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 4, 2024

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BACKGROUND

As we move into the sixth year of living with COVID-19, many transplant recipients, along with their families and caregivers, continue to experience real and ongoing concerns affecting their quality of life, including their physical, mental, and financial wellbeing.

The experiences of the transplant community since 2020 validate their concerns. For example, due to reduced vaccine effectiveness caused by immunosuppressive medications, breakthrough infections are common and can lead to hospitalization and death.[1,2,3,4,5,6,7,8] Today, transplant recipients are uncertainty about how many doses are needed to fully protect themselves against infections, which vaccine is the best, and how long the protection will last.9 Further clinical trials that include transplant recipients are needed to inform clinical practice.[9] Studies also suggest that transplant recipients have experienced significant mental health challenges as a result of the pandemic.[10,11] Transplant recipients and families also experience higher financial burdens compared to the non-transplant population, resulting in delays in medical treatment and lower health-related quality of life.[12]

From a financial wellbeing perspective, solid organ transplant (SOT) recipients experienced significant COVID-19-related costs and income loss, though economic burden data remains limited.[13] One study on hematopoietic stem cell transplant (HSCT) recipients reported high out-of-pocket costs associated with the pandemic, resulting in outcomes such as not being able to provide for basic needs, not filling prescriptions, missing medical treatments, and overall stress related to affordability.[14]

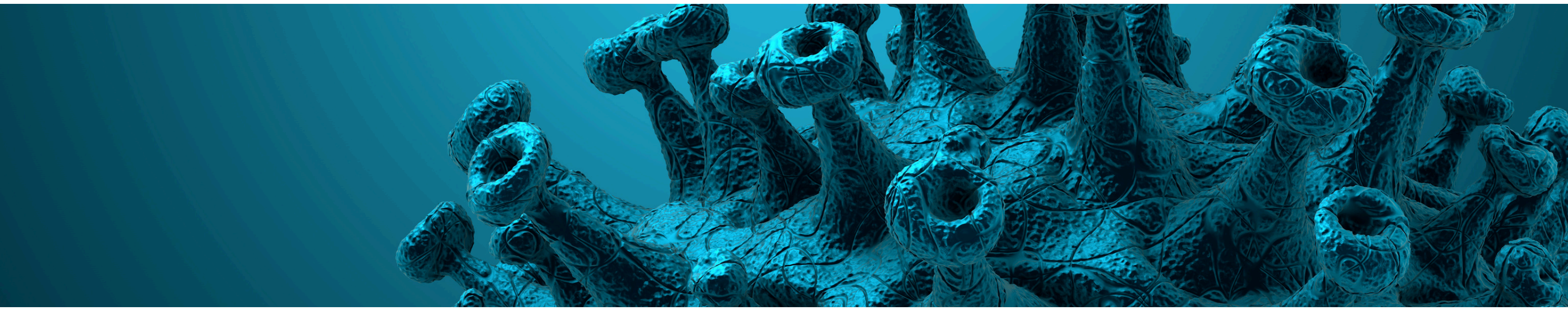
Since 2020, transplant recipients, families, and caregivers have also voiced concerns about mental and emotional distress, impacting their overall quality of life.[15,16] Prominent outcomes include anxiety, depression, and increased stress due to the pandemic[17]. Despite limited studies evaluating the psychological distress caused by COVID-19, research suggests that transplant recipients require ongoing and integrated multidisciplinary services to address the effects of COVID-19 on their mental health[10].

BACKGROUND

Further, research also suggests that SOT recipients' demographic characteristics, such as gender, age, race, or level of education may change the impact of COVID-19 on their mental health.[10,18] Another study noted that a history of mental health illness, risk perception, barriers to accessing healthcare services, and lack of coping strategies were also associated with a lower quality of life.19 The pandemic has also had psychological impacts on families, especially with families and caregivers living with pediatric transplant recipients.[20]

A factor in increased challenges experienced by recipients, families and caregivers may be limitations in the information available. Clinical trials evaluating the efficacy of COVID-19 vaccines excluded solid organ transplant (SOT) recipients.[9,21] Therefore, recipients and their families remain uncertain about the number of vaccines to get, which vaccine to get, and how long they may be potentially protected.

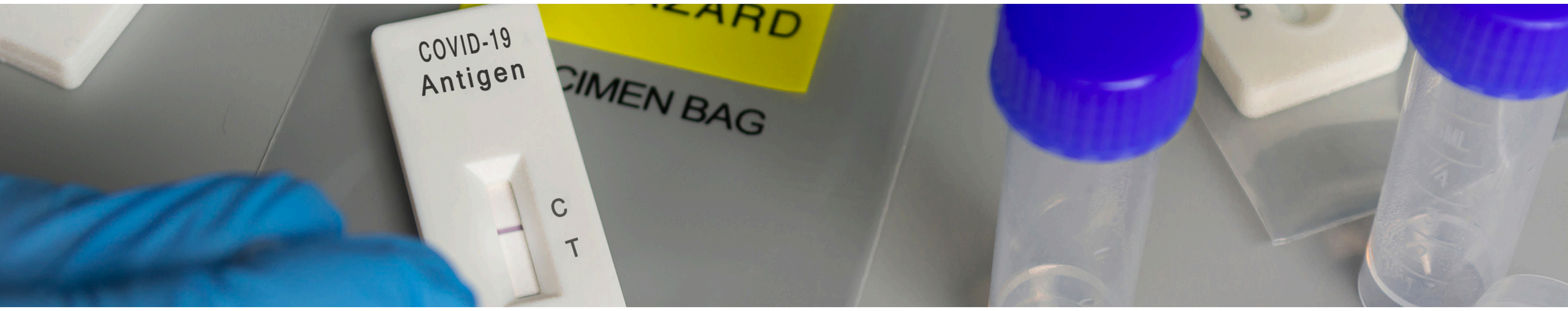
The emergence of COVID-19 variants intensifies the clinical and psychological burden on transplant recipients, families, and caregivers by adding a new level of uncertainty about how vaccines and boosters will respond to the latest variant. As new variants emerged, transplant recipients were recommended by their healthcare team to continue their uptake of vaccines and boosters, preventative treatments, and ongoing use of public health measures used during the initial stages of the pandemic.[22]



BACKGROUND

Health Canada's current COVID-19 Vaccines: Canadian Immunization Guide (accessed March 5, 2025) notes that "Immunocompromised individuals, including those receiving immunosuppressive therapy, are at increased risk for prolonged infection and serious complications from SARS-CoV-2 infection. Numerous studies have shown that immunogenicity is substantially decreased in some immunocompromised individuals when compared to healthy vaccine recipients."[23]

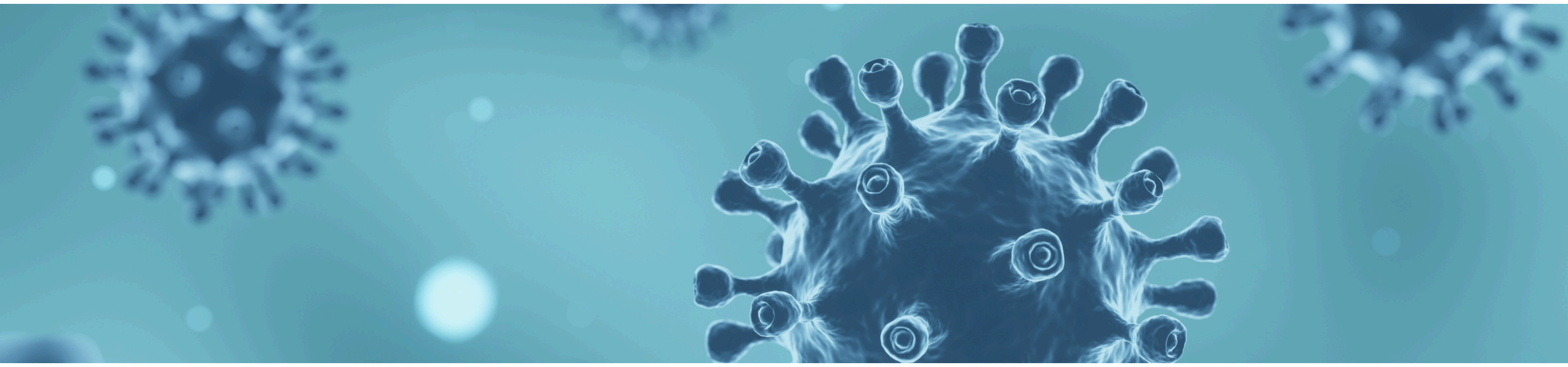
Immunogenicity refers to how well the body's immune system responds to a vaccine by producing protective antibodies. In transplant patients, decreased immunogenicity means that vaccines do not work as effectively because their immune system has a weaker response. This happens because transplant recipients take immunosuppressive medications to prevent their body from rejecting the transplanted organ. These medications lower the immune system's ability to recognize and fight infections, which also reduces the effectiveness of vaccines. As a result, transplant patients may not get the same level of protection from vaccines as people with a fully functioning immune system. Transplant patients also have worse humoral immune responses to COVID-19 vaccination compared to populations that are not immunocompromised.[24] A humoral immune response is a normal process of the immune system that involves the B Cells and antibodies to fight off infection. In transplant patients, the humoral immune response to COVID-19 may be weakened due to immunosuppressive therapy.



BACKGROUND

While research highlights the financial and mental health struggles of SOT and HSCT recipients, the voices of Canadian transplant patients, families, and caregivers navigating COVID-19 remain underrepresented in research. This is why the CDTRP is driving the TREAT-COVID project with the goal of delivering evidence-based recommendations that protect transplant patients during COVID-19 and future infectious disease outbreaks.

In December 2024, the CDTRP hosted the 3rd TREAT-COVID National Prioritization Workshop in Calgary, Alberta, to engage the transplant community and understand their top priorities.



WORKSHOP AGENDA & FORMAT

TREAT-COVID aims to recruit 2590 adult organ and stem cell transplant recipients and pediatric organ transplant recipients. In addition, the research project aims to recruit 2590 family members and/or caregivers. At the time of the Forum, recruitment had begun in Alberta and Quebec (Appendix 1). Alberta had recruited 75 SOTs and Quebec had recruited 375 SOTs. Experiences from the recruiting sites indicate that more strategies are needed to increase the number of families and caregivers enrolled in TREAT-COVID.

Therefore, this forum provided the research team and Steering Committee with an opportunity to engage with the Canadian transplant community, including patients, families, caregivers, clinicians, trainees, and researchers, to discuss recruitment strategies and barriers to enrolling in TREAT-COVID for families and caregivers (See Appendix 2 for the full agenda).

Forum Objectives:

- Share TREAT-COVID progress.
- Obtain community input that informs the TREAT-COVID recruitment strategy for caregivers.
- Provide an overview of approaches to health economics research and obtain community feedback on COVID-19 therapies, costs and benefits.

WORKSHOP AGENDA & FORMAT

With the forum's hybrid format, attendees were divided into eight discussion groups—four virtual and four in-person. Patient, family, and donor (PFD) partners comprised four groups, while researchers formed the other four. Each group had a facilitator and a notetaker. Virtual groups used Google Docs, with notetakers sharing their screens to capture discussions in real-time. Attendees could follow along, clarify points, and add their own notes. In-person groups used poster papers and sticky notes to document ideas collaboratively.

The workshop's questions 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 pediatric transplant recipient); Rienk de Vries, PFD Partner and co-lead for TREAT-COVID (adult transplant recipient); Dr. Patricia Gongal, CDTRP Executive Director; Dr. Dima Kabbani, University of Alberta; and Dr. Kednapa Thavorn, University of Ottawa. The questions were presented and discussed at the TREAT-COVID Steering Committee (see Appendix 3 for the list of Steering Committee Members).

The Forum was held during CDTRP's 2024 Annual Scientific Meeting in Calgary, Alberta. Participants included transplant recipients, families, caregivers, donor partners, researchers, clinicians, trainees, and representatives from transplant-focused organizations. This diverse group ensured broad input from Canada's donation and transplant community, bringing together a wide range of perspectives from those directly affected.

SUMMARY OF DISCUSSION
BREAKOUT SESSION #1

THEME: COVID-19 ANXIETY IS PERSISTENT IN TRANSPLANT RECIPIENTS AND THEIR CAREGIVERS, YET COVID-19 FATIGUE DRIVES RECIPIENTS AND THEIR CAREGIVERS TO DECLINE COVID-19 RESEARCH.

PFD QUESTIONS	CLINICIAN/ RESEARCHER QUESTIONS	FRANCOPHONE GROUP QUESTIONS (PFDS & RESEARCHERS)
WHAT CONVERSATIONS ARE YOU HAVING WITH YOUR FAMILY OR HEALTHCARE TEAM ABOUT COVID-19 OR OTHER VIRUSES LIKE THE FLU?	**WHAT CONVERSATIONS ARE HAPPENING BETWEEN YOU AS A CLINICIAN AND TRANSPLANT RECIPIENTS, FAMILY MEMBERS, AND CAREGIVERS ABOUT COVID-19 OR OTHER VIRUSES LIKE THE FLU?**	**WHAT CONVERSATIONS ARE YOU HAVING WITH YOUR FAMILY OR HEALTHCARE TEAM ABOUT COVID-19 OR OTHER VIRUSES LIKE THE FLU?**
Total responses (20) • Level of family or community support (5) • Value of engaging in COVID/virus related conversations within social circles (5) • Risk management (4) • Decreased conversations (3) • Communicating the risk of COVID-19 (1) • Negative attitudes toward vaccination (1) • Reduced access to testing/treatment (1)	**Total responses (11)** • Negative attitudes toward vaccination (3) • Reduced access to testing/treatment (2) • Reduced concerns about COVID (2) • Shifting patient priorities (2) • Risk management (1) • Value of engaging in COVID/virus related conversations within social circles (1)	**Total responses (3)** • Risk management (3)

SUMMARY OF DISCUSSION

BREAKOUT SESSION #1

Several themes emerged in response to the question “What conversations are you having with your family or health care team about COVID-19, or other viruses like the flu?” These themes reflect the evolving nature of public, personal, and social conversations around COVID-19 and other respiratory viruses, and highlight an evolving understanding of ongoing risks, communication patterns, and social dynamics.

While conversations about COVID-19 and other viruses may be less frequent in clinical settings, they remain meaningful in social and familial contexts, especially where PFD acknowledge that health risks remain high. One PFD noted, “There are not too many conversations we are having about COVID anymore with family – also much less with our health care teams.” Another added that they “don’t talk about vaccines to her providers.”

PFD partners continue to navigate a landscape marked by varying levels of support, access, and understanding. While conversations with healthcare providers may not be as frequent, discussions among friends and community members continue to play a crucial role.

PFDs see a value in engaging in COVID-19 and virus-related conversations within their social circle. As one PFD shared, it is “helpful to have conversations with friends, everybody in the community (not all connected to transplantation).” Another saw value in “Normalizing conversations within social networks” as a method to normalize the worry and spark conversation. These interactions are seen as important spaces for mutual support, awareness, and maintaining safe behaviors. For example, one PFD stated that “The world has moved on – [I'm] careful with friends and family if they are unwell and reminding them that we need to stay vigilant.”

SUMMARY OF DISCUSSION

BREAKOUT SESSION #1

Similarly, the level of family or community support can be a driver or barrier to conversations about respiratory diseases. Some PFDs described strong alignment and shared commitment to safety. One PFD stated, “our family is on the same page” adding that “[I] got flu/COVID-19 vaccines and do not get around my daughter when [I am] sick.” Another PFD noted that “most of my family support, use mask, take vaccines, but some don’t.” One participant, however, shared the emotional difficulty of managing health precautions alone, noting that she “lives by herself. Family is in other places in Canada. She protects herself… Her sister understands, but some friends and her brother don’t.”

PFDs also express feedback on how attitudes towards vaccination impact conversations. One PFD described distancing from a close friend stating that “one of her best friends did not take all the vaccines; now, they do not see each other as much.” These stories highlight how varying levels of support can lead to feelings solidarity, community, or strained relationships.

Several comments were made that emphasized that while COVID-19 may no longer be top of mind, PFDs remain proactive in protecting themselves and others. One PFD noted a need to take “a holistic approach to protect family,” while another explained that they “continue to take precautions – though we can’t always tell everyone because they may not be sympathetic.” Another PFD stated “most conversations we’re having are about ongoing risk management related to COVID or other respiratory diseases.”

These comments reflect an effort by PFDs to navigate risk while balancing social dynamics and personal safety. While conversations with healthcare providers may be happening less often, social engagement, especially those within the close network, remains a key tool for promoting safety and resilience.

SUMMARY OF DISCUSSION

BREAKOUT SESSION #1

Clinician-researchers described a shift in the frequency of these discussions. Their reflections at the workshop outline evolving patient attitudes, changes in access to testing and treatment, and the ongoing challenge of addressing risk in immunocompromised populations.

Participants reported that patients and healthcare providers are speaking less frequently and less urgently about COVID-19. One researcher noted, there is “less anxiety/concern for some patients as concerns have been normalized.” Another noted that the level of concern “depends on the severity of presenting concerns,” as other conditions may be prioritized during clinic visits.

Whereas PFDs participating in the workshop emphasized the need for risk management and the role of social engagement in having conversations about COVID-19, the clinician-researcher group noted a lessening of COVID-19 as a priority among patients. One researcher commented that there is “less of a concern with clinicians on COVID,” while another said, “Overall, less concern - they don’t care.”

Clinician-researchers also mentioned growing negative attitudes toward vaccines, impacting conversations about COVID-19 and respiratory diseases. One participant said that “most transplant recipients stopped vaccines after 2 or 3 doses,” and “most transplant recipients have no interest in boosters.”

Despite these perceived challenges, some clinicians continue to stress the importance of precautionary measures. One shared that they “emphasize they are immunocompromised and continue to be at risk.” Another remarked that they remain “concerned about making sure they get vaccinations and protect themselves” reinforcing risk management remains an active priority in caring for transplant recipients.

SUMMARY OF DISCUSSION
BREAKOUT SESSION #1

THEME: COVID-19 ANXIETY IS PERSISTENT IN TRANSPLANT RECIPIENTS AND THEIR CAREGIVERS, YET COVID-19 FATIGUE DRIVES RECIPIENTS AND THEIR CAREGIVERS TO DECLINE COVID-19 RESEARCH.

PFD QUESTIONS

WHAT BARRIERS ARE THERE TO TALKING ABOUT RESEARCH AND COVID-19 TO YOUR FAMILY MEMBER/CAREGIVER AND HEALTH CARE TEAM?

Total responses (10)

- Level of support (3)
    - Level of community support (1)
    - Level of family or community support (1)
    - Level of family support (1)
- Reduced concerns about COVID (3)
- Family perception of risk (2)
- Lack of communication and of up-to-date COVID information (1)
- Mental health (1)

CLINICIAN/ RESEARCHER QUESTIONS

WHAT BARRIERS ARE THERE TO TALKING ABOUT RESEARCH AND COVID-19 TO PATIENTS AND FAMILIES/CAREGIVERS?

Total responses (11)

- Lack of communication and of up-to-date COVID information (5)
- Reduced concerns about COVID (2)
- Resources (2)
- Value of engaging in COVID/virus related conversations within social circles (1)
- Reduced access to testing/treatment (1)

FRANCOPHONE GROUP QUESTIONS
(PFDS & RESEARCHERS)

WHAT BARRIERS ARE THERE TO TALKING ABOUT RESEARCH AND COVID-19 TO YOUR FAMILY MEMBER/CAREGIVER AND HEALTH CARE TEAM?

Total responses (3)

- Reduced concerns about COVID (2)
- Negative attitudes towards vaccination (1)

SUMMARY OF DISCUSSION

BREAKOUT SESSION #1

PFD partners identified a range of reasons that impact their ability to discuss research with their family and health teams.

A theme that emerged was the perception that there are reduced concerns about COVID-19. One PFD partner noted, “They are not interested, the COVID problem is resolved, the conversation has moved on from COVID to other respiratory diseases.” Another emphasized, “The world has moved on,” pointing to how COVID-19 infection counts have been removed as an individual metric and are now grouped together with other respiratory diseases.

At the same time, PFDs noted a need for “educating the general public – COVID can happen to anyone, vaccines are just protective there are no guarantees” and “information has changed so much since the beginning of COVID-19.” One PFD reflect that “she doesn’t know what is out there. No advertisement, no communication. The information is old. None of it is from the transplant clinic. Doctors from the transplant clinic don’t provide us with updates.” These statements suggest that reduced concerns may be a result of the lack of communication or up-to-date information.

The level of support a transplant recipient has also impacts their have conversations. While some caregivers continue to support health-protective behaviors, such as vaccination and masking, this support is not universal. One participant reflected, “caregivers are OK when it comes to supporting the getting of vaccines – but no more.” Another PFD said, “caregivers are just supporting patients in managing risks, continuing to advocate for staying safe, and being our own champions.” For some families, COVID-19 may be associated with trauma, making research engagement difficult. One PFD stated, “family doesn’t want to be reminded - they might be re-traumatized by filling in surveys or providing feedback.”

SUMMARY OF DISCUSSION
BREAKOUT SESSION #1

For clinician-researchers, several barriers impact having conversations about COVID-19 and research with transplant patients, their families, and caregivers. A significant barrier identified is the lack of communication and of up-to-date COVID information. One researcher pointed out, “family physicians expressed lack of information for COVID vaccine risks for donors,” while another added, “continual change of position with nurse staff” and a continual need to “inform staff in clinic about the study so they might mention it to patients but then staff change – maybe not everyone is aware of the study despite taking meetings.” One participant noted that communications “may not reflect the potential risk to transplant recipients.”

Similar to question one, clinician researchers expressed a perception that patients have reduced concerns about COVID-19. One noted, “COVID is not the biggest concern in their lives - there are much larger issues, so it's not as important or likely to participate.” At the same time, another mentioned a stop to conversations.

Time and resources are another barrier to participating in research. Researchers reported that they often struggle to make space for research conversations amid competing clinical priorities, stating that “having enough time to have conversations about research when there are other things to discuss” is an ongoing challenge. Moreover, patients may be discouraged from participating due to the “time commitment required to do studies.”

SUMMARY OF DISCUSSION
BREAKOUT SESSION #1

WHAT BARRIERS ARE THERE TO TALKING ABOUT RESEARCH AND COVID-19 TO YOUR FAMILY MEMBER/CAREGIVER AND HEALTH CARE TEAM?

PFD QUESTIONS	CLINICIAN/ RESEARCHER QUESTIONS	FRANCOPHONE GROUP QUESTIONS (PFDS & RESEARCHERS)
Total responses (11) • Availability of clear and accessible research and data (4) • Communicating the relevance of research for PFD outcomes (4) • Communicating risk of COVID (3)	**Total responses (3)** • Communicating the relevance of research for PFD outcomes (2) • Remuneration for research participants (1)	**Total responses (1)** • Communicating the risk of COVID (1)

PFD partners expressed a desire to improve how conversations about COVID-19 and related research are approached. Their statements highlight several methods that could facilitate conversation, including the availability of clear and accessible research and data, communicating the relevance and connection between research and patient outcomes, and providing continued information regarding the risk of COVID-19.

Several participants emphasized that caregivers and families need to be shown why research matters, especially when caregivers' perspectives tend to be underrepresented.

SUMMARY OF DISCUSSION
BREAKOUT SESSION #1

As one PFD responded, “reminding caregivers that even though their voices have been overlooked, this is an opportunity to be heard and to contribute.” Another echoed this statement, saying there is a need to “being much clearer on how participation in this kind of research will benefit patients as well as caregivers in the future.” Participating in research is a way to understand the impacts on caregivers better – one participant noted that it is “important to see impacts on caregivers, especially mental health.” Outside of TREAT-COVID, one participant noted a need to make CDTRP more accessible, stating, “how many transplant people in Calgary know of CDTRP? Make it more widely available, not only for CDTRP.”

PFDs also pointed to the need for accessible, trustworthy information, noting the importance of clear and accessible data. One PFD said, “I like to know about data. If healthcare providers can provide me with data,” she will learn more. Another echoed the same, noting that they are “comfortable receiving updated information” and published information. That said, there is a requirement to receiving data and information. A PFD made clear that “some people don’t want to the states. Have information that people want to know is relevant.” Another PFD explained the importance of knowledge translation in plain language, sharing a need to “build in updates about project studies with lay format to facilitate information to all participants and audiences.”

SUMMARY OF DISCUSSION
BREAKOUT SESSION #1

Another theme was the ongoing need to communicate the real risks of COVID-19, especially for immunocompromised individuals and their families. For many, the prevailing narrative that the pandemic is "over" creates frustration and disengagement. One PFD partner said, "stop saying it's over and remind people to still be careful for others." Others suggested need to "educating others that it's not just personal responsibility - you also need the community around you." Storytelling was identified as a tool to make risks more tangible relevant with one PFD suggesting a need to "share stories of impact/risk (e.g., individuals who passed due to COVID)."

Clinician-researchers acknowledge a need to communicate the relevance of research for PFD outcomes, stating that there is a need for "collecting information not just for COVID but for the purpose of information to help make decisions in the future." Another participant noted that research is "relevant for future health crisis not just COVID." For TREAT-COVID, these responses indicate a need to further develop targeted outreach and messaging for caregivers indicating that their perspectives are valuable and can contribute meaningfully to research. The group noted that offering compensation for time and expenses could make participation more feasible for families and caregivers.

SUMMARY OF DISCUSSION
BREAKOUT SESSION #2

HEALTH ECONOMICS OF COVID-19 PREVENTION OR TREATMENT OPTIONS FOR TRANSPLANT RECIPIENTS

WHAT ARE THE IMPORTANT COSTS OR SACRIFICES THAT COME TO MIND WHEN YOU THINK ABOUT COVID-19 PREVENTION OR TREATMENT OPTIONS?

PFD RESPONSES

Total responses (21)

- Availability of clear and accessible research and data (3)
- Availability of prevention or treatment options (1)
- Family support (1)
- Financial and time burden on recipients & families for managing risk (2)
- Financial burden on recipients & families for managing risk (2)
- Health risks and side effects (4)
- Mental burden due to uncertainty (1)
- Mental burden related from social interactions (2)
- Quality of life – mental health (1)
- Risk management (1)
- Shifts in social engagement and wellness (1)
- Strain on trust and communication between patient/family and health professionals (2)

CLINICIAN/ RESEARCHER RESPONSES

Total Responses (15)

- Communicating risk management strategies to recipients and their families (1)
- Communicating the importance of vaccines among recipients and their families (1)
- Expenses incurred by the health system (4)
- Financial burden on recipients & families for managing risk (3)
- Health risks and side-effects (1)
- Quality of life – mental health (3)
- Shifting patient/family priorities (1)
- Shifting public health priorities (1)

SUMMARY OF DISCUSSION
BREAKOUT SESSION #2

For transplant recipients and their families, the costs and sacrifices related to COVID-19 prevention and treatment are complex, spanning financial, safety, social, and mental health concerns.

Considerations related to health risks and safety remain a priority. PFDs stated that there are concerns about “side effects from the various treatments - especially on transplanted organs and long-COVID” and worries about “vaccine adverse reactions, unintended consequences, and unknown interaction with existing medication,” given the “lack of data specific to the transplant population.” One PFD noted that they rely on “personal research on side effects” and acknowledge that “risks are real.”

PFDs pointed to logistical and financial costs associated with managing COVID risk. These burdens often extend to caregivers as well and is a significant factor for recipients living outside of urban areas. For example, one PFD commented, “driving to get to treatment - this can be long distances for those further away from treatment centres,” was a common concern, especially since “they recently eliminated the mobile treatment units in Alberta.”

Another PFD highlighted that treatment may involve “a 3-day hospital visit, this may include hospital costs, time off work, gas/transportation costs, plus similar costs for caregivers.” Even prevention and risk management strategies have a financial implication with PFDs, commenting that there are financial costs with masking, employment considerations for patients and caregivers, and that COVID-19 related treatments “may not be covered and are very expensive.

SUMMARY OF DISCUSSION

BREAKOUT SESSION #2

Beyond physical and financial costs, PFDs discussed the mental health implications related to COVID management. One PFD noted, "family had COVID at the same time. It was mentally exhausting to go to the healthcare system to treat her daughter. Who would take care of her while they were sick. Mental support is needed." Another PFD said, "Do we socialize? At work, with friends and family," expressing the constant weighing of risks. Others described the "cost of arguing with naysayers (e.g., COVID deniers)."

PFD partners expressed frustration with the "confusion due to lack of quality research results or proofs of efficacy." One PFD described having to become researchers themselves in the absence of timely or transplant-specific updates and the need of "doing research, being as informed as possible" and listing sources like "CST, medical journals, inserts for vaccines." Some felt the U.S. was ahead with data, noting "USA more up to date with reporting adverse events." This highlights both the desire for and the importance of transparent, localized, and up-to-date information channels for transplant recipients and families.

The discussion highlighted strain on trust and communication between patients, families, and their healthcare providers. For instance, one PFD stated that "there may be relationship impact costs - where if a patient is interested in a particular treatment, but the care team may not agree." Another shared that "miscommunication or misinformation on availability of treatments" even when patients are "prioritized in the news" causes frustration.

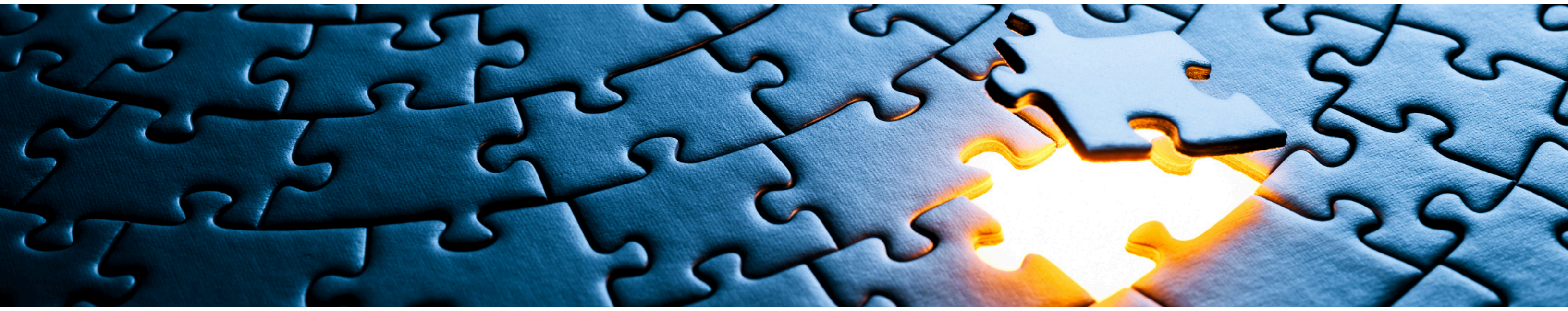
The clinician-researcher group reflected on the expenses incurred by the health system. Their statements highlighted both the initial costs of establishing mass vaccination programs and the ongoing expenses of operating intensive care units. They also considered the costs related to vaccines, clinic operations, and nursing staff for training, as well as the costs associated with intravenous treatments and the outpatient centers required to administer them.

SUMMARY OF DISCUSSION

BREAKOUT SESSION #2

The group also acknowledged the financial implications on transplant patients, families, and caregivers that impact prevention and treatment options. One researcher highlighted that patients pay for "travel, parking, out-of-pocket, cost of drugs, and time off work and not getting paid. Another expressed that basic COVID-19 testing has financial implications, noting that "COVID testing—home kits not really available, costs to go to clinics." In some cases, financial risk even influences behavior. A researcher commented that "keeping a job is more important, so they don't want to know if they are positive in case there are additional consequences like missing work."

Several comments noted the importance of quality of life on a transplant recipient's mental health as an important consideration. The statements acknowledged that there may be an "emotional burden of additional interventions and side effects which may cause additional physical symptoms. Anxiety can be associated with new treatment and hospitalization costs." This was echoed by another participant who noted that there is "anxiety around new testing." On the other hand, prevention and treatment options can have a positive effect for recipients because "mentally vaccines help you feel more protected."



SUMMARY OF DISCUSSION

BREAKOUT SESSION #2

HEALTH ECONOMICS OF COVID-19 PREVENTION OR TREATMENT OPTIONS FOR TRANSPLANT RECIPIENTS

PFD QUESTIONS

WHAT BENEFITS OR RESULTS MATTER MOST TO YOU WHEN DECIDING IF COVID-19 PREVENTION OR TREATMENT OPTION IS RIGHT FOR YOU?

Total responses (30)

- Access to reliable information to make informed choices (11)
- Communicating risk management strategies to support recipients and their families (1)
- Cultural/social factors influencing personal health decisions (2)
- Desire for prevention options (1)
- Ongoing research on the side effects of COVID-19 on transplant patients (1)
- Quality of life
    - Mental health (7)
    - Physical health (3)
- Risk management (3)
- Treatment that integrates clinical, mental, and physical considerations (1)

CLINICIAN/RESEARCHER QUESTIONS

WHAT BENEFITS, OUTCOMES, OR RESULTS MATTER MOST TO YOU WHEN CONSIDERING COVID-19 PREVENTION OR TREATMENT OPTIONS FOR TRANSPLANT PATIENTS?

Total responses (8)

- Quality of Life
    - Mental health (1)
    - Physical health (4)
    - Mental and physical health (3)

SUMMARY OF DISCUSSION

BREAKOUT SESSION #2

For many PFDs, several factors impact their decision to engage in COVID-19 prevention or treatment. The leading factors include access to reliable information to make informed choices and the impact on their quality of life.

Reliable, transparent communication from care teams was identified as a key enabler of choice. PFDs consistently emphasized the need for trustworthy, accessible data and research results. For example, one PFD stated that the “ability to make our own decisions – based on valid data provided by the care team” was required, with another echoing the statement, saying “adequate information to make an informed decision.” Within the theme of accessible access to reliable information, PFDs gave importance to “efficacy,” “safety – be careful of what you take,” and “cautious about side effects” when describing the benefits and results that matter most.

Further, PFDs expressed a desire to maintain or improve their quality of life. Their statements related to quality of life captured the importance of physical and mental health. As one participant noted, their priority is the “stability of our own health” and treatments that “prevent further complications.” Mental well-being is also a strong consideration as PFDs reflected on their experiences managing risk and navigating uncertainty. One PFD stated that the “ability to maintain dignity in our own house” is important, with another PFD noting that a benefit or result that matters is “what gets me to my acceptable version of normal” and “general peace of mind.” Another explained it this way, “knowing we are receiving the treatment benefits mental health. My daughter is 19, and she still needs support. There is always a balance.”

Some PFDs framed their decision-making around risk management. One participant shared that “prevention, and wearing masks, is needed. I live alone. Many costs are involved, and finding someone to support you is hard. I feel more safe preventing” with another PFD adding that the “more we can prevent the less we need treatment – prevention over treatment.”

SUMMARY OF DISCUSSION

BREAKOUT SESSION #2

Given these insights from PFDs, it is important for healthcare providers to understand that treatment and prevention go beyond clinical effectiveness. Patients, families, and caregivers place significant value on how different options affect their overall well-being and quality of life including both physical and mental health.

For clinician-researchers, the most important outcomes for transplant patients center on preserving quality of life. They recognize the connection between overall quality of life, fatigue, physical function, and emotional stress, acknowledging that mental and physical well-being are closely linked. At the same time, they emphasize the need to prevent serious complications, including "graft dysfunction," "rejection," and "post-COVID complications" that could lead to long-term health issues. Clinicians also highlight the association between quality of life and transplant health, understanding that reducing "emotional distress" can contribute to better overall outcomes for transplant recipients.

WOULD THE COSTS AND BENEFITS YOU MENTIONED BE SIMILAR FOR OTHER TYPES OF POST-TRANSPLANT CARE, BEYOND COVID-19 PREVENTION OR TREATMENT?

PFD RESPONSES	CLINICIAN/ RESEARCHER RESPONSES
Total response (5)	**Total response (2)**
• Added burden of infectious diseases on post-transplant care (2)	• Similarity among infectious diseases (1)
• Consistent burden of receiving care (3)	• Added burden of infectious diseases on post-transplant care (1)

SUMMARY OF DISCUSSION
BREAKOUT SESSION #2

When asked whether the costs and benefits of COVID-19 prevention or treatment reflect broader post-transplant care experiences, managing a transplant is already a complex and challenging journey. Transplant recipients and families highlight that the burden of infectious diseases, like COVID-19, adds another layer of complexity to an already challenging post-transplant journey. “COVID, or a similar type of infectious disease, is on top of all the things we already go through.” The PFD added that “there are costs related to our regular post-transplant journey that are already a burden – then on top of it we get another challenge that makes everything much more complex.”

Accessing care becomes even more difficult with one PFD noting that “the additional complexity makes it even more difficult to seek help through the normal local channels (GPs). They are already uncomfortable dealing with transplant patients, and throwing on something else like COVID makes it even harder to get local care.” One family described the frustration of seeking antibiotics for a common infection, only to find that the pharmacy couldn’t provide the necessary medication due to transplant-specific concerns, forcing them to “run to the family doctor to be able to get the medication.” This highlights the added and consistent burden that transplant recipients also experience in accessing care for minor and chronic conditions.

The clinician-researcher group noted that “for current post-transplant care, there is more robust clinical trial information available for the transplant population” compared to COVID-19, adding another layer of complexity and burden to post-transplant care.

SUMMARY OF DISCUSSION

CONCLUSION AND ACTION ITEMS

The discussions with PFDs and clinician-researchers highlight the complex challenges of navigating infectious and respiratory viruses, including COVID-19. These challenges extend beyond medical concerns to include considerations related to quality of life, financial costs, barriers to social wellness, mental health impacts, and gaps in available research.

A key action item emerging from these discussions is the need for improved knowledge translation strategies to ensure that transplant recipients and their families receive clear, evidence-based, and transplant-specific information on prevention and treatment options. Addressing safety concerns such as the long-term treatment impacts, side effects, and the effects on the transplant requires ongoing research and better dissemination of findings.

These knowledge translation strategies and communication strategies need to be rooted in patient-centred language.

For the CDTRP and the TREAT-COVID research team, the discussions around infection prevention needs and strategies, combined with the perceived lack of concern among both non-transplant recipients and, in some cases, transplant recipients by clinician-researchers underscore the urgent need for practical, targeted KT strategies that engage patients, families, caregivers, and clinicians.

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. Maxime Tremblay-Gravel
Université Laval	Dr. Sacha de Serres
Montreal Children's Hospital	Dr. Bethany Foster
University of Manitoba	Dr. Caroline Piotrowski

APPENDIX 2
NATIONAL PRIORITIZATION WORKSHOP AGENDA

Time	Speaker	Presentation
10:45am-10:50am (5mins)	Geetha Sanmugalingham	TREAT-COVID overview and first 2 Presenter Intros
10:50 am – 11:00 am (10mins)	Dr. Dima Kabbani	Demographics of participant population
11:00 am – 11:10 am (10mins)	Jad Fadlallah	Presentation 2: Emotional distress & physical function post-COVID-19pandemic onset in Solid Organ Transplant Recipients
11:10 - 11:15 am (5 mins)	Geetha Sanmugalingham	Instructions for breakout session #1
11:15 am – 11:35 am (20mins)	Breakout 1	Caregiver Recruitment strategy
11:35am –11:37am (2mins)	Geetha Sanmugalingham	Transition intro of Dr. Kednapa Thavorn
11:37 am – 11:47 am (10 mins)	Dr. Kednapa Thavorn	Presentation 3: Health Economics of COVID-19 Prevention and Treatment Options for Transplant Recipients
11:47 - 11:50 am (3 mins)	Geetha Sanmugalingham	Instructions for breakout session #2
11:50 am – 12:10 pm (20mins)	Breakout 2	Discussion on costs and benefits of COVID-19 prevention and treatment options
12:13 pm – 12:15 pm (2mins)	Geetha Sanmugalingham	Wrap up

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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REFERENCES

1. Canadian Society of Transplantation. *National Transplant Consensus Guidance on COVID-19 Vaccine.*; 2022.

2. Nierengarten MB. Poor overall survival in bone marrow transplant patients with COVID-19. *Cancer*. 2021;127(21):3919. doi:10.1002/cncr.33953

3. Parker EPK, Desai S, Marti M, et al. Response to additional COVID-19 vaccine doses in people who are immunocompromised: a rapid review. *Lancet Glob Health*. 2022;10(3):e326-e328. doi:10.1016/S2214-109X(21)00593-3

4. Miarons M, Larrosa-García M, García-García S, et al. COVID-19 in Solid Organ Transplantation: A Matched Retrospective Cohort Study and Evaluation of Immunosuppression Management. *Transplantation*. 2021;105(1):138-150. doi:10.1097/TP.0000000000003460

5. Karruli A, Spiezia S, Boccia F, et al. Effect of immunosuppression maintenance in solid organ transplant recipients with COVID-19: Systematic review and meta-analysis. *Transpl Infect Dis Off J Transplant Soc*. 2021;23(4):e13595. doi:10.1111/tid.13595

6. Qin CX, Moore LW, Anjan S, et al. Risk of Breakthrough SARS-CoV-2 Infections in Adult Transplant Recipients. *Transplantation*. 2021;105(11):e265-e266. doi:10.1097/TP.0000000000003907

7. Mazuecos A, Villanego F, Zarraga S, et al. Breakthrough Infections Following mRNA SARS-CoV-2 Vaccination in Kidney Transplant Recipients. *Transplantation*. 2022;106(7):1430-1439. doi:10.1097/TP.0000000000004119

8. Piñana JL, López-Corral L, Martino R, et al. SARS-CoV-2 vaccine response and rate of breakthrough infection in patients with hematological disorders. *J Hematol OncolJ Hematol Oncol*. 2022;15(1):54. doi:10.1186/s13045-022-01275-7

REFERENCES

9. Foroutan F, Rayner DG, Oss S, et al. Clinical Practice Recommendations on the Effect of COVID-19 Vaccination Strategies on Outcomes in Solid Organ Transplant Recipients. *Clin Transplant*. 2025;39(2):e70100. doi:10.1111/ctr.70100

10. De Pasquale C, Pistorio ML, Veroux M, et al. Mental health, COVID-19 burden and quality of life of kidney transplant recipients two years after the COVID-19 pandemic. *Front Psychiatry*. 2024;15. doi:10.3389/fpsyt.2024.1338934

11. Tanaka S, Fujita K, Yakushiji K, Bekki Y, Toshima T, Okabe Y. Depression and Quality of Life in Transplant Recipients During the COVID-19 Pandemic. *Transplant Proc*. 2024;56(8):1885-1889. doi:10.1016/j.transproceed.2024.08.034

12. Ufere NN, Serper M, Kaplan A, et al. Financial burden following adult liver transplantation is common and associated with adverse recipient outcomes. *Liver Transpl*. 2024;30(9):918. doi:10.1097/LVT.0000000000000348

13. Spinner CD, Bell S, Einsele H, et al. Is COVID-19 Still a Threat? An Expert Opinion Review on the Continued Healthcare Burden in Immunocompromised Individuals. *Adv Ther*. 2025;42(2):666-719. doi:10.1007/s12325-024-03043-0

14. Bhatia S, Dai C, Hageman L, et al. Financial Burden in Blood or Marrow Transplantation Survivors During the COVID-19 Pandemic: A BMTSS Report. *J Clin Oncol*. 2023;41(5):1011-1022. doi:10.1200/JCO.22.00461

15. De Pasquale C, Pistorio ML, Veroux P, et al. Quality of Life and Mental Health in Kidney Transplant Recipients During the COVID-19 Pandemic. *Front Psychiatry*. 2021;12. doi:10.3389/fpsyt.2021.645549

16. Cai Z, Cai X, Song Y, et al. Psychological Distress and Its Association With Quality of Life in Organ Transplant Recipients During COVID-19 Pandemic. *Front Psychiatry*. 2021;12. doi:10.3389/fpsyt.2021.690295

REFERENCES

17. Thangaraju S, Wang Y, Kee T, et al. Psychological distress and associated factors among kidney transplant recipients and living kidney donors during COVID-19. *BMC Nephrol*. 2022;23(1):80. doi:10.1186/s12882-022-02698-7

18. Bano M, Anton CM, Butts R, Triplett K. Worsening Mental Health in Adolescent Heart Failure and Transplant Patients During the COVID-19 Pandemic. *J Heart Lung Transplant*. 2022;41(4):S503-S504. doi:10.1016/j.healun.2022.01.1277

19. McKay SC, Lembach H, Hann A, et al. Health-related quality of life, uncertainty and coping strategies in solid organ transplant recipients during shielding for the COVID-19 pandemic. *Transpl Int*. 2021;34(11):2122-2137. doi:10.1111/tri.14010

20. Forner-Puntonet M, Castell-Panisello E, Quintero J, et al. Impact of COVID-19 on Families of Pediatric Solid Organ Transplant Recipients. *J Pediatr Psychol*. 2021;46(8):927-938. doi:10.1093/jpepsy/jsab058

21. Rayner DG, Nunes JT, Gou D, et al. Efficacy and safety of COVID-19 vaccination in solid organ transplant recipients: A systematic review and network meta-analysis. *Am J Transplant*. 2024;24(12):2269-2281. doi:10.1016/j.ajt.2024.07.031

22. Pullen RL. Managing patients who are immunocompromised during the COVID-19 pandemic. *Nursing (Lond)*. 2022;52(12):27-32. doi:10.1097/01.NURSE.0000892648.90577.03

23. Canada PHA of. COVID-19 vaccines: Canadian Immunization Guide. December 23, 2021. Accessed March 3, 2025. https://www.canada.ca/en/public-health/services/publications/healthy-living/canadian-immunization-guide-part-4-active-vaccines/page-26-covid-19-vaccine.html

24. Solera JT, Árbol BG, Mittal A, et al. Longitudinal outcomes of COVID-19 in solid organ transplant recipients from 2020 to 2023. *Am J Transplant*. 2024;24(7):1303-1316. doi:10.1016/j.ajt.2024.03.011