

My Transplant Experience Project

The goal of this project was to understand the lived experience of people on a transplant journey in Canada and to propose patient-focused recommendations for improving that journey.

Transplant recipients, caregivers, and living donors from all organ groups (including kidney, liver, lung, heart, pancreas, and others) took part in three activities:

Resource Inventory

Over 300 resources gathered and shared from across Canada

Online Survey

Over 990 responses between May and November 2021

Focus Groups

20 focus group members met in spring and fall 2021

What have we learned about the transplant journey?

The transplant patients, living donors, and caregivers who participated in the research shared many important insights into the transplant journey, including these:

“[...] mental support and financial support and emotional support, they all go hand in hand.”

“I had to do fundraising to stay close to the hospital for 3 months post-transplant. I also owned a home and had a family that I had to maintain. The financial obligations are astronomical and I had to declare bankruptcy not long after my transplant.”

“[...] mental health services before and after transplant. There’s so little help and what there is costs too much for those of us who are on or have been on disability because of our illness. Help is completely inaccessible for many of us.”

“[...] I think this whole journey was rougher on the people around me than it was on me.”

“I didn’t actually have a contact person to ask if I had questions about healing. When I called my pre-transplant rep she told me to call post-transplant and I had no idea who to ask for there.”



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What are the recommendations for improvement?

People with lived experience of the organ donation and transplantation system had **3 main recommendations** for improving the the transplant journey:

Prioritize mental health care

Expand access to resources and services

Improve coordination and continuity of care

The recommendations outlined in the project report concerning **mental health**, **access to resources**, and **coordination of care** represent the most common and pressing needs we heard from over 1000 survey and focus group participants from across Canada.

Where do we go from here?

The opportunities and solutions listed above have been proposed by transplant patients, living donors, and caregivers. It's important that they be heard and understood, and then implemented.

We've started by presenting the findings at multiple levels of government, and we're sharing our results with the transplant community and the public at large. You can help by sharing this important work with people you know. The project website, mytransplantexperience.ca, includes a description of the research and results, along with some of the stories we heard from people who have been on a transplant journey.

The research team would like to thank everyone in the transplant community who generously contributed their time and expertise at every phase of this project. We value and appreciate the contributions of each and every patient partner, survey respondent, and focus group member who took part.

Dr. Sandra Davidson, Principal Investigator

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For more information, or for an electronic copy of the full report, please contact us at PAAC.Project@kidney.ca, or visit the project website at mytransplantexperience.ca.

