

IMPROVING ENGAGEMENT AND EMPOWERING PATIENTS ON THEIR TRANSPLANT JOURNEY

FINAL REPORT
March 2022



ACKNOWLEDGMENTS

The Improving Engagement and Empowering Patients on Their Transplant Journey project was funded by Health Canada's Health Care Policy Contribution Program, led and administered by The Kidney Foundation of Canada, and supported by University of Calgary, the Canadian Donation and Transplantation Research Program, and the Canadian Transplant Association.

The research team includes:

- Kristi Coldwell, Patient Partner and Media Liaison
- Lydia Lauder, The Kidney Foundation of Canada
- Carrie Thibodeau, Project Manager
- Dr. Sandra Davidson, University of Calgary
- Dr. Sarah Dewell, University of Northern British Columbia
- Marc Hall, University of Calgary
- Danielle Fox, University of Calgary

This project would not have been possible without the members of the Patient/Advocate Advisory Committee (see Appendix A) of the Organ Donation and Transplantation Collaborative, who provided their invaluable expertise and experience throughout the study. The research team would particularly like to recognize the contributions of Sandra Holdsworth, Mary Beaucage, Randy Spensley, Sylvie Charbonneau, Tom Meade, Hans Vorster, and Nancy Campana.

The research team extends its thanks to all patients, donors, and caregivers who generously contributed their time and expertise at every phase of this important patient-led project. We value and appreciate the contributions of every patient partner, survey respondent, and focus group member who participated.

Throughout the report, quotes and direct feedback from participants are included to emphasize, highlight and amplify patient perspectives.

Table of Contents

- ACKNOWLEDGMENTS 2**

- EXECUTIVE SUMMARY 4**

- 1.0 INTRODUCTION AND OVERVIEW 6**
 - 1.1 Background and Context..... 6
 - 1.2 Engaging Patients, Living Donors, Families and Caregivers 7
 - 1.3 Patient Transplant Journey 8

- 2.0 PROJECT DESCRIPTION 9**
 - 2.1 The Organ Donation and Transplantation Collaborative (ODTC)..... 9
 - 2.2 The Patient/Advocate Advisory Committee (PAAC) 9
 - 2.3 The Kidney Foundation of Canada 10
 - 2.4 Objectives 10
 - 2.5 Key Activities 10

- 3.0 PATIENT ENGAGEMENT MODEL 13**

- 4.0 CENTRAL THEMES..... 14**
 - 4.1 Holistic Person-Centered Care 14
 - 4.2 Accountable Care 14
 - 4.3 Collective Impact 15
 - 4.4 Navigating Uncertainty 16
 - 4.5 Connection 16
 - 4.6 Advocacy 17

- 5.0 OPPORTUNITIES 18**
 - 5.1 Enhance Mental Health Support..... 18
 - 5.2 Establish Formal Peer Support Programs 19
 - 5.3 Improve Continuity of Care 20
 - 5.4 Improve Knowledge Acquisition 21
 - 5.5 Expand Financial and Other Supports..... 21
 - 5.6 COVID-19 tools and resources 22

- 6.0 RECOMMENDATIONS 24**
 - 6.1 PRIORITIZE MENTAL HEALTH AWARENESS AND SUPPORT 24
 - 6.2 INCREASE ACCESS TO RESOURCES AND SERVICES..... 25
 - 6.3 IMPROVE COORDINATION AND CONTINUITY OF CARE..... 26

- 7.0 CONCLUSIONS 27**

- REFERENCES 28**

- APPENDICES 29**
 - Appendix A : PAAC Members..... 30
 - Appendix B : Stakeholders and Partners 31
 - Appendix C : Patient Engagement Model 33

EXECUTIVE SUMMARY

Every year, thousands of Canadians wait for a life-saving transplant and of those, hundreds will die while on the transplant wait-list. For those patients lucky enough to receive a new heart, lung, liver, pancreas, or kidney, many will experience challenges navigating through the complex Canadian health care system and will need to learn to live with the difficulties of being an organ transplant recipient. Tens of thousands of Canadians currently live with an organ transplant and many experience challenges with mental health, financial strain, and the uncertainty of how long this new organ will last. For all the benefits of transplantation, the reality for someone receiving an organ transplant is that they are a transplant patient for life. To live with a transplant means a lifetime of immune suppressing and severe chronic inflammation medication, managing the side effects of these medications, and a lifetime of check-ups, invasive monitoring, and concerns that they may one day lose their transplant and begin the journey all over again.

To better understand and improve the collective challenges experienced by those on a transplant waiting list and those living with an organ transplant, the “**Improving Engagement and Empowering Patients on their Transplant Journey**” project was funded by Health Canada and led by the Kidney Foundation of Canada in collaboration with the Patient/Advocate Advisory Committee (PAAC) of the ODTC (Organ Donation and Transplantation Collaborative). This two-year initiative explored and analyzed the lived experience of patients and families as they journeyed through the organ donation and transplantation (ODT) system in Canada and evaluated their views on the health care system(s), processes, and informational support and service materials involved on their journey.

The objective of the report is to illuminate the barriers and challenges patients face as they navigate the ODT system and develop patient-led and patient-focused recommendations to assist the ODT system in prioritizing their services at the local, provincial, and federal levels to support patients throughout their transplant journey. This will ensure that future ODT systems transformation will be informed by the experiences of those it seeks to serve.

To inform the recommendations outlined in this report, the project solicited and collected information using three different approaches:

1. An environmental scan was conducted to assess and catalogue the current materials, resources, and services available to patients, caregivers and living donors. Over 300 resources from across Canada were gathered on topics ranging from financial support to nutrition and exercise pre- and post-transplant to medications and living donation. Information from this environmental scan was used to develop interview guides and survey questions and the full list of resources was made available via the project website, mytransplantexperience.ca
2. A pan-Canadian online survey, completed by 994 participants, was used to assess the accessibility, responsiveness, quality, sustainability, and accountability of the ODT system from the perspective of patients, living donors, and caregivers on their transplant journey.
3. Two focus groups, one held in the spring and one in the fall of 2021, each brought 20 participants together from across Canada and across organ groups to understand the lived experiences of transplant patients, donors, and caregivers across Canada.

The themes and recommendations presented in this report are based on the analysis of the survey and focus group data. Members of the PAAC played an integral role in the refinement of the recommendations based on the results and identified six overarching themes, described six areas where there are clear opportunities for improvement and are proposing three principal recommendations with a series of sub-recommendations.

The overarching themes identified by patients and families were:

- Achieving a more holistic model of care delivery, including **mental health** and **financial support**
- Increasing **access to services**, information and accountable care
- Understanding the collective and challenging **impact** the donation and transplant process has on the patient's family and support team over the course of the journey
- Navigating a high degree of **uncertainty** and never knowing when the next challenge would arise (e.g., being put as inactive on the transplant list, side effects of new medications, health complications, organ rejection)
- Building and maintaining **meaningful and integral connections** through friends and family, peer support, within the community, and with health care providers
- Accepting the importance and need to **advocate for their own care** within all levels of the health care system, and to advocate within the community to raise awareness

The three principal recommendations to be implemented across every level of the ODT system are:

1. **PRIORITIZE MENTAL HEALTH AWARENESS AND SUPPORT**

Remove stigma, increase transparency, and normalize the conversation around mental health support for transplant patients, living donors, and caregivers.

2. **INCREASE ACCESS TO RESOURCES AND SERVICES**

Ensure equitable care for all those on a transplant journey by increasing access to existing supports and expanding the range of educational and financial resources available.

3. **IMPROVE COORDINATION AND CONTINUITY OF CARE**

Ensure that the communication between and within health care teams, as well as to patients, meets the needs of patients and caregivers throughout their transplant journey.

These recommendations offer tangible, implementable, and measurable solutions to address the many challenges faced by patients, families, and caregivers coping to live with an organ transplant. These recommendations and opportunities can be implemented at the local level to enhance support and coordination across primary care, chronic disease specialist care, and specialized transplant care. The provincial health agencies and organ donation organizations can build and offer ongoing care and resources to provide accountable support over the life of the transplant patient. Additionally, federal programs and agencies can offer national support and engagement programs to provide access to timely information, while at the same time, helping to evaluate the impact of the implementation of these recommendations at the local, provincial, and federal levels.

The research team extends its thanks to all patients, donors, and caregivers who generously contributed their time and expertise at every phase of this important patient-led project.

1.0 INTRODUCTION AND OVERVIEW

1.1 Background and Context

The organ donation and transplantation (ODT) system in Canada is a complex network of interprovincial and multi-jurisdictional organizations and health authorities, which can create challenges and barriers for patients as they attempt to navigate the system and advocate for themselves. Transplantation is a lifelong journey that begins with the diagnosis of organ failure, continues through to transplant and remains with the patient as they learn to live with their new organ. A fulsome understanding of what patients, living donors and caregivers experience during their transplant journey is needed as transplant patients navigate complex situations across a complicated web of jurisdictions that do not necessarily have simple comparisons across the health sector. In 2019, there were 4,352 Canadians waiting for an organ transplant. Over 2600 organ transplants were performed in Canada in 2020 alone¹ (2128 from deceased donors and 487 from living donors), and each transplant affects not only the transplant patient or the living donor, but also their entire support network.

“With the ever-growing wait-list and increasing complexity of our transplant population, it is vital that we develop a pan-Canadian organ donation and transplantation system that is responsive to the diverse needs of our patients.”

Kristi Coldwell, transplant recipient and PAAC Co-Chair

This report was produced for the ODTTC as part of the ***Improving Engagement and Empowering Patients on Their Transplant Journey*** project, a mixed-methods study of patient lived experiences of the ODT system in Canada. A network of transplant recipients, living donors, patients currently waiting to donate or receive an organ, caregivers, and organ donor advocates from across Canada were invited to share the successes, the failures and/or gaps in their experiences with the goal of developing patient-led and patient-focused recommendations for a renewed and improved approach to ODT health services in Canada.

This project involved consultation with kidney, liver, heart, lung, and other solid organ transplant patients and their families. While the scope of this project did not cover stem cell transplants, cornea transplants or tissue grafts, the issues raised may be relevant to those communities.

There is evidence to suggest that there are gaps in the services, supports, and informational materials provided to patients. For example, a 2018 report by the Kidney Foundation of Canada examining the burden of out-of-pocket costs for Canadians with kidney failure found that 40% of patients reported that financial barriers were a significant burden to their transplant work-up. Further, 19% of respondents said they had missed purchasing medication in the last six months due to a financial barrier².

In addition, a recent publication looking at kidney transplantation and living donor kidney transplantation data found that populations marginalized by race and ethnicity in Canada face barriers accessing culturally appropriate medical knowledge and kidney transplant treatment³.

Increasingly, transplant patients, donors, and their families are turning to online crowdfunding platforms such as GoFundMe to bridge the financial gaps in the system. The results of a recent study by Pol, et. al. (2020) suggest that Canadians on a transplant journey experience significant financial difficulties not addressed by the health care system, especially living costs, medication costs, transportation and relocation expenses, and loss of income. The increase in crowdfunding campaigns highlights the financial burden experienced by transplant patients, living donors, and their families and caregivers throughout the transplant journey⁴.

In many instances, transplantation is the only life-saving option available for patients with end-stage organ failure. For others, transplantation leads to better outcomes than alternative and more conservative treatments and offer significant savings to the health system. For example, kidney transplantation is widely considered the best treatment for people with kidney failure. A transplant enables people who would otherwise be on dialysis at least three times a week for four to five hours at a time, to live a relatively normal, healthy, and productive life, while providing a less costly option for the health care system compared to dialysis. The total annual cost of dialysis ranges from \$56,000 to \$107,000 per patient. The cost of a transplant is \$66,000 in the first year, then \$23,000 in subsequent years. For each kidney transplant patient, the health care system saves up to \$84,000 annually⁵.

1.2 Engaging Patients, Living Donors, Families and Caregivers

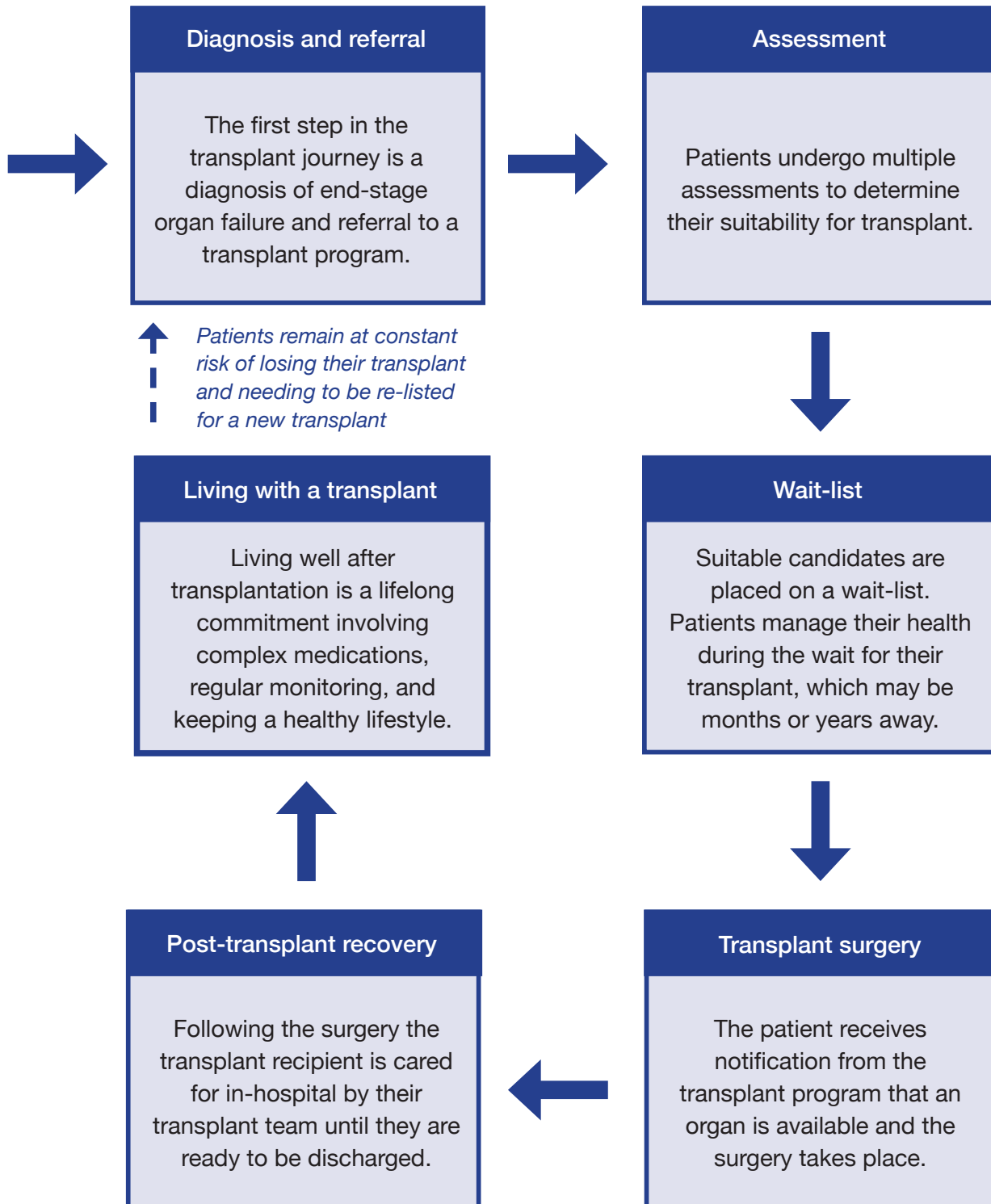
Patients can and should be enabled and empowered to help improve the system on which they depend by being asked what they are benefiting from, what is not working, what they are missing, and how the ODT system in Canada can better support them and prioritize services. This work will enable the ODT system in Canada to better understand and address the barriers facing patients and appropriately and meaningfully inform its recommendations to the federal and provincial/territorial governments on a new path forward for the ODT system in Canada.

Research has shown that people have better health outcomes when they are involved in seeking and developing answers to many of their questions for themselves, by understanding their disease(s), and by participating in decision-making about their treatment and care^{6,7}. Jamieson et al (2016) completed a thematic approach to identify kidney transplant recipients' motivations, challenges, and attitudes towards self-management and of the 5 themes identified, patient empowerment was demonstrated to foster self management and improve patient transplantation outcomes⁸. Hibbard and Greene (2013) concluded "*that policies and interventions aimed at strengthening patients' role in managing their health care can contribute to improved outcomes and that patient activation can—and should—be measured as an intermediate outcome of care that is linked to improved outcomes*"⁹.

Throughout the course of the project, participants expressed feeling engaged and empowered on their transplant journey. Empowering patients particularly from rural, underrepresented, and historically oppressed communities is key. Empowerment relates to all aspects of care including engagement, but also utilization of services and prioritization of needs. This project provided a crucial avenue of engagement and empowerment to patients and advocates to help influence and develop a better system meant to support them, and to deepen their understanding of the system and what their options are to help ensure their needs are met and their outcomes are maximized.

1.3 Patient Transplant Journey

An organ transplant is a lifelong journey for transplant recipients and their families as they navigate first the chronic disease system, then the ODT system, and then life-long follow-up as transplant patients. The journey can be further complicated if it is not linear, which can increase the difficulty of navigating the ODT system. Patients, living donors, and caregivers rely heavily on the support of their transplant team and the ODT system throughout the journey.



2.0 PROJECT DESCRIPTION

The Improving Engagement and Empowering Patients on their Transplant Journey study was a two-year project funded by Health Canada and launched in 2020. It was led by the Kidney Foundation of Canada in collaboration with the Patient/Advocate Advisory Committee (PAAC) of the Organ Donation and Transplantation Collaborative (ODTC). The project highlighted and documented the lived experience of those on a transplant journey in Canada and proposed patient-led and patient-focused recommendations on meaningful patient priorities for renewal and improvement to the organ donation and transplantation (ODT) system in Canada.

2.1 The Organ Donation and Transplantation Collaborative (ODTC)

The purpose of the ODTC is to inform thinking and open the door to action on improving Canada's ODT system performance. This ongoing initiative is funded by Health Canada and brings together stakeholders from Health Canada, the Provincial Territorial Blood Liaison Committee and Canadian Blood Services, and takes a phased and iterative approach to identify options and ideas for greater collaboration among the key actors in the pan-Canadian ODT system.

2.2 The Patient/Advocate Advisory Committee (PAAC)

The PAAC was established to recognize, underline, and ensure the crucial contributions of people with lived ODT experience were included and incorporated into the important work being done by the ODTC. The PAAC represents a formal structure within the ODTC that brings together donors, recipients, family members, and patient advocate organizations. The group seeks to support patient and advocate voices, provide representation, and ultimately to improve patients' experiences as they navigate the organ donation and transplantation system in Canada. The PAAC is crucial to the ODTC's work and success at improving the ODT system.

The PAAC's mandate within the ODTC is to:

- Review and deliberate on issues related to patients/families/advocates as proposed by PAAC members;
- Provide advice and recommendations to the Steering and Coordination committees, and to the ODTC working groups, in support of the ODTC's overall progress through the careful and strategic consideration of people's lived ODT experience;
- Report to the Steering and Coordination committees on the presence of patient/advocate perspectives in the working groups' progress, outputs, and recommendations, and on other related issues as they arise;
- Ensure adequate and relevant patient/advocate representation on each of the ODTC working groups; and
- Engage, as the need arises and as feasible, with external stakeholders on patient/advocate issues related to the ODTC's scope of activities.

2.3 The Kidney Foundation of Canada

The Kidney Foundation of Canada is committed to achieving excellent kidney health, optimal quality of life for those affected by kidney disease, and a cure.

The Kidney Foundation of Canada is the leading charity committed to eliminating the burden of kidney disease through:

- Funding and stimulating innovative research for better prevention, treatments and a cure;
- Providing education and support to prevent kidney disease in those at risk and empower those with kidney disease to optimize their health status;
- Advocating for improved access to high quality health care; and
- Increasing public awareness and commitment to advancing kidney health and organ donation.

2.4 Objectives

The collection, assessment and consideration of data on patients' lived experiences during their transplant journey is key to influencing and improving future patient experiences and outcomes on a national level as the ODT considers a pan-Canadian governance structure and works toward a pan-Canadian data and performance system.

The objective of this project was to illuminate the barriers and challenges that patients face as they navigate the ODT system and to develop patient-led and patient-focused recommendations to assist the ODT system in prioritizing their services and supporting patients throughout their transplant journey. This will ensure that future ODT system transformations will be informed by the experiences of those it seeks to serve.

2.5 Key Activities

2.5.1 Resource Inventory

The first phase of the project was to establish an inventory of products and services available to patients, caregivers and living donors. Over 300 resources from across Canada were gathered and identified on topics ranging from financial support to nutrition and exercise pre- and post-transplant to medications and living donation.

These resources were sourced from documents and links shared by individual transplant programs, national and regional resources from Organ Donation Organizations (ODO) and various professional groups, and resources published by national organizations such as KFOC and the Canadian Liver Foundation.

Throughout the project these resources were made available to participants via the project website, as follow-up resources to focus group participants, and directly via the survey and by referral. Over 60 requests for information about these resources were answered during the course of the project.

2.5.2 Survey

The project survey was intended to assess the accessibility, responsiveness, quality, sustainability, and accountability of the ODT system from the perspective of patients, living donors, and caregivers on a transplant journey. The final survey consisted of 60 questions divided into 6 sections:

- Demographics
- General questions on the transplant journey
- Materials, services, and support
- Navigating the system
- Living donation
- COVID-19

There were 3 primary pathways through the survey. Respondents completed the questionnaire either as a transplant patient, a caregiver or a living donor.

The survey was created using an iterative process in collaboration with patient partners in the PAAC, content and knowledge experts, academic researchers, and a survey design expert. The final English survey was translated into French, Traditional Chinese, Simplified Chinese, and Punjabi and then entered into Qualtrics, a robust and secure survey platform for the collection of online survey data.

The survey was launched in May 2021 and remained open to responses until November 2021. Survey links were hosted on the project web page, and the survey was promoted in May, August, and November via the social media feeds and newsletters of partners and stakeholders, including KFOC, the Canadian Donation and Transplantation Research Program (CDTRP), and the Canadian Transplant Association.

The initial target was to have as many as 200 responses from transplant recipients, living donors, and caregivers across Canada, however when the survey closed on November 15th, 2021 there were 994 participants. Of these, 120 said they were being assessed for transplant or are on the wait list, 634 characterized themselves as transplant recipients, 67 were living donors, and 145 were caregivers.

2.5.3 Focus Groups

The focus groups were instrumental in further understanding the lived experiences of transplant patients, living donors, and caregivers across Canada. There were two rounds of sessions held; the first in the spring of 2021, and the second in the fall of 2021. Each of the two rounds included a total of 20 participants from across the country, across organ groups and of varying ethnicities.

The two-hour focus group sessions were held online via Zoom, and the transcripts were analyzed using qualitative data analysis software NVivo. The questions asked during the first session, listed below, were intended to help illuminate participants' lived experience of the ODT system.

Focus group questions (Session 1)

- What do you wish you'd known during your transplant journey?
- What was done well? What improvements would you recommend?
- What products or services would have made a difference to you?
- What would help you most in your journey today?

The second round of focus group questions was intended to build off the answers obtained during the first session and delve further into certain themes.

Focus group questions (Session 2)

- What type of mental health support was/would have been most helpful to you in your journey? (psychological/psychiatric, one-on-one peer, small support groups, regular/monthly meetings)
- At what stage in your journey did/would you find mental health support most helpful?
- What specifically could be done to improve continuity and coordination of care? How can the system do better throughout the transplant process?
- What have your particular financial challenges been in accessing services and resources?
- What new concerns are coming up for you with regard to the COVID-19 pandemic? How has the pandemic changed your experience as someone navigating a transplant journey?

A select number of written responses to these focus group questions were also sought via random selection from survey participants who indicated their interest in participating further in the research study. The results from these additional 38 written responses were combined with the transcripts from the two focus group sessions for qualitative analysis.

3.0 PATIENT ENGAGEMENT MODEL

Patients, living donors and caregivers were at the centre of every facet of this project. The members of the PAAC leveraged their lived experience and expertise, as well as their professional and personal connections, to ensure the project’s success, while patients, caregivers and living donors across the country took part in the survey and focus groups.



From the initiation of the *Improving Engagement and Empowering Patients on Their Transplant Journey* project in 2019, PAAC members were involved in affirming the importance of the overall research question, defining overarching goals and outcome measures, co-designing the survey, co-developing recruitment strategies, ensuring the questions and data collection were ethical and culturally safe, reviewing recommendations, and will help disseminate the results and promote the uptake of the recommendations.

Throughout the project, both patient partners and participants were kept apprised of its progress through a website - mytransplantexperience.ca. There they were able to access not only the project survey, but also find updates, resources, and patient lived experiences shared in multiple formats.

See Appendix C for a full overview of the roles and contribution of the PAAC on this project.

4.0 CENTRAL THEMES

The study data was coded and analyzed using a convergent parallel mixed methods design whereby focus group data and survey data were collected concurrently, analyzed, and merged at the interpretation phase. Six central themes were identified:

- Holistic person-centered care
- Accountable care
- Collective impact
- Navigating uncertainty
- Connection
- Advocacy

These themes represent the aspects of the transplant journey most commonly discussed during the focus groups and form the basis of the six opportunities for improvement of the ODT system identified by participants.

4.1 Holistic Person-Centered Care

When participants described their transplant journey, many identified an overarching focus on the medical aspects of their care rather than a holistic model of care delivery that incorporated other important elements, including mental health support and financial support.

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

Throughout the project participants emphasized that a more holistic model of care was needed.

“[...] obviously the medicine is important [...] but they just need to be looked at as a whole.”

Participants suggested that it was critical that the health care team provide compassionate and comprehensive care to everyone, without making assumptions about individual care needs. While participant needs across the transplant journey varied by individual characteristics (e.g., journey stage, distance to the transplant center, income), most participants only received standard care and services. The individual factors that impacted needs were important to consider as not everyone needed the same thing at the same time. Continual assessment across the trajectory was crucial given that needs changed over time. It was the right combination of needs targeted to the individual at the right time that mattered.

4.2 Accountable Care

Numerous health system factors impact the transplant journey. Services are geographically dispersed which can make it difficult for many people to access care. Participants noted differences in service availability across their diverse locations and journey types and questioned why these differences in care existed. Many care and administrative processes were discussed as being outdated and often redundant or inefficient.

“If you don’t check your mail a whole lot because nothing else comes to you via mail anymore, it’s like, oh, great, here’s a letter telling me about my appointment I had two weeks ago that I already attended.”

Privacy concerns and other bureaucratic loops made it difficult to access the information or services that participants needed as well as making it difficult to ask or advocate for change. Some participants also recognized that private and not-for-profit organizations were often relied on to provide needed support and services not available within the health system.

Many participants described feeling in the dark about their care, feeling a lack of control, poor communication, and a lack of transparency. Transparency was especially essential since many people did not have access to their own medical records and it was often unclear where they were on the transplant wait-list and why. The rationale for changes in status or treatment plan was not always communicated to the participants.

“I feel that the communication pre-transplant would be better if there was more information being shared with me. I felt that a lot of times there would be a period of a few months [...] not having any information on my multi-score, on my wait time [...]”

Accountable care was needed to adequately prepare participants and their families across all stages of their journey; yet, many felt that health care providers did not have time to provide accountable and holistic care, or that other barriers to care provision got in the way. It was often unclear who was accountable for their care.

“There was no follow-up after. It was just sort of checking off the boxes, making sure your stitches were healed. I don’t know, I feel like there should have been somebody else along the way following up.”

The health care environment further impeded access to accountable care, with many environments not being conducive to private person-centered conversations and interactions. Concerns about privacy and confidentiality were raised by some participants.

4.3 Collective Impact

Managing a chronic complex condition and often invisible disease was difficult. Having hope, support, and empathy were critical. This was especially true in the context of the transplant journey which was often navigated with fear and uncertainty.

“I love hearing all your stories of hope. I wish [transplant patient] was sitting in here with me, but he’s feeling a little discouraged with the process.”

It is important to consider that the transplant process impacts everyone within the individual’s network. The needs/wants of the individual and those of their family and other support people were often unique and at times they could conflict, yet all were important to address.

“And frankly, you know, I think this whole journey was rougher on the people around me than it was on me.”

Many participants described the difficulty in balancing life and other medical demands with those related to their transplant. Fitting in frequent medical appointments, testing, and other requirements into daily life was often difficult to make work.

“It’s hard to get into a routine of doing things when it’s all interrupted by this [...] I lost two jobs because of appointments.”

This could be made worse under certain circumstances, such as not having access to a car or living far from the transplant centre. Although it was often very difficult for patients to make everything work, they ultimately took steps and pushed to “do what they had to”.

4.4 Navigating Uncertainty

For many participants, their transplant gave them the ability to get back to life, but this did not mean that the challenges related to their health condition were resolved. The first year post-transplant was a particularly difficult time for many participants.

“In the year following the transplant, I went through a lot of things, a lot of illnesses [...]”

Regardless, individuals at all stages of their journey reported never knowing when the next challenge would arise (e.g., being put as inactive on the transplant list, side effects of new medications, health complications, organ rejection). Many participants described living with a high degree of anxiety and uncertainty.

“I would say it’s been a very unpredictable path, which made it really hard to know what I want and to plan, future-wise [...]”

They indicated that nothing about the transplant journey appeared to be clear cut and that there were few yes/no answers (e.g., how long the wait-list will be, impact of medications, complications etc.). This was complicated by the variability in processes and protocols across programs and jurisdictions. These factors created obstacles that hindered access to transplantation. A particular time of uncertainty was “getting the call” that an organ was available, where participants would wait a long time, and then everything happened in a big rush, which was very difficult to plan for and had a profound financial and mental health impact.

4.5 Connection

Many participants described how important meaningful connections and social supports were. Connection and support came in many forms, between recipients and donors, through friends and family, peer support, within the community, and with health care providers.

“We live in a community that kind of everybody knows everybody. So I have reached out to other caregivers and even other kidney patients and transplant recipients just to sort of better understand where my husband’s at and his struggle.”

It was also a reciprocal process in the sense that it was not only important to connect with others and receive support but for people on their transplant journey to also offer support and connection to others, and to be engaged in the larger community.

“So as a patient, I have to concentrate on giving back [...] my goal for myself is to know that I always have some way to influence someone else’s life.”

Although connection was key for many participants, some described not feeling comfortable reaching out, or had other barriers to connecting. Therefore, providing the right platform (e.g., virtual, in-person, etc.), with a clear purpose (e.g., information sharing, social support) and varying format (group, individual, etc.) is important to consider as it could vary by individual.

4.6 Advocacy

Participants frequently spoke about how they needed to advocate for themselves or their loved ones and that doing so led not only to better treatment but also helped them progress faster to transplantation.

“I think my experience was probably in the top ten percent [...], and again back to the fact that I could advocate for myself, where a lot of other people couldn’t.”

“It shouldn’t be that way, but it’s human nature. If you’re an engaged patient, you will probably get a little bit better treatment.”

Ultimately many participants felt that they had to rely on themselves or their loved ones rather than the health care system.

“I spent a lot of time researching and talking to people as I was going through my donor journey, however a lot of the information that I found valuable wasn’t shared with me through the program. I did have to find it myself.”

“You have to be an advocate for yourself, both you and your donor. There’s a lot of calls from me and my donor to get tests, timing and pushing every part of the system to make it work. [...] If you just stood there, did nothing, I think it wouldn’t happen.”

Unfortunately, many participants did not know their rights and encountered other barriers to successfully advocate for themselves.

“[...] they would set up a whole set of pills in front of me. And I was so tired. [...] And I didn’t realize I could have just asked for the head nurse and she would have come in and gone over that with me.”

Advocating within the community was also important. Many participants spoke of how they shared knowledge and information about donation and transplantation to spread awareness within the community to advocate for increased organ donation.

“I have a good career. I’m married, I have a child and I’m a very grateful person. And that’s why I’m involved here, trying to add that to the community.”

Participants also spoke of how they would need to advocate to find an organ donor for living donation and what a challenging process this could be, as these were difficult conversations with no one clear approach.

5.0 OPPORTUNITIES

The six central themes that arose from the focus groups form the basis of the six primary opportunities for development for the ODT system in Canada from a patient, caregiver, and living donor perspective. These opportunities are:

- Enhance mental health support
- Establish formal peer support programs
- Improve continuity of care
- Improve knowledge acquisition
- Expand financial and other supports
- Maintain tools and resources developed during COVID-19 to enhance care

5.1 Enhance Mental Health Support

Unaddressed mental health concerns were very common among participants. 37% of survey respondents indicated that mental health was a central concern during the transplant journey, and that number rose to 52% among caregivers. Mental health concerns occurred both during the day-to-day burden of living with a chronic disease and working through the transplant process, as well as during “big” moments such as receiving a transplant or experiencing organ rejection.

Meaningful mental health support was consistently lacking, and although many programs had social workers or would refer to other mental health professionals, these visits were often seen as a checklist for transplant eligibility rather than as a meaningful treatment to manage mental health concerns.

“Some people are still going to have some mental illness problems, even during a transplant. But yet they wanted me to be all clear of my problems before they put me on the list for the second time.”

The appointments with social workers or mental health professionals would often also focus more on giving general information prior to transplantation about expectations and resources rather than helping them to address their mental health concerns. However, support was needed along the continuum for all involved.

“Mental health should be discussed frequently along this journey.”

For example, many participants did not realize how much their mental health would be impacted post-transplant, which was an emotionally turbulent time for many.

“I felt extremely guilty about someone else having to give their life for mine to go on.”

“With my first two transplants, someone had to die so I could live and that’s a heavy burden to carry. [...] I wasn’t prepared for the emotions that came up after the transplant.”

Some participants spoke of being reluctant to bring up mental health concerns for fear that it would slow their work up process and as a result, would either say nothing, or pay for private support which could be a financial burden.

“There’s so little help and what there is costs too much [...] Help is completely inaccessible for many of us.”

Given how common mental health concerns were, many participants discussed that mental health concerns should be normalized and should not impact their transplant eligibility.

5.2 Establish Formal Peer Support Programs

According to focus group participants, peer support served many purposes. For example, it offered emotional support so that people could speak to someone who could really understand what they were going through. It also offered a form of information gathering and knowledge building and it helped people to better navigate the system and advocate for themselves and their loved ones. Peer support was also seen as a way to build a sense of community awareness.

Unfortunately, peer support was rarely integrated into care trajectories. Formal peer support programs for all organ groups that are introduced early in the transplant/disease trajectory are needed.

Even when formal peer support programs existed participants often had to seek them out independently rather than being made aware of them through their health care team.

“You know, I had no idea that these things were out there, until I went and searched for them myself. And so, it would be nice if the health care teams would provide that.”

70% of survey respondents reported that peer support or mentorship programs were not recommended to them, yet most focus group participants spoke of the importance of peer support. Living donors in particular rarely had peer support recommended to them, with only 30% indicating it had been offered to them.

“Concerns were mentioned that we don’t discuss with our loved ones or with the receiver, because we want to protect them from all this.”

Peer support was not always offered at the right times and through the right formats, and it was important for their structure to be flexible to ensure they were accessible in a variety of ways.

Unfortunately, formal peer support was often not available in smaller jurisdictions or within many organ groups outside of the kidney community. Some participants had been involved in the development of peer support programs and spoke of how challenging it was to establish these due to system barriers. Other participants spoke of how they formed informal peer support groups to bridge this gap in their care.

“I got to know about six heart transplant recipients in my time that, we called ourselves the heart posse, that we continued to meet after we got our transplants.”

5.3 Improve Continuity of Care

Participants noted a lot of disjuncture in their care, and 38% of survey respondents said that their main concern during the transplant journey was the coordination of their care across multiple health care professionals. There were concerns with care coordination between speciality health care teams (e.g., dialysis clinics to transplant clinic); between speciality teams and their larger care context (e.g., transplant team to family providers); as well as within health care teams.

“If I go to my family doctor and need something done, well then, she’s not really sure what to do because of my transplant. And so I find that [...] the coordinated effort between the multi disciplines is not there.”

Poor continuity of care had consequences, including negatively impacting care experiences, delaying the progression to transplantation, and in some instances increasing the risk of adverse events. It also resulted in wasted time and health system resources, as often the same tests and procedures were being duplicated, or they would get the same appointment reminders and follow up from multiple clinics. Many participants also raised concerns about the continuity of service provision, where services or resources suddenly stopped when they were discharged from hospital or from a particular clinic.

Communication was a significant concern in this area. There was a perceived lack of communication between providers and often participants received conflicting information (or a complete lack of information).

“We found just with our experience, a huge disconnect in communication. Even when we were getting the kidney [...], our [local] team had no idea. They didn’t even know we went to London and did this.”

It was unclear for many individuals who was ultimately responsible for their care, and many participants felt that no one was. Many participants were not comfortable accessing non-specialized primary care services, despite being advised to.

“[Family doctor] looks at me, and if I go to him and I say [...] something, he’ll be like, well, what does your transplant team say?”

It was felt that they would not receive the care they needed due to both a lack of knowledge about their condition, but also due to a lack of communication between clinics. 73% of survey respondents said that they’ve seen their family doctor or general practitioner 0 to 4 times in the last year. 7% said they either didn’t have a family doctor, or they had not seen them in that time frame. Many focus group participants said that they were not comfortable talking with their family doctor about the full range of their care, including transplant-related issues.

A lack of coordination between provincial jurisdictions was also of concern. First, many participants who did not live in the same jurisdictions as their transplant team often reported significant concerns with continuity of care. Second, it was felt that there was no national effort to standardize and coordinate care and address jurisdictional issues, which could be frustrating and cause confusion with patients receiving different information across the country.

5.4 Improve Knowledge Acquisition

A lot of critical information was provided throughout the transplant journey. Receiving information early was important.

“[...] after four or five days in the hospital, they then pass me the book. Now you have a kidney transplant. It’s like, okay, I could have had that book prior to. It would have been so helpful. It had all kinds of information in it.”

While honest and factual information was needed, some participants felt that the information was sometimes provided in a way that could scare people, which could result in not wanting to move forward with transplantation. Others indicated that not enough information was provided, and they described being under-prepared for what was to come. A better balance was needed.

Several factors made it difficult for patients to receive the right information. While there was a lot of information available, it was often dispersed between different resources, organizations and people. Without information being centrally located, timely and accurate information was often difficult to access.

“Maybe having a place where transplant recipients can find out [...] what the latest news is and where we can get information in one place.”

When information was compiled and provided to patients (e.g. binders, websites) it was often too generic and would not apply to the individual’s circumstance. This information often focused on medical and procedural aspects, rather than addressing the individual real-world questions, concerns, and follow-up informational needs. Participants described not having the foresight needed to ask the right questions, while later wishing they had known more and been prepared about certain elements. It was important for these conversations to be guided towards the right type of information.

“I knew there would be a lifelong commitment to taking medication to prevent rejection. I didn’t realize how everyday things (foods, germs, bacterias, etc.) can be a danger to people with lowered immune system.”

It was important for participants to receive information at the right time and in the right environment. 71% of survey respondents reported receiving information about their transplant journey in the way that they needed most or all of the time, yet many focus group participants shared stories of receiving information in an environment where they felt rushed or were not able to engage in an authentic conversation about their questions and concerns.

5.5 Expand Financial and Other Supports

Over and above access to mental health support and peer support, there were other services that were not accessible but needed. For example, many participants reported difficulty accessing affordable and appropriate services such as physical rehabilitation, access to a dietitian, and access to pharmacy support.

“I’m finally getting help with my medication. I’m on a disability pension, [...] and I’ve – at one point some of my pills were costing me three quarters of my monthly cheque [...].”

Financial considerations were considered the main concern about the transplant journey for a majority of transplant patients, caregivers, and living donors.

“My husband gave up a very good paying job so that he could look after me. So it financially was a huge thing for us.”

Many individuals faced numerous financial barriers such as affordable lodging, paying for transportation costs, and accessible medication coverage.

“I think if more funding was available to people requiring the transplant to cover costs such as hotels, etc. 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.”

Many participants noted that some expenses were subsidized, which was appreciated; however, the out-of-pocket expenses continued to pose a significant financial burden.

“[...] it’s still really expensive [...] our deductible is \$2700 which is a lot considering [...] our income. That’s still a lot of money.”

Support services that did exist were often difficult and confusing to access, or it was unclear what was available. Approximately 60% of survey respondents reported that they were not given help in accessing the financial supports available to them.

“Guidance on how to manage, obtain, and maximize insurance (both private and public). I would even now appreciate being taught how to get the most out of the plan I pay for and how to properly use government funding.”

Accessing financial support also often required time and planning, which was difficult given that most transplant dates were not known or planned. There were also barriers in being unsure of what was needed to access these supports (e.g., keeping receipts etc.), which resulted in stressful application processes or inadequate reimbursement. Financial support was also often only available for the donor/recipient, whereas support for family and caregiver to stay and be with them was often not available.

Although it was recognized that many services were in place in Canada compared to other areas (e.g., the United States), there remained a need for proactive, accessible, and consistent resource support across all provinces.

5.6 COVID-19 tools and resources

The COVID-19 pandemic highlighted existing disjunctures across the transplant continuum. Participants explained that many of the difficulties that they encountered were exacerbated due to the COVID-19 pandemic. For example, continuity of care and access to accountable care were impacted as a lot of information was unclear and inaccessible. 50% of survey

respondents indicated that the pandemic affected their access to their health care team. Many participants further reported delays in their transplant workups among other resources and services being cancelled.

Many of the challenges that all Canadians collectively experienced because of the pandemic were magnified by people on their transplant journeys. For example, participants described feeling isolated and worried about getting COVID. 76% of survey respondents reported that their level of comfort going out in public was affected. Their worry exacerbated their pre-existing mental health concerns, and many described needing to take extra precautions to keep safe given their immunocompromised state.

“Anytime I do have to go out or be around people, I just minimize the risks at all costs, you know, like shopping early, shopping online, just not being around people. I haven’t seen my kids in two years.”

Others spoke of the fear of the unknown impact of COVID-19. Some participants spoke of hospital restrictions, where family or friends were not able to visit. This was very difficult given that many hospital stays were long and complex.

However, the pandemic also brought benefits. For example, one participant spoke of how she was able to continue to work as it was now possible to work from home. This may not have been possible prior to the introduction of COVID-19 restrictions.

Participants spoke of the impact of moving to virtual health care visits, which were previously not available. Although introducing their own challenges (e.g. poor connection, computer skills), virtual visits significantly reduced travel time and life disruption for many.

“You know we have all these different ways of communicating through text message and email and phone calls and we used that a lot. So the fact that I physically live four hours away from my transplant clinic has not been an issue. I can easily have daily conversations and have access to everybody through all the technologies that we have today.”

39% of survey respondents said that they now connect with their health care team via online appointments, while 91% reported having access to technology for virtual appointments most or all of the time.

Another participant spoke of the appreciation they had for their health care team in their role for advocating for more information and early access to vaccines, as well as empowering them to advocate more for themselves.

6.0 RECOMMENDATIONS

The patient-focused recommendations outlined in this report are based on an analysis of the opportunities derived from over 1,000 survey and focus group participants. The recommendations were reviewed and refined in collaboration with PAAC members and other stakeholders and all measures require increased accountability through targets, benchmarks and milestones to be reported on throughout the transplant journey.

6.1 PRIORITIZE MENTAL HEALTH AWARENESS AND SUPPORT

Remove stigma, increase transparency, and normalize the conversation around mental health support for transplant patients, living donors and caregivers.

6.1.1 **Integrate meaningful professional support for mental health throughout the transplant journey through referrals at key points (e.g., wait-listed, pre-transplant, post-transplant) and throughout the journey as needed**

- Train specialized mental health care providers to support those on a transplant journey.
- Expand and/or partner with existing mental health services/agencies to include more support for transplant patients and caregivers.
- Develop educational tools for patients, caregivers and health care providers to remove stigma, increase transparency, and normalize the conversation around mental health throughout the transplant journey.

6.1.2 **Ensure that health care providers have the resources and quality development indicators needed to support patients**

- These quality indicators may include validated Patient-reported outcome measures (PROMs) and/or Patient-reported experience measures (PREMs), as well as screening questionnaires on visits with direct referral to team psychologists as needed.
- Create targeted approaches to ensure mental health is explicitly addressed during appointments and check-ups with an understanding that mental health concerns will not create an unnecessary barrier to the process of getting a transplant.

6.1.3 **Establish peer support groups in transplant programs for all organ groups**

- Leverage and adapt existing expertise in peer support (e.g. the KFOC's comprehensive peer support program) and technology (e.g. telehealth and virtual meetings), that provides greater access to rural and remote patients and caregivers.
- Create targeted campaigns through health care providers, social media, disease-specific organizations, and health care professional organizations (e.g. CST, CANSW, CDTRP, etc.) to encourage distribution of information or recommendation of support groups/mentorship programs.

6.2 INCREASE ACCESS TO RESOURCES AND SERVICES

Ensure equitable care for all those on a transplant journey by increasing access to existing supports and expanding the range of educational and financial resources available.

6.2.1 Explore and expand options to increase navigational support during the transplant journey

- Develop a transplant navigator program for patients, living donors and caregivers throughout their journey. The role would be patient-centric rather than system-centric and would support patients as they navigate the ODT system and advocate for themselves.
- Leverage the evidence and best practices of patient navigators established for other complex patient populations (e.g. Cancer, Gerontology).

6.2.2 Establish and/or support an existing central online pan-Canadian repository of information and resources for all those on a transplant journey

- Ensure that patient education is made available at a time and in a manner that suits the patient.
- The repository should include education and services that are searchable by province, organ group, transplant program, and topic.
- Resources for transplant patients, living donors and caregivers should be included.
- Stakeholders at all levels should be able to contribute resources.

6.2.3 Reduce financial burden for patients and caregivers

- Ensure best practices can be scaled across jurisdictions equitably, as jurisdictional differences in resource availability are apparent. For example, the Living Organ Donor Expense Reimbursement Program (LODERP) administered by KFOC covers a wider array of transplant related costs for living donors.
- Adequate funding should be made available to address unpredictability and uncertainty around the transplant process.
- Develop and implement the use of resources about programs, subsidies, and support around finances at every stage of the transplant journey, and that these are communicated early and often with patients and families.
- Expand resources for travel and living expenses, medications, and coverage of other required services, e.g. physiotherapy.

6.2.4 Support patient advocacy for those on a transplant journey

- Establish a national transplant patient charter of rights to foster a true partnership between patients and their health care team, which will improve outcomes and increase transparency.
- Introduce this charter of rights from the beginning of the transplant journey to help build understanding and empower patients with access to self-advocacy and self-management programs.

6.3 IMPROVE COORDINATION AND CONTINUITY OF CARE

Ensure that the communication between and within health care teams, as well as to patients, meets the needs of patients and caregivers throughout their transplant journey.

6.3.1 Establish comprehensive care programs for transplant patients

- Establish and/or centralize the coordination of transplant patient care so that tests and appointments related to a patient's organ transplant or donation are coordinated through a single centre.
- Capitalize on opportunities to combine timing and location of services and tests for patients. This would increase equity by reducing travel time and the number of appointments for those in rural or remote communities.

6.3.2 Increase support for primary care providers caring for transplant patients

- Establish a standardized, evidence-based care pathway or best practice guideline specific for primary care providers and community specialists (e.g., respirologists, hepatologists, etc.) for the ongoing care of transplant patients to help ensure that they are equipped to manage the overall care of this specialized population.

6.3.3 Build on the framework established during the pandemic to offer patients, especially those living remotely and/or further from their transplant centres, virtual access to care throughout the transplant journey

- Utilize virtual health platforms to continue to connect for health care check-ins, appointments with members of the transplant team, peer support, etc.
- Ensure there is an open and consistent line of communication across the Provincial Ministries of Health, the Organ Donation Organizations (ODOs), and the transplant centres, so that information, guidelines and recommendations are consistent and clearly communicated in a timely manner. This will ensure that recommendations from ODOs and the patient's transplant care team get filtered down to patients and caregivers so they can make informed decisions.

7.0 CONCLUSIONS

The Improving Engagement and Empowering Patients on their Transplant Journey project sought to highlight and document the lived experience of patients, living donors, and caregivers on their transplant journey and to propose patient-led and patient-focused recommendations for the renewal and improvement of the Organ Donation and Transplantation system in Canada.

The recommendations outlined in this report concerning mental health, access to resources, and coordination of care represent the most common and pressing needs articulated by over 1000 survey and focus group participants from across Canada. They offer tangible, implementable, and measurable solutions to address the many challenges faced by patients, living donors, and caregivers on their transplant journey. The opportunities and solutions proposed in the report are multi-faceted and actionable across multiple levels.

As this work begins, it will be critical to take a unified approach across provinces and jurisdictions to identify challenges and opportunities that address areas of high impact. Collaboration at the provincial and national level is essential to share resources and build on existing expertise to identify and scale services and models of care that have proven successful in specific jurisdictions. ODOs, Transplant Centres and national programs are encouraged to connect and collaborate using a holistic “systems” approaches wherein other health sectors are purposefully integrated to facilitate care coordination and to prevent duplication of services.

It is important to keep in mind that while commonalities exist, every patient, donor and caregiver journey is unique and dependent on both individual and health system factors that may vary across jurisdictions. The ODT system must continue to prioritize patient-focused recommendations through the lens of those with the greatest barriers, recognizing that they may not have been fully represented in this data.

Understanding the lived experience of patients, families and donors is central to creating and supporting an ODT system that best meets the needs of those it seeks to serve. As such, transplant donors, organ recipients and their supporting networks are central to its governance structure, development and restructuring moving forward. It is imperative that this new governance structure commits, on an ongoing basis, to take the time to ask, listen, and learn from patients, donors, families, and caregivers to both continue to understand their lived experiences and to empower them to help improve it.

REFERENCES

1. Canadian Institute for Health Information. Treatment of End-Stage Organ Failure in Canada, Canadian Organ Replacement Register, 2011 to 2020. *CIHI*. 2021.
2. The Kidney Foundation of Canada. The Burden of Out-of-Pocket Costs for Canadians with Kidney Failure. 2018.
3. El-Dassouki N, Wong D, Toews DM, Gill J, et al. Barriers to accessing kidney transplantation among populations marginalized by race and ethnicity in Canada: A scoping review part 2 - East Asian, South Asian, and African, Caribbean, and Black Canadians. *Canadian Journal of Kidney Health and Disease*. 2021 Mar 3;8:2054358121996834. doi: 10.1177/2054358121996834. eCollection 2021
4. Pol SJ, Snyder J, Anthony SJ (2019) "Tremendous financial burden": Crowdfunding for organ transplantation costs in Canada. *PLoS ONE* 14(12): e0226686. <https://doi.org/10.1371/journal.pone.0226686>
5. Alberta Health Services. Prevalence of Severe Kidney Disease and Use of Dialysis and Transplantation Across Alberta from 2004-2013: Alberta Annual Kidney Care Report. April 2015.
6. Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of Internal Medicine*. 2012;27(5):520-526.
7. Mahoney ER, Stock R, Tusler M. Do increases in patient activation result in improved self-management behaviors? *Health Services Research*. 2007;42(4):1443-1463.
8. Nathan JJ, Hanson CS, Josephson MA, et al. Motivations, challenges, and attitudes to self-management in kidney transplant recipients: A systematic review of qualitative studies. *American Journal of Kidney Diseases*. 2016; 67(3):461-478.
9. Hibbard JH, Greene J. What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs*. 2013;32(2):207-14.doi:10.1377/hlthaff.2012.1061
10. Macklin, J.A., Djihanian, N., Killackey, T., & MacIver, J. (2019). Engaging Patients in Care (EPIC): A Framework for Heart Function and Heart Transplant– Specific Patient Engagement, *CJC Open*. 1(2), 43-46. <https://doi.org/10.1016/j.cjco.2019.01.002>
11. Allard J, Durand, C, Anthony S, et al. Perspectives of patients, caregivers and researchers on research priorities on donation and transplantation in Canada: A pilot workshop. *Transplantation Direct*. 2017;3(2): e127. doi:10.1097/TXD.0000000000000639

APPENDICES

- A PAAC members**
- B Stakeholders and partners**
- C Patient engagement model**

Appendix A : PAAC Members

Members of the Patient/Advocate Advisory Committee	
Name	Title/Institution/Representation
Kristi Coldwell (co-Chair)	Transplant (heart) recipient Senior Advisor, Transplant Advocacy, Transplant Research Foundation of British Columbia
Lydia Lauder (co-Chair)	National Director, Programs and Public Policy, Kidney Foundation of Canada
Mary Beaucage	Transplant (kidney) recipient Co-Chair, Can-SOLVE CKD Patient Governance Circle
Nancy Campana	Patient advocate
Sylvie Charbonneau	Living kidney donor
Maryanne D'Arpino	Senior Director, Safety Improvement and Capability Building Canadian Patient Safety Institute
Sandra Davidson	Living donor Dean of nursing, University of Calgary
Sean Delaney	Transplant (kidney) recipient Associate Director, Organ Listing and Allocation Canadian Blood Services
Shelby Gielen	Transplant (liver) recipient
Sandra Holdsworth	Transplant (liver) recipient CDTRP Patient Co-Lead Theme 5 Former provincial Director of the Canadian Transplant Association
Wendy Kudeba	National Director, Marketing & Communications, Kidney Foundation of Canada
Tom Meade	Transplant (kidney) recipient Volunteer Past President of the Atlantic Branch of Kidney Foundation of Canada
Elizabeth Myles	Executive Director, Kidney Foundation of Canada
Randy Spensley	Transplant (kidney) recipient Engagement Officer-Community Initiatives, Kidney Foundation of Canada—British Columbia
Michael Sullivan	Transplant (heart) recipient National Director (Ontario), Canadian Transplant Association
Émile Thérien	Donor family representative
Hans Vorster	Transplant (kidney) recipient Patient Partner, Patient Governance Council, Can-SOLVE CKD Co-Chair, Canadian Nephrology Trials Network
Sarah Douglas	Policy Analyst, Health Programs and Strategic Initiatives

Appendix B : Stakeholders and Partners

Advocacy/Patient Organizations	
Name	Organization
Elizabeth Myles	The Kidney Foundation of Canada
Sadia Baig	
Hélène Boisvert	
Suzanna D'Aprile	
Val Dunphy	
Shannon Fogarasi	
Sue Fong	
Jill Goth	
Lauren Kapphahn	
Wendy Kudeba	
Lydia Lauder	
Craig Lindsay	
Trina Ralph	
Flavia Robles	
Pia Schindler	
Anthony Tirone	
Philippe Vincent	
Manuel Escoto	Canadian Donation and Transplantation Research Program
Chelsea Patriquin	
Brenda Brown	Canadian Transplant Association
Jan Clemis	
Nem Maksimovic	Canadian Liver Foundation
Eunice Mamic	Cystic Fibrosis Canada
Kelly Ablog-Morrant	BC Lung Association
Canadian Blood Services	
Name	Organization
Amber Appleby	Canadian Blood Services
Sean Delaney	
Clay Gillrie	
David Hartell	
Peggy John	
Jenny Ryan	

Other Stakeholders and Partners

Name	Organization
Ed Ferre Cindy Luo	BC Transplant
Katherine Waks	International Transplant Nurses Society
Dr. Joanne Kappel Dr. Holly Mansell	University of Saskatchewan
Corinne MacNab	Canadian Association of Nephrology Social Workers
Clare Payne	Trillium Gift of Life Network
Erin Schimpf	Saskatchewan Health Authority Transplant Program
Betty Wolfe	Saskatchewan Health Authority Donation Program
Amanda Workman	Nova Scotia Health Authority
Jo-Anne Woolridge	Newfoundland & Labrador Transplant Program
Michelle Mackey	Newfoundland & Labrador Transplant Program

Appendix C : Patient Engagement Model

Stakeholders and partners

PAAC members were instrumental in building the network of stakeholders and partners for the project, including ODOs, transplant programs, and regional and national advocacy organizations such as the KFOC and the Canadian Liver Foundation. These partnerships facilitated the gathering of an extensive inventory of resources for transplant patients and those who support them.

Inventory of resources

PAAC members and project participants shared resources useful to them on their own journey, and organizations such as KFOC, the Canadian Transplant Association and many others were consulted. This helped facilitate the building of a large inventory of resources for Canadians on a transplant journey.

Patient network

The patient network that made up the project's focus groups was built via direct recommendations from PAAC members, key organizations such as the Canadian Transplant Association, and members of the ODTG.

Survey

The questions in the online survey were derived in collaboration with PAAC members over multiple meetings in early 2021, who also assisted in pilot testing the survey in the spring of 2021. PAAC members, project participants, and stakeholders helped to promote the survey through their personal and professional networks. The research team also promoted the survey via multiple presentations at the national level, including during the CDTRP Patient, Family and Donor Research Forum in November 2021.

Focus groups

The focus group questions were similarly derived in collaboration with the patient partners in the PAAC over multiple meetings, and some members with peer support experience served as facilitators during the focus group sessions. Per the patient partners' recommendations, each of the two sessions made up four groups of approximately 4 to 6 individuals.

Final report

The final report is based on the analysis of the survey and focus group data. Members of the PAAC played an integral role in the refinement of the recommendations based on the results.