



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

JUNE 9, 2023



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BACKGROUND

With increased access to and distribution of vaccines, the availability of COVID-19 therapeutics, and the easing of government public health measures, the perception among the general public is that COVID-19 is over.

While many Canadians have moved on from COVID-19, transplant patients, their families and caregivers, and other immunocompromised patients remain at high risk of severe outcomes due to COVID-19.

In response, The Canadian Donation and Transplantation Research Program (CDTRP) has established a national, multi-disciplinary team with an agile and collaborative research framework to address emerging research questions.

The project, Addressing Critical Issues and Therapeutics Emerging in Transplantation in COVID-19 for Transplant Recipients (TREAT-COVID), seeks to address urgent and emerging issues by incorporating the priorities of patients, families, caregivers, clinicians, and researchers. Central to TREAT-COVID's adaptive design is regular engagement and co-development of research priorities and knowledge mobilization planning with patients, their families and caregivers, and the Pan-Canadian transplant community.

National Prioritization Forums are held every six months, and the first Forum was held during CDTRP's June 2023 Patient, Family, and Donor Research Forum. This was the fifth National Forum hosted by CDTRP since 2021, with previous forums influencing the direction of TREAT-COVID and the PREVent-COVID-19 study.

The Forum's attendees included patients, families, caregivers, health professionals, researchers, and clinicians. Together, they participated and identified the most urgent emerging research questions and issues confronting transplant patients, families, and caregivers.

FORUM OBJECTIVES

TREAT-COVID'S first National Prioritization Forum provided a venue for engagement with transplant patients, families, caregivers, clinicians, and researchers. In doing so, the objective was to develop an understanding of COVID-19 research question priorities. This was accomplished through four mechanisms:

- 1** Share updates on TREAT-COVID progress made over the last year.
- 2** Identify the priority questions the community wants answered through the TREAT-COVID research project.
- 3** Gain every participant's perspective, including adult and pediatric transplant recipients, their families, caregivers, and researchers.
- 4** Align the research goals of TREAT-COVID with the priorities of the community.

LIST OF THE FORUM'S CONTRIBUTING EXPERTS AND PARTICIPANTS

(IN ALPHABETICAL ORDER)

Name	Affiliation
Amy Fump	PUBLIC CONTRIBUTOR
Ashley Logan	CDTRP PFD PARTNER
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Sean Delaney	CDTRP PFD PARTNER
Sherrie Logan	CDTRP PFD PARTNER
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FORUM PRESENTATION STRUCTURE

OVERVIEW OF 2022 MENTAL HEALTH AND COVID-19 PRESENTATION

CDTRP Patient, Family, and Donor (PFD) partners Sherrie Logan (caregiver to a pediatric liver transplant recipient), and Rienk de Vries (heart transplant recipient) provided an overview of results from their mental health and COVID-19 presentation during the CDTRP 2022 Patient, Family and Donor Research Forum.

The top three research objectives identified by patients and families in 2022 include a need to develop approaches that (1) address the top challenges, (2) provide better mental health supports and resources to help patients and families/caregivers navigate the pandemic, and (3) improve patient and family quality of life outcomes during pandemic times.

The **top challenges** experienced by transplant patients and their families during the pandemic were identified as:

- Anxiety/fear/depression
- Information overload and lack of tools
- Social isolation
- Government and healthcare policy
- Family impacted.
- Disappointment and anger

**These results were utilized in the development of
TREAT-COVID's research questions.**

TREAT-COVID OVERVIEW

CDTRP Executive Director Dr. Patricia Gongal followed with an overview and progress update of TREAT-COVID. TREAT-COVID will address issues and questions experienced by transplant patients and their families by providing actionable knowledge to policymakers, clinical decision-makers, and transplant patients and their families to navigate the pandemic. Specifically, **TREAT-COVID seeks to understand and address questions related to:**

- 1.COVID-19 therapeutic safety and effectiveness in transplant recipients.
- 2.Mental health impacts of COVID-19 on immunocompromised patients and families and developing strategies to improve well-being.
- 3.The economic burden and value of emerging and existing pre-prophylaxis (preventative treatment) and therapeutic options for COVID-19 in transplant patients.

The direction of these three questions is the result of prior engagement with patients, families, and other stakeholders. Given the ongoing evolution of COVID-19, time lags in the translation of research, and decentralized public health measures, the intention of patient, community, and stakeholder engagement is to understand changing priorities and co-develop actionable responses.

TREAT-COVID will aim to recruit 2500 solid organ and stem cell transplant recipients with a matched enrolment of a family/caregiver from 11 Canadian transplant centers to address these questions (Appendix 1). The data will be collected from research participants through surveys focused on clinical, mental health, and financial information.

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.

RESEARCH PRIORITIZATION BUILDING

Following the formal presentations, participants were asked to reflect on the challenges discussed in the 2022 PFD Research Forum. Participants then engaged in two exercises to gain insights into their current research priorities.

Exercise one divided participants into two groups - one comprising transplant recipients and the other consisting of caregivers. Researchers in attendance were invited to select one of the two groups to share their perspectives.

By leveraging the interactive features of Jamboard, the two groups participated in an online exercise that asked them to answer what questions researchers should be asking related to COVID-19 specific to:

- Clinical/COVID-19 treatment
- Mental health and wellness
- Financial burdens they are facing
- Other topics

Exercise two brought both groups together to review and discuss the results of the Jamboard brainstorming activity to reflect on the identified questions. The group discussion gave participants time to elaborate, validate, and challenge what other's had written.



Priorities

- 1.
- 2.
- 3.

DISCUSSION

RESEARCH PRIORITIZATION RESULTS

The Jamboard brainstorming exercise produced 46 unique questions from patients, families/caregivers, and researchers. These questions were then categorized into 14 subthemes. Reference Appendix 2 for a complete list of the 46 questions. Where possible, this report identifies the perspective of each question (i.e., patient, caregiver, researcher).

Transplant Recipient Working Group

The Transplant Recipient Working Group, which included researchers, identified 30 **ongoing and outstanding questions**. They are categorized as follows:

- Clinical & COVID-19 Treatment (19)
- Mental Health and Wellness (5)
- Financial Burden (1)
- Other (5)

The 19 **clinical/COVID-19 treatment questions** are broken down into the following sub-themes:

- Safety and efficacy of vaccines and therapeutics (5)
- Standardization of care across Canada (7)
- Long-term impact of COVID-19 infection on transplant outcomes (4)
- The role and influence of research in the translation of better care and outcomes (3)

The five **mental health and wellness** questions are broken down into the following sub-themes:

- Guidance on which public health measures patients should follow (2)
- Resources to help patients navigate ongoing stresses (3).

One question related to **financial burden** was raised, and it focused on the types of support available to patients unable to work.

Outside of the three primary TREAT-COVID themes, five additional questions were included in the 'other' section in Jamboard. These questions are related to **patient care** and can be broken down into the following sub-themes:

- Impact of COVID-19 on transplantation and post-transplantation care (2).
- The role of researchers in advocacy to support patient care (2)
- Patient empowerment and partnership in their care (1).



Caregiver Working Group

The Caregiver Working Group identified 16 **ongoing and outstanding questions**. They are categorized as follows:

- COVID-19 Treatment (3)
- Mental Health and Wellness (8)
- Financial Burden (1)
- Other (4)

The three **clinical/COVID-19 treatment questions** are broken down into the following **sub-themes**:

- Access to information (1)
- Safety and efficacy of vaccines and therapeutics (2)

The 8 **mental health and wellness questions** are related to:

- The availability and usefulness of mental health resources and understanding (8)

One question related to **financial burden** was asked, and it focused on understanding the challenges experienced by multi-transplant homes.

Outside of the three primary TREAT-COVID themes, four additional questions were included in the '**other**' section in Jamboard. These questions are related to **patient care** and can be broken down into the following sub-themes:

- Standardization of care across Canada (1)
- Long-term impact of COVID-19 infection on transplant outcomes (1)
- Impact of TREAT-COVID knowledge mobilization (1)
- Stronger engagement and representation of transplant patients, families, and caregivers (1)

In reviewing the prioritization exercise results, a few takeaways emerge.

The anxiety, fear, depression, and other mental health needs expressed by transplant recipients in 2022 have shifted towards the prioritization of tools and policies to support better care and health outcomes.

In describing this shift, one patient partner stated:



"THIS speaks to how recipients and families have found throughout that transplant journey that we are on our own. We become resourceful and learn how to navigate as best as we can. Last year, the focus was on that... when we fell into a loss and didn't know what to do. This last year, we figured it out as best we can. This is not to say there aren't a lot of impacts, but it speaks to transplant in general, where those supports aren't there for us, and we have to get resourceful and rely on ourselves. Perhaps this speaks to the shift."

Another patient partner noted

"We always have to figure it out ourselves and because COVID is always changing, we ask our doctors what precautions we can do, what can't we do, and it is unclear. So more resources and guidance of what we can or can't do would be helpful."



Transplant patients and caregivers expressed different priorities.

Whereas transplant patients prioritized research questions related to clinical/COVID-19 treatment, including ongoing safety and efficacy of vaccines and therapeutics, standardization of care across Canada, and the long-term impact of COVID-19 infection on transplant outcomes, families and caregivers primarily focused on mental health and wellness and the need for resources.

During the discussion, several transplant patients expressed the ongoing stigmatization family members experience because of wearing masks and following other public health measures to protect their loved ones. In turn, it causes added pressures and burdens on transplant recipients themselves, who now need to navigate these interactions with their loved ones. While this burden wasn't a priority during the Jamboard session, it speaks to the increased need to engage with patients and families to understand the real experiences of patients and their families.

From a family and caregiver perspective, TREAT-COVID aims to support families and caregivers by comprehending the ongoing challenges faced by the transplant community, ultimately improving the overall experience during COVID-19 and other public health crises.

While attendees did not prioritize questions related to the economic and financial side, this could be the result of who attended and who did not attend the session. More importantly, it emphasizes a need to engage the broader transplant population further, including patients, families/caregivers, and communities not traditionally involved in donation and transplantation health research.

NEXT STEPS

The TREAT-COVID project team will host its **2nd National Prioritization Forum** on December 6, 2023, during CDTRP's 10th Annual Scientific Meeting. The session will share the study's progress and will ask participants to share their thoughts on how the project team can improve the recruitment of patients, caregivers, and families. Forum participants will also help identify the communication strategies that will best encourage:

- Patients, families, and caregivers to participate in the project.
- Researchers and clinicians to recruit PFDs into the project.
- Focus on strategies that increase confidence, reduce complacency, and increase convenience.

The results of the Forum will support the continued alignment of research priorities with the priorities of the transplant community and the changing healthcare landscape.



ACKNOWLEDGEMENT



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APPENDIX 1

TREAT-COVID PARTICIPATING SITES AND RESEARCHERS

Participating Centre	Researcher
BC Children's Hospital (BC)	Dr. Tom Blydt-Hansen and Dr. Hana Mitchell
Vancouver Coastal Health (BC)	Dr. Sara Belga
University of Alberta (Alberta)	Dr. Dima Kabbani
Children's Stollery Health (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 (Québec)	Dr. Édith Renoult
Institut de cardiologie de Montréal (Québec)	Dr. Normand Racine
Université Laval (Québec)	Dr. Sacha de Serres
Montréal Children's (Québec)	Dr. Bethany Foster

APPENDIX 2

JAMBOARD RESULTS CATEGORIZED INTO SUB-THEMES

TRANSPLANT RECIPIENT WORKING GROUP

SUB-THEME 1

- How many shots? How often? Does it differ by organ or immunosuppression treatment? - *Researcher*
- Is one vaccine formula better than another and if so, why? Does it vary by organ or by patient? - *Researcher*
- What is the most effective treatment for COVID-19 for transplant recipients? - *Researcher*
- What is the efficiency of therapeutics vs. current variants? How can we shorten the updating of both to retain efficiency as new variants emerge? - *Patient*
- What are the long-term effects of the vaccines? - *Patient*

SUB-THEME 3

- What are the lasting effects of COVID-19 infections on the transplant graft and its function? - *Patient*
- What is known about the impacts on transplant patients' existing comorbidities (i.e. kidney disease, lung function, etc.) from COVID-19 infection? - *Patient*
- What are patient outcomes of getting COVID-19 beyond die/not die? How do they differ across patient types, i.e., age or other comorbidities - *Patient*
- Long-term impact on patients' overall health due to infection? How do we tease out what the result of COVID-19 or more transplant-specific causes is? - *Patient*

COVID-19 THERAPEUTICS



SUB-THEME 2

- Can we coordinate the messaging between provinces? - *Patient*
- Can we standardize vaccine intervals to a national standard? - *Researcher*
- How can we get more consistent treatment across Canada? - *Patient*
- Will vaccines be required every 6 months? *Patient*
- We need to work with other immunocompromised groups so our concerns are addressed in a timely manner, and the loopholes patients and caregivers had to go through to get vaccines. - *Patient*
- Establishing protocols for Paxlovid and enabling patients to acquire Paxlovid in advance of, say, travelling, with instructions.
- The pandemic proved scientists could work together to solve issues effectively and very well to solve problems. Why is COVID treated so differently in each province? - *Researcher*

SUB-THEME 4

- How do we accelerate access to new vaccines or treatments for new variants of COVID-19? - *Researcher*
- How can we ensure that research for new therapeutics continues and that there continues to be an investment in this area with patients involved early? - *Patient*
- We learned from innovation that nicotine plants could be a solution until WHO refused to approve. Could this research still benefit COVID research? or perhaps another virus? - *Researcher*

SUB-THEME 1

- What are the specific precautions that transplant recipients should be taking? My doctors are unclear on what risks should be taken and what I shouldn't do relating to public. - *Patient*
- I would like to see some specific outlines of what we can and can't do now that we have vaccines. Like if I can start seeing family and friends again indoors or not. - *Patient*



MENTAL HEALTH & WELLNESS

SUB-THEME 2

- What resources will be available to help with mental health issues? Isolation may have triggered PTSD, and concern of catching COVID or other viruses has been overwhelming. - *Patient*
- We need to focus on mental health and look at ways to provide support to the transplant community to support one another. - *Patient*
- The Pandemic drove home the lack of mental health services in Canada, but can we ensure ALL transplant patients, donors, and families have access to services in all programs now? – *Researcher*

TRANSPLANT RECIPIENT WORKING GROUP

- Will there be compensation if we are unable to go to work because of risk of infection - *Patient*



FINANCIAL BURDEN

SUB-THEME 1

- What safety measures and protocols were put in place during the pandemic to ensure the successful transplantation and recovery of patients? - *Patient*
- Did the pandemic affect access to post-transplantation care and support? If so, how did patients manage to receive the necessary assistance? - *Researcher*



PATIENT CARE (OPEN SECTION)

SUB-THEME 2

- How can researchers champion patients' ongoing needs, and how can we all advocate for more awareness and funding? - *Patient*
- How can researchers support policymakers/help inform decision-making? - *Patient*

SUB-THEME 3

- How can patients be empowered to protect themselves and speak against the dominant narrative, especially when there is a power imbalance, i.e., from one's own doctor? - *Patient*

SUB-THEME 1

- How can we get up-to-date information and recommendations for treatment and advice? - *Caregiver*

SUB-THEME 2

- How do COVID-19 therapies interact with current transplant protocols, especially immunosuppressants?
- How do lifestyle approaches like sleep, nutrition etc., affect immunity to COVID for transplant patients?



**COVID-19
TREATMENT**

Caregiver Working Group

- Will mental health resources be sufficient to address the needs of transplant patients with long COVID? – *Researcher*
- What mental health supports exist for transplant recipients? – *Caregiver*
- What resources are most helpful to promote the mental health and well-being of pediatric transplant patients and their caregivers/family members? – *Researcher*
- Have the resources that can promote health and well-being in pediatric transplant patients and their caregivers/family members changed since before COVID-19? – *Researcher*
- A portal to access up-to-date information resources on COVID-19 issues to check in periodically to assess risk and options for adapting and staying as healthy as possible.
- As a caregiver living with a recipient, are there any protocols for dealing with COVID-19 in the home.
- What is "normal" - the baseline for mental health and wellness we aspire to? – *Researcher*
- What was the impact of COVID stress on caregivers/family members and patients? – *Researcher*



- What unique challenges face multi-transplant homes (especially for children)? How does this intersect with financial stress? - Researcher



FINANCIAL BURDEN

SUB-THEME 1

- Question related to the long-term impact of COVID-19 infection on transplant outcomes.

SUB-THEME 2

- Will there be a unified approach nationwide to address possible future COVID protocols?



PATIENT CARE

SUB-THEME 3

- How can we make sure the framework developed has more universal applicability to other pandemics or similar disruptive events?

SUB-THEME 4

- Which patients aren't we reaching and how can we reach out to them?