



The Canadian **DONATION** and
TRANSPLANTATION Research Program

Programme de recherche en **DON**
et **TRANSPLANTATION** du Canada

COVID-19 VACCINATION IN TRANSPLANT PATIENTS

COMMUNICATION OF RESEARCH WITH PATIENTS AND FAMILIES WORKSHOP REPORT

APRIL 23, 2021

PREAMBLE

Communication of Research with Patients and Families Workshop Report | April 23rd, 2021

The Canadian Donation and Transplantation Research Program (CDTRP) is coordinating a national research strategy to better understand COVID-19 vaccination issues in transplant recipients, including how effective they are and questions around transplant-specific safety.

The process began with an expert panel to identify key knowledge gaps. Held on January 6, 2021, the panel included experts in solid organ and stem cell transplantation, transplant infectious diseases, immunization, public health, and patient and family partners.

On January 29, 2021, CDTRP hosted a Stakeholder Workshop with expert and community stakeholders, with the goal of seeking the input of the Canadian stakeholder community about priority topics for study and how to move the priority research ideas forward to implementation in an aligned and coordinated way.

In addition to directly connecting with public health authorities and policymakers regarding research on vaccination in transplant recipients, CDTRP remains committed to ongoing dialogue with patients, families, and donors throughout the research process. On April 23, 2021, CDTRP hosted a second National Workshop, focused on **communication of research with patients and families**. Kristi Coldwell (heart recipient) and Nem Maksimovic (Canadian Liver Foundation) co-chaired the workshop, which included 18 patient, family, and donor partners and representatives from partner organizations with education or communications roles. These participants represented a diverse group from across Canada and included different transplant recipients, age groups, cultural backgrounds, and gender representation, as well as caregivers of pediatric recipients.



LIST OF PARTICIPANTS AND THEIR AFFILIATION

Name	Affiliation
Katie Bain	Canadian Donation and Transplantation Research Program (CDTRP)
Mary Beaucage	Patient, Family, Donor Research Partner
Brenda Brown	Canadian Transplant Association (CTA)
Kristi Coldwell	PFD & Workshop Co-Chair
Mélanie Dieudé	Canadian Donation and Transplantation Research Program (CDTRP)
Manuel Escoto	Canadian Donation and Transplantation Research Program (CDTRP)
Ross FitzGerald	Canadian Blood Services (CBS)
Patricia Gongal	Canadian Donation and Transplantation Research Program (CDTRP)
Kuljit Grewal	Patient, Family, Donor Research Partner
Sandra Holdsworth	Patient, Family, Donor Research Partner
Stéphanie Larivière	Canadian Donation and Transplantation Research Program (CDTRP)
Lydia Lauder	The Kidney Foundation of Canada
Rahul Mainra	Canadian Society of Transplantation (CST)
Nem Maksimovik	Canadian Liver Foundation & Workshop Co-Chair
Marla Marshall	Patient, Family, Donor Research Partner
Joanna Mitchell	Patient, Family, Donor Research Partner
Chelsea Patriquin	Canadian Donation and Transplantation Research Program (CDTRP)
Kim Soutar	Patient, Family, Donor Research Partner
Lindsay Thompson	Cell Therapy Transplant Canada (CTTC) Patient, Family and Caregiver Advisory Group
Larry Worfolk	Patient, Family, Donor Research Partner
Paul Yeounha	Patient, Family, Donor Research Partner
Elaine Yong	Patient, Family, Donor Research Partner



WORKSHOP OBJECTIVES

The workshop's central objective was to develop consensus answers to two fundamental questions on COVID-19 vaccination in transplant participants:

A. As a transplant recipient or family member, what information do you need around COVID-19?

B. When, how, and where should that information be delivered?

After an overview of the agenda and key objectives, the co-chairs invited participants to vote on their preferred topics within each question for discussion.

For **Question A**, participants could choose their top two topics from (1) safety; (2) effectiveness; (3) getting back to normal; (4) accessibility, policies, and eligibility; or (5) other topics not already covered. **Safety** and **effectiveness** were the top two topics identified by participants.

For **Question B**, participants could choose their top two topics from (1) consistency of messaging; (2) barriers to effective communication; (3) preferred sources of information or; (4) other topics not already covered. **Consistency of messaging** and **barriers to effective communication** were the top two topics identified by participants.

After a series of parallel breakout discussions, participants were brought back to the main group to discuss closing thoughts, concerns, and the next steps.

SAFETY **CONSISTENCY OF MESSAGING**
EFFECTIVENESS
BARRIERS TO EFFECTIVE COMMUNICATION



DISCUSSION SUMMARY

QUESTION A:

AS A TRANSPLANT PATIENT OR FAMILY MEMBER, WHAT INFORMATION DO YOU NEED AROUND COVID-19?

EFFECTIVENESS

Whether the vaccines work on immunocompromised individuals remains a top concern and question for transplant recipients. Some patients have heard that recipients who have received both doses are not showing the antibodies and efficacy indicated in clinical trials. Despite the knowledge gap, health teams are still urging patients to receive the vaccines.

Participants expressed an information gap regarding the interaction between anti-rejection medication and vaccine success. Specifically, questions remain whether one vaccine is better than another for transplant recipients and if success is impacted by the specific medications patients must take. In some cases, patients have been advised to reduce their immunosuppressive drugs to have more success with the vaccine. Many expressed concern to adhere to this, but inevitably all agreed that the transplant team, or main healthcare provider, were the trustworthy source of information and advice.

The pediatric caregiver perspective voiced how other regular-schedule vaccines (non-COVID) have not been as effective in children post-transplant. Concerns remain about how all recipients, including pediatric patients, can get tested or receive information regarding antibodies. For example, when a post-transplant pediatric recipient receives their Hepatitis B vaccine, the transplant clinic will test for antibodies. Until now, there is no confirmation that post-vaccine testing will occur or if a standard for effectiveness will be established based on antibodies.

As research moves forward, patients want to know how effectiveness will be measured. Participants expressed the need to establish methods to understand clear metrics, especially since discussions continue regarding a potential need for a third vaccine. For example, will metrics be different depending on the type of organ or stem cell recipient?

Given the diverse population and unique variables within each patient and organ population, it is essential to take a patient-centred approach post-vaccination to determine the effectiveness.

SAFETY

A shift has occurred in the perception of vaccination safety among transplant recipients. Whereas the primary concern used to be whether vaccination was safe for patients this is no longer the case, given the large number of recipients who have received a vaccine. Participants acknowledged that they had not heard information about recipients going into rejection post-vaccination, though they have heard of patients who received two doses and experienced adverse health outcomes.

Current safety concerns are rather tied with issues related to the efficacy of vaccines. For example, if vaccines are not as effective, how safe are patients in the community? Given that research shows vaccines are not as effective after only the first dose, will this change after the second dose? How often will patients need to receive vaccines? What are the long-term effects, and how will the vaccine interact with anti-rejection medication?

Participants recognized that transplant patients are not a large population, and at this point, there is limited data on effectiveness. More research on immunocompromised patients is needed, and participants expressed the need for further cooperation among Canadian and international research groups to help expedite research and limit duplication.

Participants also expressed concerns regarding the need to achieve herd immunity. Patients remain unsure of how the population will attain herd immunity, given that research is uncertain of how effective vaccines are long-term. From the transplant perspective, concerns remain about reliance on herd immunity because it will be impossible for patients to know who is not vaccinated.

From the caregiver perspective, participants express frustration that caregivers have not been prioritized for vaccination. This is a significant concern in light of current knowledge indicating vaccines are not as effective for immunocompromised patients.

Overall, participants recognized that information is complex. Conflicting research and differences among provincial vaccination programs add to safety and efficacy concerns.



QUESTION B: WHEN, HOW, AND WHERE SHOULD THAT INFORMATION BE DELIVERED?

CONSISTENCY OF MESSAGING

Transplant centres must have consistent messaging. Patients rely on their transplant programs to either provide the information or point them to the source of information. Participants expressed irritation that there was limited communication from their transplant centre, meaning patients remain responsible for accessing and compiling information from a number of sources including social media, on occasion. Ineffective communication, such as transplant centres leaving automated voice messages/emails, were also mentioned as part of the frustration.

As a solution, it would be beneficial if the transplant centres developed patient-centred communication strategies, including the use of a navigator, to help patients receive accurate information, or at least point to one credible source of information, rather than having patients rely on the ever-changing news or other sources. A patient-centered approach, with a dedicated communications professional or team, is critical because transplant recipients may have different requirements (i.e. different organs, pediatrics, stem cells). Participants agreed it would be helpful for groups disseminating information not to work in silos.

On the other hand, participants understand that provincial differences create inconsistencies in messaging. However participants suggested transplant centres communicate with one another to coordinate the information patients receive on a larger scale. It is challenging to provide information from a national perspective, but these inconsistencies lead to frustration and stress for patients.

Participants also recognized how socioeconomic issues and unique considerations for populations based on geographic locations (rural vs. urban) and age groups (adult vs pediatric) impact access to information and vaccination. It is vital for transplant teams and others to distribute information to consider these differences when developing their communication materials and strategy.



BARRIERS TO EFFECTIVE COMMUNICATION

Information, guidelines, and recommendations are constantly changing. Participants expressed that ongoing changes make it difficult to understand what information is reliable and what is misinformation. For example, these changes often leads to the spreading of misinformation, especially on social media. It can be difficult, especially among those with reduced health and scientific literacy, to assess reliable information.

Participants agreed it is important for communicators to consider how the social determinants of health impact information delivery and communication. Patients are diverse, and some do not have the necessary tools (i.e., computers, emails, and the internet) to receive information.

Provincial policy differences also lead to confusion and frustration as it can be challenging to assess what information pertains to one's specific situation. The politicization of COVID-19 is viewed as a significant barrier towards effective communication because patients are unsure of whose advice to follow. Is it the Chief Medical Officer? Elected officials? The bureaucracy? Everyone's message is different.

Participants spoke about the need for interprovincial cooperation, especially among national transplant stakeholders, to work together, advocacy for common goals (i.e. all transplant recipients must receive their second dose within the recommended time), and share similar messaging.

Participants discussed the value of having one source of reliable information, such as a central and trustworthy information hub. Participants also spoke about the merits of CDTRP's Patient Portal as the hub for the transplant community (see: <https://portal.cdtrp.ca/en>) However, questions remain about the utility of a central information hub if patients do not know this exists or if the information is not updated to keep pace with ongoing scientific results and policy changes.

Patients agreed that information needs to come from their transplant centres. Given the amount of information available to the public, receiving communications from their transplant centres is highly valued because it is localized and considers the current situation in their province. Any information is better than no communications.



Because of the lack of standard communications practices, participants spoke about the need to do their own research by visiting reliable websites such as The Canadian Transplant Association or The Kidney Foundation for further information. Recognizing not everyone has access to these resources, two ideas were raised: (1) have transplant peer support programs led by patients who can answer COVID-19 related questions and (2) have a dedicated staff member within transplant centres to answer COVID-19 questions.



WRAP-UP DISCUSSION

Patient participants emphasized that these discussions regarding COVID-19 vaccination and the delivery of information must continue. There is a need to further elaborate the discussion on what kind of information the transplant community requires. The view was voiced that this is a pre-requisite for effective communication strategies to be developed and implemented.

Patients and families have many long-term questions. Will patients need a third dose? An annual dose? Can patients still get infected by COVID-19 if they and their close social networks are also fully vaccinated? If so, what does that mean? Does it mean death?

Finally, participants engaged in a robust conversation about the role of pharmaceutical companies and knowledge translation. Specifically, participants agreed that these companies need to consider the impact of vaccination on immunocompromised patients, especially if vaccination because a yearly need. While it is important to appropriately manage the role of pharmaceutical companies to avoid conflicts of interest, there are mechanisms available to create partnerships for educational programs. Information must be made accessible and user-friendly so patients can understand the results.

RECOMMENDATIONS

PRIORITY INFORMATION TO COMMUNICATE TO TRANSPLANT RECIPIENTS AND FAMILIES

- Do the vaccines work in transplant recipients? Is one type of vaccine better than another? Is effectiveness impacted by the specific medications patients must take?
- How will effectiveness be measured? Will some type of standard test for effectiveness be established, like some other post-transplant vaccines? Will the test for effectiveness change depending on the type of transplant?
- If vaccines are not very effective in transplant recipients, how safe are patients in the community?

WHEN, HOW, AND WHERE INFORMATION SHOULD BE DELIVERED

- **Transplant centres** are a critical trusted source of information, but in many instances patients and families feel frustrated with the communications they receive directly from their centre, finding them insufficient and inconsistent.
- Patients and family participants recommend that centres develop **patient-centred communication strategies**, consider transplant peer support programs led by patients who can answer questions, or at least coordinate to all point to one credible source of information.

The inconsistency of advice from elected officials, public health authorities, and individual health professionals is a significant barrier, as it leads to patients being unsure of whose advice to follow. There is a need for better **interprovincial cooperation** among all groups towards common messages and a **clear single source of credible information** that is adequately resourced and updated.

