



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

12 JUNE, 2025



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BACKGROUND

On June 12, 2025, the Addressing Critical Issues and **TheRapeutics E**merging in **TrAnsplantaTion** in **COVID-19** (TREAT-COVID) Steering Committed hosted the 4th TREAT-COVID National Prioritization Workshop. This virtual workshop was hosted during the Canadian Donation and Transplantation Research Program's (CDTRP) Patient, Family, and Donor Research Forum.

TREAT-COVID is designed to generate actionable evidence so that clinical guidelines, policy and supports can be better tailored for transplant recipients and their families in the context of COVID-19 (and potentially other future emerging infectious threats). The National Forums provide a space for patient, family, and donor (PFD) partners, researchers, and clinicians to come together and engage in meaningful discussion about the TREAT-COVID.

Forum Objectives:

- Share clinical data and information about vaccines, COVID-19 infections and COVID-19 treatment from the TREAT-COVID study across recruiting sites.
- Convene a PFD panel conversation on what information goes into making decisions around COVID and other infectious diseases.
- Obtain community input on communication & knowledge translation material that PFDs need to make informed decisions on the upcoming infectious disease season.

MEETING AGENDA

The workshop's questions for the panel discussion and breakout groups were developed by a smaller working group of TREAT-COVID's Steering Committee: Geetha Sanmugalingham, CDTRP Research Manager and project lead for TREAT-COVID; Sherrie Logan, PFD Partner and co-lead for TREAT-COVID (family member/caregiver to a young adult transplant recipient); Rienk de Vries, PFD Partner and co-lead for TREAT-COVID (adult transplant recipient); Manuel Escoto, CDTRP Director of Patient, Family, and Donor Partnerships and Knowledge Mobilization; Dr. Patricia Gongal, CDTRP Executive Director.

The Agenda of the workshop is at Appendix 2.

SUMMARY OF DISCUSSION

Several key lessons have emerged during the current period of the world living with COVID-19. Current strains are causing less severe illness compared to earlier variants, though the virus continues to evolve. Vaccines remain available and are recommended by the National Advisory Committee on Immunization (NACI) and other international vaccine advisory bodies. Antivirals remain an important tool for early treatment and continue to show effectiveness against newer strains. However, access to COVID-19 testing has become more limited, making it challenging to track cases as closely as in previous years. Furthermore, there is a noticeable decrease in available data, which may affect future public health planning and response efforts.

As of May 2025, 842 individuals had enrolled in the TREAT-COVID study. A data analysis led by Dr. Dima Kabbani reviewed information from 638 participants. This data analysis excluded 204 cases due to incomplete data or because they involved pediatric patients. Of the analyzed participants, 527 were solid organ transplant (SOT) recipients, and 111 were family members or caregivers. Of the SOTs, 36% were kidney transplant recipients, 25% were lung transplant recipients, 24% were liver transplant recipients, 8% were heart transplant recipients, 3% were kidney-pancreas transplant recipients, 3% were combined transplant recipients, and 1% were islet transplant recipients. Data shows that the median time since their transplant is six years. Key early insights from TREAT Data:

- Over 90% of SOT have received at least two doses of a COVID-19 vaccine.
- During the 2024-2025 season, 55% of SOTs received the most recent COVID-19 vaccine. Approximately 20% did not receive their vaccine, and over 20% did not know.
- From a family member/caregiver perspective, 86.5% received at least two doses of a COVID-19 vaccine. 4.5% had not received the vaccine, and 9% were unsure.
- During the 2024-2025 season, 45.9% received a vaccine, 21.6% did not receive a vaccine, and 32.4% were unsure.

SUMMARY OF DISCUSSION

- 64% of SOTs had previously had COVID-19 at least once before enrolling in TREAT-COVID, 30% responded no, and 5.5% did not know.
- Of the SOTs who had COVID-19, approximately 30% have had COVID twice, and 8.6% have had three infections.
- For family members/caregivers, 60% had COVID-19 before enrolling, 35% did not

Dr. Kabbani highlighted several key challenges faced in TREAT-COVID data collection. Enrollment for the study was delayed, and recruitment progressed slowly, resulting in small sample sizes at the time of analysis that limited the ability to answer important questions. Much of the COVID-19 data collected so far has been collected retrospectively, relying on participants' recall. Additionally, there were gaps in the data due to incomplete questionnaires and missing information, particularly regarding vaccination records. Furthermore, as is common in similar studies, SOT recipients, their families, and caregivers who participated in TREAT-COVID may not be fully representative of the broader Canadian SOT population, which limits the generalizability of the findings.

The full presentation can be access through this [link](#).

Following the presentation by Dr. Kabbani, CDTRP's TREAT-COVID Project Manager, Geetha Sanmugalingham, facilitated a panel discussion with TREAT-COVID's PFD Research Co-leads, Sherrie Logan (caregiver to a young adult liver transplant recipient) and Rienk de Vries (heart transplant recipient), along with CDTRP's PFD Partner, Lindsay Thompson (stem cell recipient).

SUMMARY OF DISCUSSION

PFD CONVERSATION: A PANEL DISCUSSION WITH ORGAN AND STEM CELL RECIPIENTS AND CAREGIVERS.

QUESTION: WHAT INFORMATION IS NEEDED TO MAKE INFORMED DECISIONS ABOUT COVID AND OTHER INFECTIOUS DISEASES?

Trust in Healthcare Providers: The PFD partners identified their healthcare providers, particularly transplant teams, as their primary and most trusted source of information. PFDs emphasized the importance of providers who engage in “normal conversations” and take the time to explain information in ways that are respectful and supportive. This relationship was described as central to feeling informed and “treated like a human being.”

Public Information: In addition to healthcare providers, participants consulted reputable research sources, including journal articles, current studies, and platforms such as PubMed. The PFD partners recognize that although public media sources, including newspapers and public health updates, are not transplant-specific, these sources provide valuable context to support decision-making. As one participant explained, families make decisions using “the best information we have at the time,” acknowledging that different families may approach this process in different ways.

Navigating Uncertainty: The caregiver described the transplant journey as filled with inherently uncertain, noting that “on this transplant journey, there is a lot of uncertainty, even without any kind of infection or pandemics like COVID-19. When we add additional layers of uncertainty, it becomes anxiety-provoking and causes PTSD.” To manage this, the PFD noted that families relied on conversations with transplant teams, family physicians, and other trusted healthcare professionals to ask questions and as a tool to understand and assess individual risks.

Peer Support: During the discussion, the value of peer support groups was highlighted. Specifically, peer support groups offer a space for individuals to share their experiences, learn from others, and receive emotional support. These groups often included transplant recipients, caregivers, and clinical experts, fostering a collaborative environment for discussion and decision-making.

SUMMARY OF DISCUSSION

PFD CONVERSATION: A PANEL DISCUSSION WITH ORGAN AND STEM CELL RECIPIENTS AND CAREGIVERS.

Use of Digital Tools: Digital resources, such as online respiratory virus dashboards tracking RSV, influenza, and COVID-19 trends, were identified as helpful tools. These platforms provided data on transmission rates and local trends, allowing families to assess their personal exposure risks. These tools are especially helpful during peak respiratory disease season, such as the fall, when children return to school.

Community Awareness: One participant discussed the importance of raising awareness in the broader community about the ongoing vulnerabilities faced by immunocompromised individuals. With declining vaccination rates and the perception that “the rush of COVID has passed,” some individuals who continue to take precautions, such as masking, have felt stigmatized. This highlights the need for continued education and public understanding to foster a supportive environment for transplant recipients, families, and caregivers and other immunocompromised people.

QUESTION: WHAT WAS A MEASUREMENT YOU USE OR USED IN THE PAST TO UNDERSTAND THE RELATIVE RISK IN YOUR PROVINCE/CITY AND YOURSELF/FAMILY?

Local News and Local Trends: One PFD partner described relying on local news reports as a primary source for understanding what was happening in their area. These updates helped them gauge the current situation and make informed decisions about precautions and activities for their family. While local news is a source of information, the PFD partner noted that miscommunication, misunderstanding, or outright misinformation can be amplified on social media. The PFD partner noted that the COVID-19 response shifted over time from a public health focus to a more politicized issue, especially as different viewpoints on pandemic management, public health guidance, and vaccination emerged.

SUMMARY OF DISCUSSION

PFD CONVERSATION: A PANEL DISCUSSION WITH ORGAN AND STEM CELL RECIPIENTS AND CAREGIVERS.

The PFD partner reflected on the need for greater community engagement and broader participation in TREAT-COVID to support data collection and analysis, allowing for better information for the transplant community.

Wastewater Surveillance as a Proactive Measure: Another participant emphasized the importance of wastewater surveillance data as a proactive tool for monitoring community risk. They described how tracking viral load in wastewater provided early signals of rising infection rates well before increases are seen through hospitalizations or mortality data, which are more reactive measures. This PFD partner valued wastewater data because it allowed them to make informed decisions about personal risk, such as when to wear a mask or limit exposure, based on trends in a specific area. They also raised concerns that the general public may not fully understand or have access to this type of data, highlighting an opportunity for education and broader dissemination.

Challenges with Information Sharing: The PFD partners discussed the potential value of centralizing COVID-19 information through platforms like the CDTRP patient portal. However, they acknowledged that doing so would require mechanisms to ensure the information remains current, accurate, and accessible. Without these systems in place, there is a risk that information becomes outdated.

SUMMARY OF DISCUSSION

FACILITATED BREAKOUT SESSION #1; GROUP 1

QUESTION: WHAT DO YOU NEED (WHAT KIND OF INFORMATION, TOOLS, OR DATA) TO MAKE INFORMED DECISIONS?

Clear and Plain Language Data: Information should be presented in plain language. As appropriate, statistics and data can help illustrate risks and benefits to SOT recipients, families, and caregivers. Complex medical terminology should be simplified using lay language summaries. Several tools are available to support the translation of scientific communication into accessible language. In the UK, for example, there is a website that translates scientific terminology into plain language. This ensures that everyone, regardless of their background, can access and interpret critical health information.

Visual and Multimedia Tools: Graphics and visuals can effectively communicate findings. Infographics that compare immunocompromised populations with the general population can help explain the differences in risk and why vaccination remains necessary for transplant recipients, their families, and caregivers. The use of different tools and formats can demonstrate how quickly COVID-19 spreads and why vaccination supports SOTs health outcomes. An example of a video showing the effectiveness of social distancing was shared by participants <https://www.youtube.com/watch?v=wJ2NMD3VWio>.

Targeted Resources for Patients and Caregivers: As outlined in the presentation by Dr. Kabbani, the rate of SOTs, families, and caregivers who continue to receive COVID-19 vaccines has declined from over 90% who received at least two vaccinations, to 55% of TREAT-COVID SOTs and 45% for family members/caregivers. Currently, we are unable to explain why rates have declined. Therefore, there remains a need for tailored resources that explain the role of vaccines, treatment options, and potential outcomes. These materials should be designed and tailored for the specific audience: patients, families, and caregivers.

SUMMARY OF DISCUSSION

FACILITATED BREAKOUT SESSION #1; GROUP 1

Transparent Safety and Side Effect Data: PFDs expressed a need for balanced information about vaccines, including both benefits and potential risks. Accessible information should also be tailored to respond to ongoing questions and concerns. For example:

- Are there any reports of hospitalization, rejection, or infection linked to vaccination?
- Have there been deaths among transplant recipients who received the vaccine?
- What are the short-term and long-term side effects, both positive and negative?

This transparency helps build trust and enables individuals to weigh their personal risk factors.

Understanding Barriers to Vaccination: Understanding why individuals may hesitate or refuse vaccines remains important. For example, some individuals delay vaccination because they want more time to ensure there are no serious complications. Addressing these concerns with accessible data can help support informed choices.

In summary, group one outlined the following recommendations, as requirements for informed decision-making:

- Accessible, accurate, and relevant information to inform decision-making.
- Use of different formats and tools to present information and data, so the transplant community can better understand the importance of vaccination and treatment decisions.
- Targeted campaigns and resources specific to patients, family members, and caregivers.
- Empowering patients, families, and caregivers with these tools fosters trust, reduces uncertainty, and ultimately improves health outcomes.

SUMMARY OF DISCUSSION

FACILITATED BREAKOUT SESSION #1; GROUP 2

Access to Accurate and Current Information: Participants identified difficulty finding accurate and up-to-date information. It was noted that public data is often outdated or inconsistent across jurisdictions. When vaccines first became available, for example, there was confusion over why the U.S. Food and Drug Administration approved vaccines earlier than Health Canada and why public health policies varied between countries and provinces.

This lack of clarity created frustration and uncertainty for transplant patients when deciding if it was safe to engage in everyday activities, such as visiting indoor public spaces. Having access to information about emerging variants, wastewater signals, and vaccine effectiveness (i.e., whether the current vaccine addresses the current strain) would help patients, families, and caregivers assess the risks of exposure and make informed choices about masking and social interactions.

One participant expressed an ongoing challenge in finding accurate information and went into “hibernation,” staying home for over two years. For some patients, families, or caregivers, and from a research perspective, it is important to understand the mental health impacts these decisions have on the overall health and well-being of patients, families, and caregivers.

Understanding of Broader Infectious Disease Risks: Beyond COVID-19, participants expressed an interest and concern about other emerging infectious diseases, such as measles. Specifically, participants noted that understanding the landscape of infectious disease threats is important for transplant patients and their caregivers to protect themselves.

Guidance for Transplant Recipients and Caregivers: A challenge identified by participants was that transplant centres are not always entirely up to date on current vaccination guidelines.

SUMMARY OF DISCUSSION

FACILITATED BREAKOUT SESSION #1; GROUP 2

One PFD partner commented that “the onus falls on the transplant recipient to learn about the vaccine schedule and what is currently available.” In other words, transplant recipients, families, and caregivers are responsible for researching and managing their vaccine knowledge independently.

In summary, group two outlined the following recommendations, as requirements for informed decision-making:

- Timely, localized, and accessible data on disease risks, vaccine guidelines, and emerging health threats.
- Clarity and effective delivery of information so patients, families, and caregivers can make informed choices that protect both their physical health and mental well-being.

SUMMARY OF DISCUSSION

FACILITATED BREAKOUT SESSION #2; GROUP 1

Several barriers were identified that make it difficult for patients, families, caregivers, and different communities to access the reliable, up-to-date information they need to make informed decisions.

Fragmented communication: Information is shared across multiple platforms, by different sources, making it difficult for the transplant community to access trustworthy and accessible information. While there are existing and credible platforms, such as NACI, up-to-date information is not shared in a coordinated way that makes it accessible to everyone.

Participants discussed the need for a centralized portal for Canadians that hosts current, reliable, and credible information. Currently, the CDTRP hosts the Patient Portal, a centralized hub for resources for pre- and post-transplant recipients, families, caregivers, and potential living donors, including information related to COVID-19.

Many patients rely on conversations with their transplant team to receive information. It was suggested that transplant centres should have a role not only in sharing information with patients but also in helping to disseminate it to the broader community.

SUMMARY OF DISCUSSION

FACILITATED BREAKOUT SESSION #2; GROUP 1

Use of medical and scientific terminology: The breakout session attendees suggested using lay summaries and simple, short, plain-language updates to provide updates. One participant suggested using videos presented like “breaking news” as a strategy to help individuals access information quickly and easily.

Addressing these barriers will require:

- A central, national platform for trusted by Canadian transplant recipients, families, and caregivers. The platform should produce plain-language resources.
- Mechanisms to update a national portal so information is updated in real-time based on new data.
- A formal, coordinated approach that engaged knowledge users to disseminate standard messaging and updates to the transplant community.

SUMMARY OF DISCUSSION

FACILITATED BREAKOUT SESSION #2; GROUP 2

Limited Transplant-Specific Information: A concern raised was that transplant teams are not fully equipped to provide information tailored to transplant recipients. While transplant teams have a central role in patient care, they often lack up-to-date, detailed guidance specific to the complex needs of immunocompromised individuals. This gap leaves patients and their families without a clear understanding of how evolving public health guidance applies to their unique circumstances. As a result, the burden falls on transplant recipients and caregivers to seek out, interpret, and act on information independently.

Gaps in Data: Public reporting of healthcare data has impacted trust in public health reporting. Participants noted that during the early stages of the COVID-19 pandemic, tools such as Alberta's Respiratory Illness Dashboard were widely used and trusted. However, over time, changes in reporting practices, reduced transparency, and political debate eroded confidence in these sources. Therefore, the data becomes unreliable. Participants expressed frustration with the removal of data reporting tools and reduced public access to clear, timely information.

Lack of Standardization Across Provinces: Participants highlighted that, because healthcare and public health are provincial responsibilities, there are inconsistent policies and approaches to managing infectious diseases across the country. This lack of a standardized approach creates confusion for transplant patients. Differences in reporting practices make it challenging to determine the most appropriate protective measures.

Addressing these barriers will require:

- Standardized national approaches to infectious disease reporting.
- Transparent, accessible, and timely public health data.
- Better integration of transplant-specific guidance into healthcare teams.
- Strengthened advocacy networks to amplify the voices of transplant recipients and their families

DISCUSSION

The conversations and insights gathered from TREAT-COVID's National Prioritization Forum remain an important pillar of engagement, not only with PFD partners but also with knowledge users within Canada's donation and transplant ecosystem. The discussions and breakout sessions highlighted the ongoing need for accessible, relevant, timely, and transplant-specific information to support patients, families, and caregivers in navigating COVID-19 decision-making.

In many ways, the themes from this National Prioritization Forum reaffirm what we have learned from previous sessions: a significant gap remains in how COVID-19 information is mobilized, communicated, and disseminated. Addressing this gap requires a coordinated and sustainable knowledge mobilization strategy.

In its initial phase, TREAT-COVID focused on implementing an integrated knowledge translation framework that actively engaged knowledge users, including PFD partners, community-based organizations, clinicians, researchers, and other partners in shaping the project. This collaborative approach also leveraged existing relationships to support outreach and recruitment efforts, ensuring the study reflected real-world needs and priorities.

As data and findings continue to emerge, the next phase of TREAT-COVID must prioritize the dissemination of knowledge in formats that are accessible and timely, not only for transplant patients, families, and caregivers, but also for the broader transplant ecosystem. This includes healthcare providers, researchers, policymakers, and community organizations who have a role in supporting informed decision-making and shaping policy and practice.

The CDTRP's Patient Portal, already well-developed and a credible source of information, is positioned to serve as the central platform for this next phase. By expanding its role to include real-time TREAT-COVID updates, educational resources, and research, the portal can become the national hub transplant transplant-specific COVID-19 information.

APPENDIX 1

TREAT-COVID RECRUITMENT SITES



British Columbia

- BC Children’s Hospital
- Vancouver General Hospital
- St. Paul’s Hospital

Alberta

- University of Alberta Hospital
- Stollery Children’s Hospital

Manitoba

- University of Manitoba *

Ontario

- SickKids
- University Health Network
- London Health Sciences Centre

Quebec

- Institut de Cardiologie de Montreal
- CHUM
- CHUQ (Laval)
- Montreal Children’s Hospital

APPENDIX 2

NATIONAL PRIORITIZATION WORKSHOP AGENDA

Speaker	Presentation
Geetha Sanmugalingham	TREAT-COVID overview: Ongoing objectives and introduction
Dr. Dima Kabbani	TREAT-COVID: Progress and Path Ahead
Rienk de Vries Sherrie Logan Lindsay Thompson	PFD conversation: What information is needed to make informed decisions about COVID and other infectious diseases?
Geetha Sanmugalingham	Instructions for breakout session
Breakout room session	Topic: Making informed decisions on COVID-19 and other infectious diseases
Geetha Sanmugalingham	Wrap-up session



APPENDIX 3

TREAT-COVID STEERING COMMITTEE

The TREAT-COVID Steering Committee consists of researchers, patient, family donor partners, and CDTRP staff. The full list of the steering committee is below:

- Dr. Tom Blydt-Hansen
- Dr. Catherine Burton
- Rienk de Vries
- Manuel Escoto
- Dr. Patricia Gongal
- Dr. Dima Kabbani
- Sherrie Logan
- Dr. Istvan Mucsi
- Dr. Caroline Piotrowski
- Dr. Tim Ramsay
- Geetha Sanmugaligham
- Dr. Sarah Shalhoub
- Dr. Kednapa Thavorn
- Dr. Lori West



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