

## Role of Patients in Organ Donation and Transplantation Governance Models and Decision-Making Processes

### What is this project about?

#### Project background

While there is recognition of the need to include patients in decision-making roles in healthcare governance structures – including in organ donation and transplantation (ODT), how to best involve them in these structures is not well understood.

Indeed, there's a need to develop strategies that enable patients to have a greater say in ODT related decisions that affect them.

#### Objectives

The project aims to conduct an environmental scan of patient-centered governance models in Canada's healthcare sectors and make recommendations on patient involvement. The recommendations will inform the Organ Donation and Transplantation Collaborative (the Collaborative) as they move forward on the development of a pan-Canadian ODT governance model.

#### Overview of activities

- Examine existing models of patient involvement in organizational governance structures in Canadian healthcare sectors.
- Describe the commonalities and differences in the governance structures that include patient involvement.
- Identify existing methods of evaluating patient governance models in Canadian healthcare sectors.
- Develop recommendations or considerations for a patient governance model to inform the work of the Collaborative.

EXPECTED COMPLETION IN 2022

### How will the project improve the organ donation and transplantation system in Canada?

The project will contribute to:

- Promoting the involvement of patients in the ODT pan-Canadian governance model and decision-making processes.
- Increasing knowledge on inclusion of patients in governance models and its potential benefits.
- Providing guidance for the future pan-Canadian ODT model that includes a patient engagement strategy.
- Improving the accessibility, quality, responsiveness, accountability and sustainability of the ODT system thanks to a greater implication of patients in decision-making.

### Project Support

The project is led by *SPOR (Strategy for Patient-Oriented Research) Evidence Alliance*, which is supported by the Canadian Institutes of Health Research (CIHR) under Canada's Strategy for Patient-Oriented Research (SPOR).



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*"This initiative will provide recommendations to inform patient engagement in organizational governance for ODT and others in a significant way."*

**The Organ Donation and Transplantation Collaborative** is an initiative led by Health Canada with provinces and territories (except Québec), Canadian Blood Services, patients, families, clinicians and researchers. Funded by Health Canada, the project *Role of Patients in Organ Donation and Transplantation Governance Models and Decision-Making Processes* contributes to the Collaborative's vision to achieve organ donation and transplantation system improvements that result in better patient outcomes and an increase in the number and quality of successful transplantations. For more information, please consult the Organ Donation and Transplantation Collaborative ([the Collaborative](#)) website.