

Defining Future Research Priorities in Donation and Organ and Stem Cell Transplantation with Patients, Families, Caregivers, Healthcare Providers and Researchers Within the Canadian National Transplant Research Program

Ballesteros-Gallego et al. (2018)
<https://doi.org/10.1097/TXD.0000000000000791>

For which topic were research priorities identified?

donation and organ and stem cell transplantation

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

Patients, families, and caregivers have a unique understanding of the diseases they live with and provide care for every day. Their experience and expertise are important and should be taken into consideration when determining research priorities.

What was the objective?

to gather the perspectives of Canadian patients, families, caregivers, researchers, and healthcare professionals on what research priorities were important to them in the field of organ and hematopoietic cell transplantation and donation within the Canadian National Transplant Research Program

What was the outcome?

a ranking list of 20 research questions

How long did the research prioritization take?

April 2015 - November 2015

Which methods were used to identify research priorities?

survey; workshop

How were the priorities for research identified exactly?

Step 1: pilot workshop to design survey questions and identify research priorities. Step 2: survey: participants were asked to rank 14 research priorities. Step 3: workshop: background lecture and small group discussions: participants were asked: According to your experience, what research priorities should be developed within the CNTRP?, to incite and facilitate discussion a list of the top 28 research priorities was provided to all participants, after small group discussions participants came back together for plenary session, each group presented its top 3 research priorities identified, afterwards participants voted anonymously on their top 3 priorities for transplantation and for organ/stem cell donation

Which stakeholders took part?

Survey: 505 participants: patients, caregivers, researchers and healthcare professionals. Workshop: 46 participants: kidney transplant recipients, HCT recipients, waitlisted patients, lung transplant recipients, heart transplant recipients, liver transplant recipients, multi-organ transplant recipients, caregivers, researchers and healthcare professionals (physicians, surgeons, psychologists, nurses, social workers, dietician, pharmacists, and physiotherapists).

How were stakeholders recruited?

Survey: Recruitment was primarily done through professional and patient associations that had agreed to distribute and promote the survey invitation to their members. These groups included (i) professional organizations, such as the Canadian Society of Transplantation and the Canadian Blood and Marrow Transplant Group; (ii) health charities, such as the Kidney Foundation of Canada and the Canadian Liver Foundation; (iii) patient advocacy groups, such as the Canadian Transplant Association (CTA); (iv) organ donation organizations, such as Transplant Québec, Trillium Gift of Life and Canadian Blood Services; and (v) members of the CNTRP research network. Facebook and Twitter were also used. The survey was also promoted during the launch of the 2016 Transplant Games in Toronto in April 2015. Workshop: To recruit participants, a purposive method (for researchers and HCPs) and a snowball and purposive sample method (for patients and caregivers) were used. To recruit researchers and HCPs, the research team therefore selected individuals who they believed would provide and generate valuable information. For patients, a purposive and a snowball strategy was used that involved inviting patients to suggest other participants for both these participants were recruited from different age groups and regions of Canada, and with different experiences, areas of expertise, and so on.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the