

Perspectives of Patients, Caregivers and Researchers on Research Priorities in Donation and Transplantation in Canada: A Pilot Workshop

Allard et al. (2017)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5367744/>

For which topic were research priorities identified?

donation and transplantation

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

It is vitally important to seek input from key stakeholders to increase the quality and relevance of health-related research and accelerate its adoption into practice. Patients and caregivers have rarely been involved in setting research priorities in the transplantation and donation field.

What was the objective?

to discuss research priorities within the Canadian National Transplant Research Program during a priority-setting exercise with patients, caregivers, organ donors and researchers

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

one day, August 2014

Which methods were used to identify research priorities?

workshop

How were the priorities for research identified exactly?

Step 1: workshop: participants were asked to recall their experience related to transplantation and/or donation and to express the challenges they have faced that research should address. Step 2: data processing: thematic analysis. Step 3: after the workshop: participants were asked to fill in evaluation form to include any additional comments or insights they had on the topic. Step 4: results of analysis sent to participants for validation. Step 5: literature review to validate research gaps

Which stakeholders took part?

15 participants: patients and caregivers had diverse experiences with regard to donation and transplantation: 3 participants were heart transplant patients, 1 was a kidney-pancreas transplant patient, 1 was a liver-lung transplant patient, 1 was a lung transplant patient, 1 was a stem cell transplant patient, 1 was a patient waiting for a kidney transplant, 1 was a kidney donor, and 1 was the parent of a lung transplant patient and cornea donor, researchers worked in 5 different areas of transplantation and donation: intensive care and donation, translational medicine in kidney transplantation, pancreatic islet transplantation, heart transplantation, and ethics

How were stakeholders recruited?

A purposive and snowball sample methodology was used: the sample had to be small to allow discussion (15 participants) and diverse (recipients of different organs, organ donors, patients awaiting an organ, caregivers and researchers from different fields of expertise). Recruitment was made either through treating physicians, the Collaboration and Patient Partnership Unit of the Université de Montréal (a patient partnership-focused organization) or a list of patients who had previously expressed their interest in participating in research projects. Patients invited had to be fluent in French.

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 process.