you stay involved over 2 years?

Statements regarding motivators to participate produced 48 statements. 44 focused on patient, family, caregiver motivators, and 4 on researcher motivators. These statements are categorized as follows:

- **Accessibility (8)**
- **Acknowledgement (4)**
- **Advancing knowledge (23)**
- **Communicating benefits (13)**

The leading motivator for patients, families, and caregivers is their desire to advance knowledge. Statements included a desire to make it better for future patients, inform future practice, contribute to better research, and improve health outcomes for transplant recipients and their caregivers. As a research network, these findings are not surprising as PFD partners involved with CDTRP have a strong belief in the value of utilizing their voice and lived experience to advance knowledge and science.

SUMMARY OF DISCUSSION

The challenge becomes integrating this value to the general transplant population, many of whom are likely not involved in research or may be experiencing study fatigue. As outlined by the Forum participants, TREAT-COVID's recruitment, communications, and knowledge mobilization strategy must clearly communicate the benefits of the study, ensure accessibility, and acknowledge participate for their involvement.

As we enter year 4 of COVID-19, we cannot ignore that some are experiencing COVID-19 fatigue or, as we heard during our 1st National Prioritization Forum, patients have accepted that there are no supports and have moved on to deal with COVID-19 themselves.

This is why TREAT-COVID has implemented a communications strategy that (1) highlights why COVID-19 still matters to transplant recipients and their caregivers (2) frames the study not only around COVID-19, but that results will inform future health challenges and (3) seeks to improve overall communications between transplant programs and patients. In other words, the value of this study has COVID-19 and non-COVID-19 implications for improving the transplant journey.

Ways to communicate so we reach everyone: What are some specific communications platforms, media, locations, or organizations that would reach recipients and families across the country?

The question regarding communication strategies produced 75 statements, all focused on methods of communicating to patients, families, and caregivers. These statements are categorized as follows:

SUMMARY OF DISCUSSION

- **Media and communication channels (9)**
- **Patient, family, donor partners (16)**
- **Social media (18)**
- **Transplant and hospital research programs (19)**
- **Transplant focused patient facing community organization (8)**
- **Transplant focused professional organizations (4)**
- **Other (1)**

Partnership with Canada's transplant ecosystem is required to reach patients, families, and caregivers in British Columbia, Alberta, Manitoba, Quebec, and Ontario. Without partnerships to support this project, this study will not be successful in recruiting 2590 patients and 2590 family members or caregivers.

These results affirm TREAT-COVID's partnership strategy, which involves connecting with various partners within our donation and transplant ecosystem, including professional organizations, transplant programs, patient-facing charities, and community-based transplant support groups. CDTRP will also leverage the connections of its PFD partners, including the PFD Advisory Committee, to act as 'Recruitment Champions.'

Forum participants highlighted a need to use non-transplant focused media and communication channels to reach potential participants more broadly, many of whom many are not connected or involved within Canada's donation and transplant research ecosystem.

With this goal in mind, it is advised that TREAT-COVID incorporates a media strategy into the recruitment campaign. This strategy should be presented as a call to action, emphasizing that COVID-19 continues to affect the immunocompromised community. As needed, this strategy should also include the human element by featuring patient stories and experiences to show that the pandemic continues to impact transplant recipients and their families/caregivers.

SUMMARY OF DISCUSSION

People so we all leverage our networks: Who can act as credible sources, influencers, or leaders to communicate across the country?

The question focused on people who can help support this work produced 76 statements, all focused on methods to support patient, family, and caregiver recruitment. These statements are categorized as follows:

- **Community based organizations (6)**
- **Health professionals, non-transplant (4)**
- **Patient, family, donor partners (25)**
- **Study partners (2)**
- **Transplant and hospital research programs (6)**
- **Transplant focused community organizations (19)**
- **Transplant professionals (13)**
- **Other (1)**

As with question #3, Forum participants acknowledged the need for the broad transplant ecosystem to be involved and champion TREAT-COVID. These results are not surprising as PFD partners have previously acknowledged the influence and credibility of transplant programs, organizations, and charities have in disseminating information (18). Again, Forum participants recognized the influence PFD partners, who are viewed as leaders and advocates, have in recruiting others in the transplant community to join initiatives.

Outside of the transplant community, Forum participants highlighted a need to engage with community-based organizations and non-transplant health professionals. Given that TREAT-COVID will provide strategies and recommendations to improve the transplant experience for all patients, it is crucial that these outputs are relevant to Canada's diverse transplant population.

SUMMARY OF DISCUSSION

Building partnerships is a key for TREAT-COVID, reflected in the development of a comprehensive partnerships strategy prioritizing BIPOC and SGM health focused community-based organizations. These organizations have long-standing relationships and credibility with their community members.

This strategy recognizes that building partnerships with the non-transplant community is crucial, not only for recruitment but also for broader dissemination of donation and transplant patient information.

The foundational principle of these relationships is co-development. This is being accomplished through meaningful collaboration with community partners in the following areas:

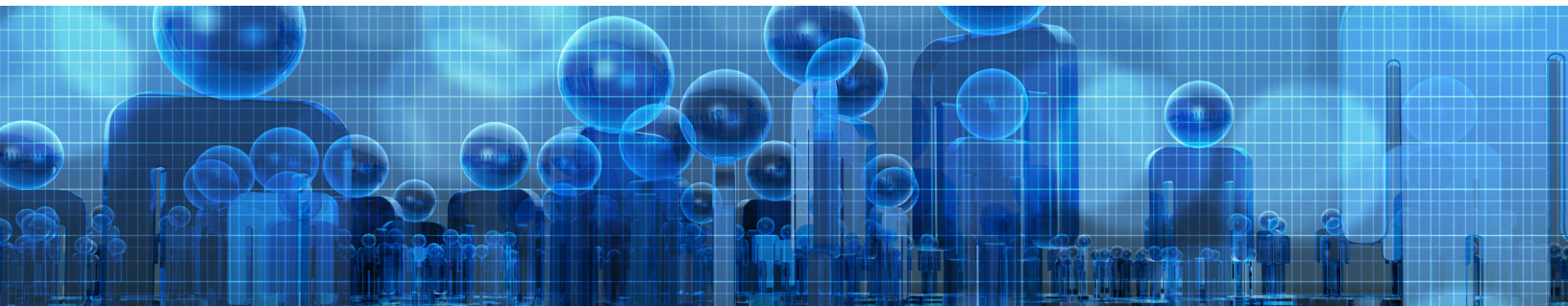
- **Co-development or validation of culturally appropriate and informed recruitment materials and outreach strategies.**
- **Co-development or validation of culturally appropriate and informed knowledge mobilization plans and materials that reflect community members' experience with COVID-19.**
- **Invitation and participation during National Prioritization Forums prioritizing space for community members to share concerns and perspectives and inform research and policy priorities.**

SUMMARY OF DISCUSSION

Outreach efforts also include opportunities to co-present to community members. As research advances, community partners (and members with lived experience) will be invited to join as research partners in the different sub-studies or as members of the PFD advisory Group (appendix 3).

Through these partnerships and discussions, TREAT-COVID has amended its recruitment materials and the online Data Platform based on feedback. The team intends to do the same in the process of developing knowledge translation tools and materials.

With recruitment beginning in 2024 and two National Prioritization Forums to be held (June 2024 and December 2024), it is recommended that TREAT-COVID outreach efforts adapt by going into community spaces to host additional prioritization discussions (virtual and in-person) rather than relying on community members to join TREAT-COVID events. It is important to recognize the real and perceived power dynamics associated with health research, especially for the BIPOC and SGM communities. Further, outreach efforts should consider working with community leaders/members to ensure that communication and recruitment efforts are trauma-informed. This is key, especially for those who have had a challenging time with COVID-19 and accessing resources or treatment.



APPENDIX 1

TRANSPLANT PROGRAMS RECRUITING STUDY PARTICIPANTS

Participating Centre	Researcher
BC Children's Hospital	Dr. Tom Blydt-Hansen and Dr. Hana Mitchell
Vancouver Coastal Health	Dr. Sara Belga
University of Alberta	Dr. Dima Kabbani
Stollery Children's Hospital (Alberta)	Dr. Catherine Burton
The Hospital for Sick Children (Ontario)	Dr. Upton Allen and Dr. Chia Wei Teoh
London Health Science Centre (Ontario)	Dr. Sarah Shalhoub
University Health Network (Ontario)	Dr. Istvan Mucsi and Dr. Arjun Law
Centre hospitalier de l'Université de Montréal	Dr. Édith Renoult
Institut de cardiologie de Montréal	Dr. Normand Racine
Université Laval	Dr. Sacha de Serres
Montreal Children's Hospital	Dr. Bethany Foster



APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q1: BARRIERS TO RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
Internet and phone access Research methods reliant on internet in some rural areas - difficult connecting It can be intimidating if someone doesn't understand the language - best to use lay terms Language barriers Going through only CDTRP channels can be limiting Hard to hear about the study as a family member Struggle to reach diverse population, like all studies Some older people may not use social media and the way to reach this crowd is through their primary physician	Accessibility	Patients Families Caregivers

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q1: BARRIERS TO RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
Not a lot of ways to benefit from the study as it's happening	Lack of benefits	Patients Families Caregivers
Do the question offer something that no one has asked before		
The research questions need to feel more meaningful (research fatigue around Covid things)		
Impact of contribution?		
Controversial subject		
Timing - it is respiratory season - are people thinking about this?		
May feel that their voices will not be heard or relevant		
No matter how easy participation is made (i.e. phone calls, follow up, letters) it just won't happen		
Patients and caregivers may also feel "what is the point" as there are very little supports that exist related to Covid for these vulnerable populations		

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q1: BARRIERS TO RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
There needs to be a clear understanding of the value and benefit of participating in this study Feeling of powerlessness in the face of Covid “there is nothing you can do about it” Sick of talking about sickness	Lack of Benefits	
Mental and emotional burden Hard for parents Medical trauma Stigma to disclose mental health struggles	Mental health Implications	Patients Families Caregivers
Can scales really capture the experience? i.e. why not qualitative components Attrition when motivation in low	Other	

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q1: BARRIERS TO RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
Logistics and access to research coordinators in each clinic difficult and needs to be skilled in the approach	Patient Approach	Patients
Lack of trust in recruiter		Families
Avoidance of coercion to participate		Caregivers
Where is my data (and labour) going		Researchers
Suspicion of how research results would be used		
Control of data		Patients
Confidentiality		Families
Some people just don't want to share personal information under any circumstances	Privacy concerns	Caregivers
Anonymity laws		Researchers
Lots of dropout – loss of follow up	Research study fatigue	
Competing studies		Patients
Negative past experiences in studies		Families
		Caregivers

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q1: BARRIERS TO RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Distinguished from spam</p> <p>Social value? Unclear value</p> <p>Participants and clinician burden – too many studies</p> <p>Lack of motivation</p> <hr/> <p>Healthcare team are overwhelmed with caring with patients</p> <p>Contacts</p> <p>Time needed to manage</p> <p>Overlapping recruitment</p> <p>Coordination (self enroll vs clinical enroll)</p> <p>Competing studies</p> <p>Lack of time in clinics</p> <p>Lack of information</p> <p>Resources</p> <p>For researchers, there are other demands and this may lead to barriers to recruitment</p>	<p>Research study fatigue</p> <hr/> <p>Study site Concerns</p>	<p>Patients</p> <p>Families</p> <p>Caregivers</p> <hr/> <p>Researchers</p>

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q1: BARRIERS TO RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>It could also depend on the specific resources researchers have (i.e. funding, coordinator)</p> <p>For researchers/clinicians there can be a conflict of interest</p> <p>Time, but also competing research with other work targeting the same patients</p> <p>Who is doing interviews?</p> <hr/> <p>Long commitment</p> <p>The commitment – initial and recurrent</p> <p>More time if you get sick</p> <p>Very low compensation</p> <p>Long questionnaire</p> <p>People who are sick are less likely to have the capacity to participate</p> <p>Time commitment (2 years, every 3 months)</p>	<p>Study site Concerns</p> <hr/> <p>Time Commitment</p>	<p>Researchers</p> <hr/> <p>Patients Families Caregivers</p>

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q1: BARRIERS TO RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Frequency and interaction</p> <p>Time constraints can be an issue - the questionnaires or surveys might be too long and it is especially challenging if they have current health issues where it makes it difficult to spend an amount of time to focus on a questionnaire</p> <p>Time commitment for paper questionnaires</p> <p>To reach family and caregivers is harder - we have access to the patients directly, and for caregivers, they have to be invited by the patient. Their priorities is to take care of their family member and research can be a secondary concern/issue</p>	<p>Time Commitment</p>	<p>Patients Families Caregivers</p>

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q2: MOTIVATORS FOR RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
Facilitated participation. Research coordinator wearing a mask Location: Transplant games in Ottawa Inclusion Good French translation Translate to multiple languages Multiple ways to fill out survey Making it easy to find the information, with QR codes	Accessibility	Patients Families Caregivers
Compensation Recognition: presentation, co-authorship Acknowledgement Honorary	Acknowledgement	

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q2: MOTIVATORS FOR RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
Trying to make it better for future participants	Advancing Knowledge	Patients Families Caregivers
Chance to be heard		
Chance to advance knowledge in science to inform future practice		
This is not the last time we should be mass communicating with patients – this matters to patients		
Passionate about helping future recipients and caregivers “I can help”		
Solving problems for others in your community.		
Having a say in future emergencies.		
Competing message from government that COVID is over.		

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q2: MOTIVATORS FOR RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
There was already a mental health problem before COVID – patients need help and this research can help get funding for mental health resources	Advancing Knowledge	Patients Families Caregivers
This will help their loved ones – they also want to see a difference		
Long-term impact		
Contribute to Data and research		
Desire to give back to the community		
Help inform/make change (mental health/wellness, economic, therapeutic)		
Why stayed involved? Altruism - we want to improve stuff, and be part of the action, have ideas and what others to hear about them.		
Not framing the study around COVID but around other issues that are affecting the transplant community		

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q2: MOTIVATORS FOR RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
Desire to improve things for people coming behind us	Advancing Knowledge	Patients Families Caregivers
Valuable information for future similar pandemic scenario		
There is still a lot to know about COVID		
Some patients and caregivers are still struggling, so more research is needed to know what's out there which can be helpful		
It's a unique opportunity to make a contribution, it's exciting		
Improve outcomes		
Gather information, data, inform research from patient perspective.		

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q2: MOTIVATORS FOR RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
General knowledge about COVID COVID risk There is still a lot to know about COVID It should be clear why research is important - this is why patient partners can be/should be part of the process. When there is a patient already involved, a family member might feel like everything will be said by the patient. If people feel they are making a difference, it drive motivation to stay connected/involved. Maybe this is more constant feedback throughout the process to tell them how this is making a difference Connecting with them to share their personal gains in this may help to keep them engaged	Communicating benefit	Patients Families Caregivers

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q2: MOTIVATORS FOR RECRUITMENT

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
It gives patients a sense of purpose, coming out of a difficult situation	Communicating benefit	Patients Families Caregivers
Giving updates of what is going on in the study - sometimes we say benefits will be in the future. But even if it is a small update/finding, they may find it relevant and encourage them to stay motivated/involved in the study		
The process of engaging with each other is important as patients and family members to make things change and not being isolated		
It's part of getting important data		
Important to communicate data to participants and not wait from them to advocate to get them		
Research coordinators as partners. Required in role		Researchers

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q3: WHAT ARE SOME SPECIFIC COMMUNICATIONS PLATFORMS, MEDIA, LOCATIONS, OR ORGANIZATIONS THAT WOULD REACH RECIPIENTS AND FAMILIES ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Interviews on local media stations with participants</p> <p>Newsletter and eMarketing</p> <p>Videos that are short.</p> <p>Subway and bus ads</p> <p>Media – daily news and radio</p> <p>Hospital websites</p> <p>At the UofA, we get an employee and student digest (~40K reach) and if I hear about it and are someone impacted, could be another way to engage.</p> <p>Newsletters</p> <p>Acknowledging that we need to adjust channels to cater to all ages and preferences.</p>	<p>Media Communication Channels</p>	
<p>Dragon boat competitions</p>	<p>Other</p>	<p>Patients Families Caregivers</p>

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q3: WHAT ARE SOME SPECIFIC COMMUNICATIONS PLATFORMS, MEDIA, LOCATIONS, OR ORGANIZATIONS THAT WOULD REACH RECIPIENTS AND FAMILIES ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>SPOR Units</p> <p>Communication through existing patient partners</p> <p>Circulate social media links to CDTRP PFD partners to amplify to their contacts and networks</p> <p>Can high school community service hours account? i.e. participation = 12 hours</p> <p>Cascading recruitment – encourage participants to recruit others</p> <p>Social networks</p> <p>Patient partners posting to personal and transplant networks on social media.</p> <p>Referral/suggestions from existing participants</p> <p>Family reunion, family Christmas letter, family meeting at the dinner table.</p> <p>Transplant games</p>	<p>Patient</p> <p>Family</p> <p>Donor</p> <p>Partners</p>	<p>Patients</p> <p>Families</p> <p>Caregivers</p>

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q3: WHAT ARE SOME SPECIFIC COMMUNICATIONS PLATFORMS, MEDIA, LOCATIONS, OR ORGANIZATIONS THAT WOULD REACH RECIPIENTS AND FAMILIES ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Living donation groups</p> <p>Support groups</p> <p>There are a lot of family members involved in organizations mentioned above</p> <p>Accessible online sources for caregivers.</p> <p>Informal and formal networks to help disseminate the information (e.g. family members...)</p> <p>Word of mouth</p>	<p>Patient</p> <p>Family</p> <p>Donor</p> <p>Partners</p>	<p>Patients</p> <p>Families</p> <p>Caregivers</p>
<p>Social media support group (Facebook pages/groups) X 11</p> <p>Social media videos that are short</p> <p>Social media also helps - know your audience and who you are targeting.</p>	<p>Social media</p>	

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q3: WHAT ARE SOME SPECIFIC COMMUNICATIONS PLATFORMS, MEDIA, LOCATIONS, OR ORGANIZATIONS THAT WOULD REACH RECIPIENTS AND FAMILIES ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Aiming to reach younger demographics through social media platforms.</p> <p>Having a TikTok video talking about the research project</p> <p>Social platforms that young people use, e.g. Instagram (not Facebook any longer, but is still useful for adults population so all social media platforms have a value)</p> <p>Social Media posts</p>	Social media	Patients Families Caregivers
<p>Posters in public locations (clinics, hospitals)</p> <p>Centre for Living Donation</p> <p>Posting flyers/info sheets at hospital and research institutions</p>	Transplant and hospital research programs	

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q3: WHAT ARE SOME SPECIFIC COMMUNICATIONS PLATFORMS, MEDIA, LOCATIONS, OR ORGANIZATIONS THAT WOULD REACH RECIPIENTS AND FAMILIES ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
In person connection	Transplant and hospital research programs	Patients Families Caregivers
Hospital communication – doctors contacting the patient.		
Email patients		
Transplant Centre website		
Posters in waiting room with QR Code		
Screens in family medicine waiting room		
Transplant outpatient – clinics, advertising boards and postings		
During Transplant clinic follow-up		
Recruitment posters in all Canadian clinics.		
Contact folks in clinics.		
Some people have emailed me, called me to be part of studies and from there, I was able to be part of stuff that I would have missed out on.		

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q3: WHAT ARE SOME SPECIFIC COMMUNICATIONS PLATFORMS, MEDIA, LOCATIONS, OR ORGANIZATIONS THAT WOULD REACH RECIPIENTS AND FAMILIES ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Suggestion is that the transplant coordinator or doctor has something to hand out during their clinic.</p> <p>Email blast from the transplant clinics</p> <p>Transplant clinics, transplant pharmacies, labs, etc.</p> <p>Transplant clinics have lists of transplant population and volunteers that may be helpful</p> <p>Letters for groups who do not have access to emails</p>	<p>Transplant and hospital research programs</p>	<p>Patients</p> <p>Families</p> <p>Caregivers</p>
<p>Transplant Ambassador Program X 3 – Candice Coghlan and Sue McKenzie</p> <p>Living Transplant Podcast</p> <p>ACB Organ Health YouTube Channel</p> <p>The Kidney Foundation X 2</p> <p>Kidney Link</p>	<p>Transplant focused patient facing community organization</p>	

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q3: WHAT ARE SOME SPECIFIC COMMUNICATIONS PLATFORMS, MEDIA, LOCATIONS, OR ORGANIZATIONS THAT WOULD REACH RECIPIENTS AND FAMILIES ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Billboards with QR codes at virtual events, newsletters, and eMarketing</p> <p>Transplant organizations i.e. Ottawa Gift of Life, Kidney Foundation, Transplant Ambassador Program (TAP) etc.</p> <p>Use the existing network (CST, Support units, KFOC, Liver Foundation, other disease groups such as Heart and Stroke, Alberta Lung, Canadian PBC Society, COPD, Cancer Society, the CTA, Caregiver Association of Canada, Asthma Society, people that are immunocompromised...) and their social media platforms</p>	<p>Transplant focused patient facing community organization</p>	<p>Patients Families Caregivers</p>
<p>Allied Health Organizations/Network</p> <p>Canadian Society of Transplant</p> <p>Health Canada ODT Collaborative X 2</p>	<p>Transplant focused professional organization</p>	

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q4: WHO CAN ACT AS CREDIBLE SOURCES, INFLUENCERS, OR LEADERS TO COMMUNICATE ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Engage local cultural groups</p> <p>Hospice networks (North landmark contact is Jan Watson)</p> <p>Local, provincial, national hospice volunteers and staff</p> <p>Peer support groups</p> <p>One thing that has helped is reaching out to specific organizations/community-based organizations and partners who have long-standing credibility with community members.</p> <p>There is a need to reach out to communities who are not traditionally engaged in research</p>	<p>Community-based organizations</p>	<p>Patients</p> <p>Families</p> <p>Caregivers</p>
<p>Primary care physicians</p> <p>Alain Vadeboncoeur</p> <p>Caroline Quach</p> <p>Quebec respiratory health network</p>	<p>Health professionals, non-transplant</p>	

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q4: WHO CAN ACT AS CREDIBLE SOURCES, INFLUENCERS, OR LEADERS TO COMMUNICATE ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
Ask Ryan Reynolds to do a push on IG	Other	
Brenda Brown, CTA	Patient, Family, Donor Partners	Patients Families Caregivers
Dave Smith, CDTRP Patient Partner		
Willow Pill, Drag Queen, Tx recipient		
Jaime Watt, Writer, communications, patient		
Cristine Howorun, media, patient		
Great Action Models		
UHN Patient Group		
Tina and Joel Proulx, Ottawa Gift of Life Chairs		
Sandra Holdsworth, Transplant Games		
Need to engage with support groups to get them onsite		
Patient partners		

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q4: WHO CAN ACT AS CREDIBLE SOURCES, INFLUENCERS, OR LEADERS TO COMMUNICATE ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
Any Canadian celebrities with transplant?	Patient, Family, Donor Partners	Patients Families Caregivers
Patient Facebook groups		
Heather Talbot, Donor families as a channel to reach recipients		
Advocacy Groups, committees, and groups		
Facebook groups targeting recipients		
Stollery has a Facebook group for pediatric hearth transplant families		
Post on Facebook groups i.e. CTA in each province.		
Have a booth at Transplant Games in Ottawa, August 3 – 9		
Churches		
Having transplant recipients to share and communicate their experiences		
A caregiver talking about why we are doing this study		

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q4: WHO CAN ACT AS CREDIBLE SOURCES, INFLUENCERS, OR LEADERS TO COMMUNICATE ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>It needs to be somebody from each group, family member, young, old, patients, speaking different languages... (as this is a collaborative study)</p> <p>Ensure representation, not only having famous people but also normal people who represents diverse population groups to be able to relate to them</p> <p>Simon Keith</p>	<p>Patient, Family, Donor Partners</p>	<p>Patients Families Caregivers</p>
<p>Combined and common effort between researchers, patients, funders (Astella, Pfizer, Moderna)</p> <p>Collaborative demonstration of unity within the study - patients, researchers, funders, Health Canada, and drug companies</p>	<p>Study partner</p>	

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q4: WHO CAN ACT AS CREDIBLE SOURCES, INFLUENCERS, OR LEADERS TO COMMUNICATE ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
UHN's medical Director Lung Transplant TGLN e-newsletter Can Trillium ask families? Organizational network websites and newsletters Direct email (walks, tx groups) Posters/postcards in clinics.	Transplant and hospital research programs	Patients Families Caregivers
Kidney Foundation leadership and peer support) Health Charity leaders Transplant Ambassador Program Canadian Transplant Association Canadian Liver Heart and Stroke Canadian Lung Association	Transplant focused patient facing community organization	

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q4: WHO CAN ACT AS CREDIBLE SOURCES, INFLUENCERS, OR LEADERS TO COMMUNICATE ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Kidney Foundation</p> <p>Support groups, CTA regional Facebook groups</p> <p>Circle of Excellence Program</p> <p>In BC: BC Transplant, TRFBC, Children’s Organ Transplant Society</p> <p>Kidney Foundation, Canadian Transplant Association, Liver Foundation</p> <p>Elizabeth Myles, Kidney Foundation</p> <p>Brenda Brown, CTA president</p> <p>Fundraisers/walks</p> <p>In person promotion at exciting events – conferences, support groups.</p> <p>Kidney Foundation</p> <p>Kidney Walk</p> <p>Transplant games</p>	<p>Transplant focused patient facing community organization</p>	<p>Patients</p> <p>Families</p> <p>Caregivers</p>

APPENDIX 2

RESEARCH PRIORITIZATION RESULTS AND DISCUSSION

Q4: WHO CAN ACT AS CREDIBLE SOURCES, INFLUENCERS, OR LEADERS TO COMMUNICATE ACROSS THE COUNTRY?

<u>Statement</u>	<u>Theme</u>	<u>Audience</u>
<p>Dr. John Gill, CST</p> <p>Clinicians, research assistance, institute and department leads, patient partners, existing participants.</p> <p>Dr. Kara Doucette, U of A</p> <p>Dr. Deepali Kumar, UHN</p> <p>Dr. Shahid Musain, UHN</p> <p>Dr. Ramesh Prasah, Medical Director St. M</p> <p>Michelle Nash, Research Coordinator</p> <p>Dr. Istvan Musci</p> <p>Dr. Bryce Kiberd</p> <p>Clinicians on social</p> <p>Transplant nephrologists, National and provincial organizations, ODOs, Canadian Blood Services.</p> <p>Leaders of networks</p> <p>Dr. Lori West (Member of the order of Canada), Dr Kabbani, Dr. Bogoch, Doctors who talked about COVID, some athletes, World Transplant Athletes, Pharmacists, Nurse Practitioners, trusted professionals</p>	<p>Transplant professionals</p>	<p>Patients Families Caregivers</p>

APPENDIX 2

APPENDIX 3: DESCRIPTION OF PFD ADVISORY GROUP

RECRUITMENT CHAMPION

- UTILIZE CDTRP'S TREAT-COVID COMMUNICATION MATERIALS AND SHARE THEM WITH THEIR NETWORKS/SOCIAL MEDIA.
- SHARE MATERIALS IN LOCAL OUTREACH EVENTS, CLINICS, AND OTHER VENUES AS APPROPRIATE.
- SHARE PERSONAL STORIES/LIVED EXPERIENCES DURING TREAT ACTIVITIES/MEDIA STORIES, AS APPROPRIATE.
- CONNECT WITH PROSPECTIVE PARTICIPANTS WHO WANT TO SPEAK WITH A PATIENT.
- FEEDBACK ON RECRUITMENT PARTNERS, MATERIALS, AND STRATEGY,
- LEVERAGE CONNECTIONS WITH PARTNERS (INDIVIDUALS AND ORGANIZATIONS).
- SUPPORT THE EVALUATION OF RECRUITMENT STRATEGIES.

NATIONAL PRIORITIZATION FORUMS

- CO-DEVELOP QUESTIONS AND VALIDATE THE DIRECTION OF FORUMS 3 AND 4.
- FACILITATE/MODERATE DISCUSSION DURING THE FORUM.
- REVIEW OF FORUM REPORTS FOR FEEDBACK.
- ATTEND MEETING, AS REQUIRED.

APPENDIX 2

APPENDIX 3: DESCRIPTION OF PFD ADVISORY GROUP

RESEARCH PARTNERS

- FOCUS GROUP: CO-DEVELOPMENT OF FOCUS GROUP QUESTIONS, CO-FACILITATE, VALIDATE.
- SCREENING TOOL: CO-DEVELOPMENT/REVIEW/FEEDBACK OF SCREENING TOOL.
- PFD PARTNER FOR SUB STUDIES:
- REVIEW KNOWLEDGE MOBILIZATION MATERIALS TARGETING PATIENTS, FAMILIES, CAREGIVERS.
 - CONSULT ON RESULTS/LANGUAGE – IS IT UNDERSTANDABLE?
 - INTERPRET THE RESULTS OF DATA AND MAKE RECOMMENDATIONS.
 - CO-DEVELOP ON LAY ABSTRACT.
 - CO-DEVELOP ON KEY MESSAGES.

NATIONAL PRIORITIZATION FORUMS

- CO-DEVELOP QUESTIONS AND VALIDATE THE DIRECTION OF FORUMS 3 AND 4.
- FACILITATE/MODERATE DISCUSSION DURING THE FORUM.
- REVIEW OF FORUM REPORTS FOR FEEDBACK.
- ATTEND MEETING, AS REQUIRED.

ACKNOWLEDGEMENT

This report was produced based on content for TREAT-COVID's 2nd National Forum and was written by Manuel Escoto, reviewed, and edited by Demitra Yotis, Patricia Gongal, Sherrie Logan, and Rienk de Vries. Designed by Cendrine Tolomio.

This work was financially supported by Health Canada, FRQS, AstraZeneca, University Hospital Foundation (Alberta), Transplant Research Foundation of British Columbia, and the Canadian Institute of Health Research. The views expressed herein do not necessarily represent their views.



REFERENCES

1. Canadian Society of Transplantation. National Transplant Consensus Guidance on COVID-19 Vaccine.; 2022. https://www.cst-transplant.ca/_Library/Coronavirus/National_Transplant_Consensus_Guidance_on_COVID_Vaccine_2022_1_final_1_.pdf
2. Nierengarten MB. Poor overall survival in bone marrow transplant patients with COVID-19. *Cancer*. 2021;127(21):3919. [doi:10.1002/cncr.33953](https://doi.org/10.1002/cncr.33953)
3. Canadian Institute for Health Information. Summary statistics on organ transplants, wait-lists and donors | CIHI. Accessed February 8, 2024. <https://www.cihi.ca/en/summary-statistics-on-organ-transplants-wait-lists-and-donors>
4. Canadian Society of Transplantation. Canadian Society of Transplantation - Programs & OPO's. Accessed February 8, 2024. <https://www.cst-transplant.ca/cgi/page.cgi/transplant-programs-opos.html>
5. The Canadian Donation and Transplantation Research Program. CDTRP Research Priorities. Accessed March 12, 2024. <https://cdtrp.ca/en/research/>
6. Davydow DS, Lease ED, Reyes JD. Posttraumatic Stress Disorder in Organ Transplant Recipients: A Systematic Review. *Gen Hosp Psychiatry*. 2015;37(5):387. [doi:10.1016/j.genhosppsy.2015.05.005](https://doi.org/10.1016/j.genhosppsy.2015.05.005)
7. Fox DE, Hall M, Thibodeau C, et al. The experiences of patients, caregivers and donors on transplant journeys in Canada: A convergent parallel mixed methods study. *J Eval Clin Pract*. n/a(n/a). [doi:10.1111/jep.13942](https://doi.org/10.1111/jep.13942)
8. Rainer JP, Thompson CH, Lambros H. Psychological and psychosocial aspects of the solid organ transplant experience—A practice review. *Psychother Theory Res Pract Train*. 2010;47(3):403-412. [doi:10.1037/a0021167](https://doi.org/10.1037/a0021167)
9. Rodrigue JR, Reed AI, Nelson DR, Jamieson I, Kaplan B, Howard RJ. The Financial Burden of Transplantation: A Single-Center Survey of Liver and Kidney Transplant Recipients. *Transplantation*. 2007;84(3):295. [doi:10.1097/01.tp.0000269797.41202.79](https://doi.org/10.1097/01.tp.0000269797.41202.79)



REFERENCES

10. Klarenback S. Financial Burden of Kidney Disease. Accessed January 23, 2024. https://kidney.ca/KFOC/media/images/PDFs/3-2-1-NAT-Burden_of_Out-of-Pocket_Costs.pdf
11. Gordon EJ, Prohaska TR, Sehgal AR. The financial impact of immunosuppressant expenses on new kidney transplant recipients*, †. Clin Transplant. 2008;22(6):738-748. doi:10.1111/j.1399-0012.2008.00869.x
12. Denzen EM, Thao V, Hahn T, et al. Financial impact of allogeneic hematopoietic cell transplantation on patients and families over 2 years: results from a multicenter pilot study. Bone Marrow Transplant. 2016;51(9):1233-1240. doi:10.1038/bmt.2016.103
13. Canada FCA of. Consumer Vulnerability: Evidence from the Monthly COVID-19 Financial Well-being Survey. Published November 29, 2022. Accessed January 23, 2024. <https://www.canada.ca/en/financial-consumer-agency/programs/research/consumer-vulnerability.html>
14. Improving Engagement and Empowering Patients on their Transplant Journey. https://kidney.ca/KFOC/media/images/PDFs/PAAC-Project_Final-Report-EN.pdf
15. The Canadian Donation and Transplantation Research Program. COVID-19 Vaccination in Transplant Recipients: CDTRP National Initiative. Accessed January 23, 2024. <https://cdtrp.ca/wp-content/uploads/2021/05/Communication-of-Research-with-Patients-and-Families-Workshop-Report.pdf>
16. Hall VG, Solera JT, Al-Alahmadi G, et al. Severity of COVID-19 among solid organ transplant recipients in Canada, 2020-2021: a prospective, multicentre cohort study. CMAJ Can Med Assoc J J Assoc Medicale Can. 2022;194(33):E1155-E1163. doi:10.1503/cmaj.220620
17. Fox D, Hall M, Thibodeau C, et al. Impact of the COVID-19 pandemic on Canadian transplant journeys: a mixed methods study. BMJ Open. 2023;13(12):e068347. doi:10.1136/bmjopen-2022-068347
18. The Canadian Donation and Transplantation Research Program. COVID-19 Vaccination in Transplant Recipients: CDTRP National Initiative. Canadian Donation and Transplantation Research Program. Accessed February 29, 2024. <https://cdtrp.ca/en/publications/covid-19-vaccination-in-transplant-recipients-cdtrp-national-initiative>

