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# ENVIRONMENTAL SCAN ON THE ROLE OF PATIENTS IN GOVERNANCE MODELS AND DECISION-MAKING FOR THE ORGAN AND DONATION TRANSPLANTATION SETTING

## FINAL REPORT

**Prepared for:** The Organ Donation and Transplantation Collaborative (ODTC)

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## Executive Summary

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Few studies exist on the involvement of patients and the public in healthcare service governance structures. To bridge this gap, the KTP conducted a scan of patient-centered governance models within health care sectors. This included a grey-literature document review and key informant interviews. For the document review, 40 unique documents across 10 organizations were identified through grey literature reviews, website searches, and participant interviews. Eleven participants were recruited from 11 pre-determined Canadian and international health care organizations to participate in semi-structured key informant interviews.

Based on the findings of the document review and interviews, known patient engagement activities were summarized for 9 of the organizations for which sufficient data on their engagement activities was available. Commonly conducted patient engagement and governance activities included: membership on governance and advisory bodies; providing input on research priorities; and, participation in multiple aspects of research conduct, including proposal and funding reviews, project leadership, and dissemination activities.

Five frameworks to support patient engagement activities were also identified from the scan. These included: the International Association for Public Participation (IAP2) Spectrum of Public Participation, the Carman Multidimensional Framework, the Health Canada and Public Health Agency of Canada Guidelines on Public Engagement, the Canadian Agency for Drugs and Technologies in Health (CADTH) Framework for Patient Engagement in Health Technology Assessments, and the Montréal Model.

The document review revealed that patient and public involvement in organizational governance structures exist in the policy, education, research, and service fields. Common suggestions for improving patient/public interactions include: encouraging open communication, allowing for patient/public input, creating an equitable system for populations with described vulnerabilities to fully participate, and raising awareness of systemic racism and Indigenous rights.

The document review also uncovered limitations in existing patient/public governance models including: underrepresentation of equity-seeking groups, tokenism, and power imbalances. Patients may not be aware of opportunities to become involved in an organization's governance structure. Even when patients joined in governance, they are often not provided the appropriate training nor are they provided clarity on the organization's expectations of their involvement. Conversely, fostering patient engagement in all stages of the research process, encouraging inclusivity and diversity in patient/public representatives, and building partnerships with patients/public are key facilitators to good governance engagement.

All interview participants (n=11) emphasized the importance of the patient partner's voice in every stage of a research and decision making process. They perceived this could be done by encouraging co-developing/co-leading with patient partners (n=11) to ensure their lived experiences within the healthcare system are represented and informing project focus or decision-making (n=5). Furthermore, many participants (n=10) highlighted suggestions for increasing patient engagement activities within governance models, including: encouraging co-development of engagement activities (n=6); providing



capacity building opportunities (n=4); increasing Equity, Diversity, and Inclusion (EDI) and accessibility (n=4); and promoting trust (n=1) and openness (n=1) with patient partners.

Similar to the document review, interview participants (n=5) flagged power imbalances, tokenism, non-meaningful engagement, and lack of EDI as challenges to patient engagement in governance models. Participants also highlighted the importance of open communication with patients, which can be accomplished by using a readily accessible Terms of References to outline the rules and responsibilities of patient partners (n=7) and clear and transparent communications (n=4).

All participants (n=11) highlighted that their organizations provide capacity-building opportunities to patient partners once they join the organization; organizations also provide varied supports including psychological/emotional supports (n=2) to ensure patients can successfully participate in engagement activities. Organizations also employ tailored compensation (n=6) and reimbursement (n=4) strategies to ensure patients are appropriately compensated for their time.

Based on the results of the document review and key informant interviews, recommendations have been provided for consideration when designing a patient governance strategy for organ donation and transplantation in Canada including: building on existing models for patient engagement, employing EDI principles to governance activities, and creating a supportive engagement environment for patients.

The information and recommendations in this report can be used to inform and support the development of a model for patient involved governance of organ donation and transplantation in the Canadian healthcare setting.

# **Environmental Scan on the Role of Patients in Governance Models and Decision-Making for the Organ Donation and Transplantation Setting**

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## **1. Introduction**

Since 2018, The Organ Donation and Transplantation Collaborative (ODTC) has been working to improve the Canadian healthcare system and ensure that Canadians have timely and effective access to quality organ donation and transplantation services. A recent report commissioned by Health Canada identified that a governance gap exists within the ODTC (1). The lack of a single governance table with clear roles and responsibilities has hindered collaboration among federal, provincial and territorial governments, and ODTC partners.

Very few publications are available to advise on patient and public involvement within governance structures of health services and healthcare sectors. This gap has contributed to ongoing tension between the desire for evidence-based practice and patient and public involvement within health policies. Accordingly, there is a need to explore patients' roles in governance models, particularly in decision-making roles. Further, clarity is required to understand patients' involvement in organ donation and transplantation in the Canadian context.

Enhanced understanding of existing models of patient and public governance structures will aid in addressing the gaps and enable opportunities to design and implement a new model for patient and public engagement that goes beyond the current operations at the ODTC. The purpose of this project is to support internal operational considerations and planning, in alignment with pan-Canadian governance priorities identified by the ODTC.

To fulfil this gap, the Knowledge Translation Program (KTP) conducted an environmental scan of patient-centered governance models used within healthcare sectors. This scan included 1) a review of organizational documents (see Appendix A) and 2) interviews with key stakeholders at targeted organizations (see Appendix B). The purpose of this scan is to inform the ODTC's discussions and their development of a public and patient governance model.

The specific research objectives of this scan are to:

- a) Examine existing models of patient and public involvement in organizational governance structures in healthcare sectors in Canada and similar high-income countries.
- b) Describe the commonalities and differences in the governance structures that include patient/public involvement.
- c) Identify existing methods of evaluating patient/public governance models in healthcare sectors in Canada and similar high-income countries.
- d) Develop recommendations or considerations for a patient and public governance model for the ODTC strategic planning.

The purpose of this report is to provide results from the environmental scan and present recommendations for points to consider when developing a plan for patient and public involvement in governance for organ donation and transplantation in Canada.

## 2. Methods

This investigation was guided by the ODTG working group and implemented by the KTP team. This study implemented a two-phased qualitative descriptive approach. First, a document review identified existing models of patient/public governance or engagement, strategies, and challenges to patient/public governance and engagement from organizations identified by the ODTG working group (see Appendix A). Second, semi-structured key informant interviews were conducted by members of the KTP team with representatives from pre-selected Canadian and international healthcare organizations (see Appendix B). International organizations were selected from similar high-income countries to Canada, including Australia, the United States of America, and the United Kingdom.

### 2.1 Recruitment

#### *Key Informant Interviews*

Participants were eligible for key informant interviews if they were an organization member or patient partner with knowledge of their organization's patient/public engagement activities.

The following methods were used to recruit key informants:

#### **Circles of Contact**

The ODTG working group provided a list of potential participants and their email addresses based on their circle of contacts. The KTP team then contacted these individuals using a standard interview email invitation and study information sheet. After receiving the initial email invitation, interested individuals contacted the KTP team directly.

#### **Hand Searching**

The KTP team reviewed the pre-determined organizations' websites and identified relevant individuals to contact via an email interview invitation. Interested individuals could respond to this invitation and would then receive a standard email response from the research team explaining the next steps.

#### **Snowball Recruitment**

Consenting interview participants made initial contact with others within their circle of contacts who they thought would be interested in the study, and provided them with the study information sheet. Of these individuals, those interested in the project contacted the KTP team and were sent standardized emails. This process enabled the KTP team to inform interested participants if they met the project's eligibility criteria.

### 2.2 Data Collection

#### *Document Review*

The ODTG working group co-developed a set of inclusion and exclusion criteria with the KTP (see Appendix A). The KTP searched for relevant grey literature documents using the pre-determined list set of inclusion/exclusion criteria and list of sources (see Appendix A). They reviewed the websites of targeted organizations and identified associated relevant grey literature (i.e., website pages, strategic plans, reports, terms of reference, etc.) that described the organization's patient/public governance or

engagement model and activities. This search was limited to organizations selected by the ODTG working group and to documents published in English from January 2016 to January 2022. January 2016 was selected as a reasonable cutoff date by the ODTG working group.

Interview participants were also asked to highlight any relevant documents that described patient/public engagement strategies, governance activities, and impacts.

### ***Key Informant Interviews***

The KTP team attempted to recruit 1-2 key informants per organization (see Appendix B) to interview. Interviews were conducted virtually using teleconferencing or video-conferencing software and took place in Spring 2022. A semi-structured interview guide in English (see Appendix C) was co-developed with the ODTG working group and was informed using the Objectives, Goals, Strategies and Measures (OGSM) framework (2). Demographic data (e.g., sex, gender) was not collected. The interview guide consisted of open-ended questions that enabled respondents to provide detailed answers on the following:

- The types of patient/public engagement and governance models within their organization's approaches, policies, and activities
- The impact of these engagement models
- Lessons learned based on their experiences in these engagement processes
- Suggestions for their own and other organizations

Two research team members attended the interviews - one was responsible for conducting the semi-structured interview and the other took detailed notes. All interviews were audio-recorded.

## **2.3 Data Analysis**

### ***Document Review***

Two analysts on the KTP team independently reviewed 5 randomly selected documents and coded the data using a data abstraction template (see Appendix D). The template noted demographic information about the document, in addition to key categories of interest (e.g., goals of patient/public governance or engagement activities). Agreement between the two KTP analysts was checked using a percent agreement. Once 75% agreement was achieved, the analysts continued to proceed with single coding for the remaining documents.

### ***Key Informant Interviews***

The interview data were analyzed using a rapid analysis approach, which allowed for the use of rigorous methods to quickly categorize qualitative data (3). Directly following an interview, one research team member reviewed the notes and audio recording to ensure all important details were accurately transcribed.

Once the interview notes were verified, two research team members applied a coding framework (see Appendix E) based on the OGSM framework and the objectives of the project to the interview notes. Two analysts initially coded the first transcript together to develop an understanding of the coding tree. They then individually coded the second transcript, compared their work to ensure mutual understanding and

made slight modifications to the coding tree. All remaining transcripts were double coded and discrepancies were discussed in consensus meetings. Following resolution of all discrepancies, a matrix was created to develop summaries of the themes present in the data.

### 3. Results

Data from the document review and interviews are presented separately below. These data were triangulated and used to develop the summaries and recommendations presented in [Section 4](#) and [Section 5](#) respectively.

#### 3.1 Document Review Findings

Forty (40) unique pieces of grey literature were reviewed. Tables 1, 2 and 3 summarize the number of documents reviewed by organization, by country and by type of document. The findings of the document review are summarized using predetermined categories in Table 4.

**Table 1. Number of Documents Reviewed by Organization**

Organization	Number of Documents
First Nation's Authority in BC	7
Canadian Partnership Against Cancer	5
Donate Life Australia	1
Organ Procedure Transplantation Network	1
NIHR   National Institute for Health Research	10
CADTH (pan-Canadian)	10
SPOR Evidence Alliance	3
Patient-Centred Outcomes Research Institute (US)	2
Alberta Health Services	1
INESS (Quebec)	0
<b>TOTAL</b>	<b>40</b>

**Table 2. Number of Documents Reviewed by Country**

Country	Number of Organizations	Number of Documents
Canada	6	26
The United States	2	3
United Kingdom	1	10
Australia	1	1
<b>TOTAL</b>	<b>10</b>	<b>40</b>



**Table 3. Number of Documents Reviewed by Document Type**

Document Classification	Number of Documents
About Us	4
Annual Report/Reviews	13
Missions/Visions/Values	3
Other	3
Program/Initiative Description	15
Terms of Reference	2
<b>TOTAL</b>	<b>40</b>

**Table 4. Results of Grey-Literature Document Review**

Category	Findings
Examples of areas of work using patient and public involvement in organizational governance structures	<ul style="list-style-type: none"> <li>• Policy</li> <li>• Education</li> <li>• Research</li> <li>• Identity Management</li> <li>• Services</li> </ul>
Audiences involved in patient and public governance models	<ul style="list-style-type: none"> <li>• Chief Medical Officer</li> <li>• Provincial Health Officer at the Ministry of Health</li> <li>• Representatives from the primary care sector, charities, and research organizations</li> <li>• Patients, caregivers/families, and users of health systems or those who have direct experience with topic of interest</li> <li>• Researchers and clinicians</li> <li>• Federal leaders responsible for the planning and delivery of healthcare policies</li> <li>• Representatives from First Nations, Inuit and Métis governments, organizations, and communities</li> </ul>
Commonalities among governance structures	<ul style="list-style-type: none"> <li>• <i>No data available</i></li> </ul>
Differences among governance structures	<ul style="list-style-type: none"> <li>• <i>No data available</i></li> </ul>

Category	Findings
<p><b>Methods of evaluating patient/public governance models</b></p>	<p>Examples of identified evaluation methods reported in the document review include:</p> <ul style="list-style-type: none"> <li>• Regular monitoring and reporting on organizational outcomes with patient/public input</li> <li>• Using evaluation principles consisting of reciprocal accountability, wisdom, partnership, responsibility, respect, and action orientation</li> </ul>
<p><b>Suggestions for improving patient/public relationships with organizations</b></p>	<p>Examples of common recommendations for improving patient/public relationships with organizations include:</p> <ul style="list-style-type: none"> <li>• Incorporating increased awareness of systemic racism and Indigenous rights when considering Federal and Provincial commitments in addressing inequalities</li> <li>• Focusing on building an equitable system and trust with all patients/public members, especially vulnerable populations who may require additional support</li> <li>• Creating a coordinated, pan-Canadian collaboration between organizations, federal leaders, patients, and the public with a collective goal of impact</li> <li>• Considering and incorporating input received through current and previous engagement processes</li> <li>• Ensuring clear communication and a trusting relationship is fostered</li> <li>• Creating targets and measurable plans (e.g., ensure that a proposed plan and target outcome is measurable over a 10-year timeframe)</li> </ul>

Category	Findings
<p><b>Published limitations to consider in future patient/public models</b></p>	<ul style="list-style-type: none"> <li>• Focusing too heavily on specific target outcomes and less so on indirect findings can minimize the progress of other initiatives that address inequalities</li> <li>• Equity seeking groups are often underrepresented in spaces that are created to provide patients a voice in governance</li> <li>• There can be lack of awareness of available opportunities for participants, a lack of resources, and a misalignment between users' aims and organizations' aims</li> <li>• Tokenism and power imbalances can play a role in some patient public governance models</li> <li>• A lack of preparation and training for patients involved in governance models can hinder good patient/public governance</li> <li>• Not clarifying the organization's expectations to patients before they become involved can hinder good patient/public governance</li> </ul>
<p><b>Strengths of existing models</b></p>	<ul style="list-style-type: none"> <li>• An understanding of participant's motivation and expectations; this is important in fostering a safe environment and promoting participation</li> <li>• Having diversity in patient/public representatives</li> <li>• Fostering patient engagement at all stages of the research process</li> <li>• Participation in multi-network research and building external collaborations</li> <li>• Ensuring political commitment</li> <li>• Building partnerships with patients/public members</li> <li>• Upholding principles of inclusivity</li> <li>• Being deliberate in engagement activities</li> </ul>

### 3.2 Key Informant Interview Findings

Participants' demographic information (e.g., sex, gender) were not collected. The following themes were found in eleven participant interviews:

#### ***Existing Patient Engagement Models***

A variety of patient engagement models/strategies were highlighted by interview participants:

- Internal organizational best practices (further information not provided) (n=4)
- IAP2 Spectrum of Public Participation (4) (n=3)
- Carman Multidimensional Framework (5) (n=2)
- Health Canada and Public Health Agency of Canada's Guideline on Public Engagement (6) (n=2)
- Montreal Model (7) (n=2)
- Patients First Strategy (n=2)

#### ***Patients at the Center of Engagement***

Models used by the participants' organization differed among the participants, however, all participants emphasized the importance of incorporating patient experiences. All participants (n=11) highlighted that their organization is focused on integrating the voices, diverse perspectives, and unique experiences of patients and families at all steps of the decision-making process. Participants also noted that they are moving towards co-leading patient engagement programs.

#### **Illustrative Quote**

*"The goal is to get the patients, users, or caregivers experience of what it is to live with a particular to disease and be able to implement the knowledge within the evaluation projects, so not only by literature reviews but also by completing the knowledge with actual experience about the actual disease, how they dealt with it, what are the experiences within the health systems, are all the cares organized, etc."*  
– P04

#### ***Risks and Challenges to Patient Engagement***

Participants mentioned tokenism (n=3), non-meaningful engagement (n=1), lack of Equity, Diversity, Inclusion (EDI) considerations in the engagement framework/model (n=2) and staff fatigue (n=1), as risks and challenges to patient engagement.

Another participant also noted complications around power sharing in the decision making process (n=1).

One participant (n=1) suggested that they perceived no risks associated with engaging patients.

#### **Illustrative Quote**

*"Risk is engaging in less than meaningful ways and also engagement fatigue for staff. We need to support staff well and ensure they are feeling like they are contributing and leading meaningful engagement."* – P07

## ***Common Patient Engagement Recruitment Strategies***

The following sub-themes were perceived as common patient engagement recruitment strategies:

### **Established Patient Networks**

Participants reported that a variety of recruitment strategies are used to engage patient partners. Three prominent strategies for recruitment are the use of patient databanks (n=3), patient networks (n=3), or alliance memberships (n=2). These strategies rely on having an existing pool of patients that can be contacted when a relevant project arises, such as a governance activity.

### **Internet and Social Media**

Open door application recruitment processes were highlighted by most participants (n=6). This entails organizations displaying information about patient engagement on their website or actively recruiting patient partners through their social media channels.

### **Screening Interviews**

Some participants (n=3) mentioned that for initial recruitment, their organizations opted to conduct interviews to learn more about the applicant's interest in and suitability for patient engagement roles.

### ***Purpose of Patient Partners Within Organizations***

Participants (n=5) highlighted that they look for patient partners to share their lived experiences within the health care system. This helps to bridge the gap between the experiences of organizations' staff and patients with the goal of having lived patient experiences inform the focus of projects.

### **Illustrative Quote**

*"The role is the embedded lived experience, to give the continuity of experience to the project, and to break down the barriers among experts. It is also about patients sharing and bringing in new ideas and looking at new ways to add to the experience journeys. They bring this wider view to the table." – P07*

### ***Roles of Patient Partners Within Organizations***

A variety of roles are available for patient partners within organizations, including:

- Project advisor (n=8)
- Peer reviewer (n=2)
- Lead presenter (n=2)
- Co-project leads (n=2)
- Paper author (n=1)

Patient partners may also be involved in variety of activities, such as:

- Suggesting new project ideas (n=4)
- Participating in the conduct of research projects (n=4)
- Decision making power/voting on key decisions (n=2)

### ***Tailoring Roles to the patient***

Participants (n=2) described tailoring the roles assigned to patient partners based on the patient's experience. This was used as a strategy for determining what projects patients may work on, in addition to assigning particular project sub-tasks to patients.

### ***Support Provided to Patient Partners***

Participants outlined several supports offered to patient partners to ensure they are able to comfortably and feasibly participate in engagement activities. Examples of these supports included:

- Travel support/expense coverage (n=3)
- Psychological/emotional support, e.g., grief support (n=2)
- Access to child care, especially for patients on advisory committees (n=2)
- Physical support, e.g., ensuring buildings have wheelchair ramps (n=2)

### **Illustrative Quote**

*“As part of our consent, we are able to offer emotional support – usually have someone on standby or are able to connect somebody who can offer that support.” – P01*

### ***Capacity Building for Patient Partners***

All participants (n=11) reported that their organization provides capacity building opportunities for their new and existing patient partners. These capacity building opportunities can take the form of orientations, trainings, or information sharing meetings. Organizations prioritized offering virtual content, with an aim to make information accessible for patient partners.

### ***Compensation Strategies***

Most participants (n=7) outlined compensation strategies. These strategies were different across participants' organizations and within organizations, depending on the patient partner's role. One organization conducted an environmental scan to harmonize their compensation rate with Strategy for Patient Oriented Research (SPOR) entities in Canada (8). Recognition (e.g., including a patient's name on a paper) was also noted by some participants (n=2) as a compensation strategy.

Reported compensation rates (in CAD):

- Single event participation (workshop or focus group) (n=3): \$25
- All patient Partner engagements (n=2): \$25/hr
- Expert committee participation (n=1): \$130/hr
- Non decision making role on projects (n=1): \$100/hr
- Committee participation (n=1): \$35/hr

### **Illustrative Quote**

*“We co-developed a patient compensation/appreciation policy and have various ways. For example, we provide a \$25/hour that was agreed upon initially but if more heavily involved we provide additional compensation like transportation or child care. All of our policies are on our website.” – P02*

### **Reimbursement Strategies**

Some participants (n=3) outlined reimbursement strategies that their organizations extended to patient partners. These strategies involved reimbursing any out of pocket expenses (e.g., travel) required for project participation. Some participants' (n=2) organizations cover only reimbursements, while another participant's (n=1) organization provides compensation in addition to reimbursement.

### **Communication with Patient Partners**

Participants (n=4) emphasized the importance of transparent communication with patient partners. Participants note that the perceived benefits of transparent communication include clarity in position responsibilities and increased comfort for patient partners.

### **Illustrative Quote**

*"We try to really keep them in the loop. So for all of their contributions, will be informed of the development of the project." – P05*

### **Patient Partner Terms of Reference**

Many participants (n=7) highlighted that their organizations' Terms of Reference generally outline rules and responsibilities of patient partners, compensation, support structures, and other relevant information. Terms of Reference help patient partners determine whether they want to participate and keep the organization accountable.

### **Importance of using an Equity, Diversity, and Inclusion (EDI) lens for engagement**

All participants (n=11) outlined the importance of focusing on increasing diversity, equity, inclusion, and accessibility of patient engagement initiatives. They suggested that this can be done by improving staff members' cultural competencies through training, increasing representation in the patient recruitment processes, recognizing and addressing accessibility concerns along with the diverse needs of patient populations. Participants also emphasized the need for an EDI lens when designing, implementing, and co-leading engagement activities with patients.

### **Illustrative Quotes**

*"We are thinking of providing cultural safety training to everyone to be mindful as we do some work with Indigenous people and this can help with power and oppression that may exist on the team." – P02*

*"Need to recognize different impairments as some of the sectors will have accessibility problems in doing that. A hybrid between face to face and virtual is good especially in big countries like Canada and Australia." – P09*

### **Participant Suggestions for Patient Engagement Activities**

Participants (n=10) provided a number of suggestions and guidance on developing and implementing patient engagement activities, including:

- Involving patient partners in the co-development of engagement activities (n=6)
- Increasing diversity, inclusion, and accessibility of patient engagement initiatives (n=4)

- Providing capacity building opportunities to patient partners (n=4)
- Providing patient partners with opportunities to engage in peer-to-peer support (n=1) (i.e., patient partners help one another)
- Emphasizing open mindedness in the planning process (n=1)
- Developing trusting relationship with patient partners (n=1)

### **Illustrative Quotes**

*“We have learned that by engaging patient partners across all committees as opposed to a patient council, we were able to ensure that patient perspectives were integrated across the model of governance.” – P04*

*“Being transparent about recruitment, decisions, results sharing. Be open and flexible but be willing to give up power as families are involved in co-creation and partnership. Build this over time.” – P01*

### **Measuring and Monitoring Patient Engagement**

Many participants (n= 8) described measurements, methodologies, and strategies to track patient engagement.

Participants noted the following methods/measures/to track patient engagement:

- Surveys, Interviews, focus groups, and reports (n=7)
- Patient Engagement in Research Scale – PEIRs method (n=2)
- Guidance for Reporting Involvement of Patient Partners - GRIPP tool (n=2)
- Health Canada toolkit (n=2)
- Patient Engagement Advisory Committee (PEAC) (n=1)
- McMaster Health Forum Survey (n=1)
- Try to include at least 2 patients per project (n=1)

Three participants (n=3) mentioned that their organizations do not have concrete standards of measurement, but two of those organizations have completed reports/evaluations to measure their patient engagement.; specific details on how these evaluations were completed were not described. One organization is currently creating standards to measure patient engagement in their work.

### **Illustrative Quotes**

*“For our specific projects with patients involved, we use GRIPP (reporting guidelines for public involvement in research projects). It contains lots of reflective questions that we encourage our staff to use as they write out the results following engagement in specific projects which is helpful for continued reflection and improvement.” – P01*





## **4. Summary of Engagement Activities and Models**

The document review and key informant interviews provided an overview of the patient and public engagement and governance activities conducted by several organizations. These activities are summarized in Table 5 below.

There were also several models for patient and public engagement and governance identified during the data collection and analyses. These models are summarized in Table 6.

**Table 5. Summary of Engagement Activities by Organization**

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
<b>SPOR Evidence Alliance (SPOR EA)</b>	<ul style="list-style-type: none"> <li>IAP2 Spectrum of Public Participation</li> </ul>	<p><b>Governance Committee Membership</b></p> <p>Patients are members of each of the 6 governing committee for the SPOR-EA. Patients participate in committee activities and are involved in decision-making through consensus discussion with the other members of each committee. Where decisions cannot be reached by consensus, majority vote is used.</p>	<p>All committee members are encouraged to serve a 2 year term (or 2-3 years for co-chairs).</p>	<p>Potential committee members can apply and new members will be selected by the principal investigator and committee when needed.</p>
		<p><b>Project-Specific Engagement</b></p> <p>Patients participate in project activities in a variety of capacities, depending on the needs of the project. Some of these roles include</p> <ul style="list-style-type: none"> <li>Co-leading projects</li> <li>Providing peer reviews</li> <li>Authoring papers</li> <li>Presenting materials</li> <li>Developing learning materials</li> <li>Co-leading courses</li> <li>Championing submitted project ideas</li> </ul>	<p>Variable depending on the capacity in which the patient is engaged, the needs of the project and the level of interest of the patient</p>	<p>Patients are recruited to participate in projects primarily through existing networks.</p>

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
<b>National Institutes for Health and Care Research (NIHR)</b>	<ul style="list-style-type: none"> <li>Not specified</li> </ul>	<b>Research Topic Submission</b> Members of the public can submit their ideas for new research topics to NIHR to be considered for future research	Not Specified	The submission form is publically available on the NIHR website.
		<b>Research Proposal Review</b> Members of the public can provide feedback on research proposals relevant to their experiences to the committees who making funding decisions	Not Specified	Members of the public can submit an application to become a reviewer and are matched to review applications that are relevant to their personal experiences.
		<b>Research Champion</b> Volunteers participate in events and activities to raise awareness about health and care research such as: <ul style="list-style-type: none"> <li>Giving talks and interviews</li> <li>Supporting resource development</li> </ul>	Not Specified	Interested members of the public can contact the local research champion coordinator to discuss their interest in the program. These contacts are listed publically on the NIHR website.

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
		<p><b>Public Committee Member</b></p> <p>Members of the public can join committees that assess research proposals for funding. These committees usually include 20 people, with membership from local government, clinicians/practitioners, academics and members of the public/patients.</p>	<p>Committee tenure is 2 years with possibility of the 2-year extension. Members may only serve on a committee once.</p>	<p>Applications are accepted once a year and interviews are held to determine who best matches the needs of open positions.</p>
<p><b>Alberta Health Services (AHS)</b></p>	<ul style="list-style-type: none"> <li>IAP2 Spectrum of Public Engagement</li> <li>Patient First Strategy</li> </ul>	<p><b>Strategic Clinical Networks (SCN)– E-Advisor</b></p> <p>A member of the public can become an advisor and provide feedback on materials, documents and policies for the SCNs by email</p>	<p>Not Specified</p>	<p>Email and telephone contacts are provided for patients interested in becoming involved in the Strategic Clinical Networks (SCNs).</p>
		<p><b>Strategic Clinical Networks – Storyteller</b></p> <p>Patients can become storytellers to share their healthcare story with groups to provide a patient perspective to the group</p>	<p>Not Specified</p>	
		<p><b>Strategic Clinical Networks Occasional Events Attendee</b></p> <p>Patients or members of the public can join one-time events such as focus groups or workshops to share their experiences and perspectives on SCN topics</p>	<p>Not Specified</p>	

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
		<p><b>Strategic Clinical Networks - Committee Member</b></p> <p>Members of the public can become a member of one of the core committees or working groups that make up the SCNs.</p>	<p>A committee member may serve a 2-3 year term and then may remain a member of the network after completion of their committee term.</p>	
		<p><b>Patient and Family Advisory Group</b></p> <p>Patients and Family members can join the council as members. The Council has approximately 30 members who participate in many committees and initiatives throughout AHS to provide patient and family perspectives, experiences and insights.</p>	<p>Council members serve a minimum 3-year term and up to a maximum of 6 years. The council meets monthly from September to June.</p>	<p>Interested patients and family members can email the council to express their interest and discuss available patient and family advisor opportunities.</p>

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
<b>Canadian Partnership Against Cancer (CPAC)</b>	<ul style="list-style-type: none"> <li>IAP2 Spectrum of Public Participation</li> </ul>	<p><b>Engagement Methods</b></p> <ul style="list-style-type: none"> <li>Participating in national or regional dialogues to improve cancer care</li> <li>Involvement in key committees, networks and councils to contribute a patient perspective</li> <li>Attending conferences, focus groups, surveys or other similar events</li> <li>Contributing to key reports and communications to add a lived experience perspective</li> </ul>	<p>Not Specified</p>	<p>CPAC provides an email contact for patients or family members interested in becoming an involved advisor and puts out engagement calls through social media and their website.</p>
<b>Donate Life Australia (DLA)</b>	<ul style="list-style-type: none"> <li>Not Specified</li> </ul>	<p><b>Community Engagement Group</b></p> <p>Group is composed of 21 members from community organizations, transplant committee organizations and donor family organizations. Provides input and advice on relevant topics.</p>	<p>Committee meets 3 times a year.</p>	<p>Approaches community organizations such as advocacy groups to nominate someone to join a committee. Also tries to ensure representation of both urban and rural patients as well as represent Indigenous groups.</p>

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
		<p><b>Clinical Committees</b></p> <p>The clinical committees all include at least one patient to contribute their experiences and perspectives</p>	Not Specified	<p>Approaches community organizations such as advocacy groups to nominate someone to join a committee. Also tries to ensure representation of both urban and rural patients as well as represent indigenous groups</p>
<p><b>Organ Procurement and Transplantation Network (OPTN)</b></p>	<ul style="list-style-type: none"> <li>Not Specified</li> </ul>	<p><b>Board of Directors and Committee Participation</b></p> <p>The OPTN Board of Directors and committees includes membership from organ donor and recipient patients and family members.</p>	Not Specified	Not Specified

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
		<p><b>Public Comment Period</b></p> <p>OPTN invites public comment when developing policies and proposals using several mechanisms including:</p> <ul style="list-style-type: none"> <li>• Outreach to stakeholder organizations that include patient groups</li> <li>• Comments from other OPTN committees that include public representation</li> <li>• Discussions at in-person regional meetings held during the public comment periods each year</li> <li>• Online open public comment forum that is open twice a year</li> </ul>	Not Specified	Details about the public comment periods are available on the OPTN website.
<p><b>Canada's Drug and Health Technology Agency (CADTH)</b></p>	<ul style="list-style-type: none"> <li>• CADTH Framework for Patient Engagement in Health Technology Assessment</li> </ul>	<p><b>Open Feedback Calls</b></p> <p>CADTH seeks feedback from patient groups that have patient and/or family memberships and a public presence on their reimbursement and funding algorithm projects.</p>	Not Specified	CADTH posts their open requests for feedback from groups



Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
	<ul style="list-style-type: none"> <li>IAP2 Spectrum of Public Participation</li> </ul>	<p><b>Symposium Participation</b></p> <p>Patients can attend the yearly CADTH symposium and/or volunteer to review abstracts submitted to the conference as part of the Abstract Review Committee</p> <p><b>Involvement in Scientific Advice, Health Technology Assessments and Optimal Use Projects</b></p> <p>Patients and family members can become involved in a project to provide their perspectives to the project. Participating patient/family members would join some project meetings and review drafts of documents throughout the project</p> <p><b>Board of Directors and Expert Committees</b></p> <p>CADTH's Board of Directors and expert committees have 2-3 seats for members of the public to contribute their perspectives and experiences.</p>	<p>Not Specified</p> <p>Varies from project to project. Project timelines typically vary from one month to one year in length</p> <p>Board and committee members serve 2 -3 year terms and meet monthly.</p>	<p>online and in their weekly newsletter. They request reviews from groups rather than individuals to capture a diversity of experiences, and will connect interested individuals with relevant patient groups if they wish to contribute to a review.</p> <p>Interested individuals apply during open calls for members and a selection committee determines who is a good fit for open positions.</p>

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
<b>Patient-Centred Outcomes Research Institute (PCORI)</b>	<ul style="list-style-type: none"> <li>Carman Multidimensional Framework</li> </ul>	<p><b>Serve on an Advisory Panel</b></p> <p>PCORI has 5 advisory panels that provide recommendations to the Board of Governors and Methodology Committee. Each committee requires a certain number of patients, caregivers or representatives of patient advocacy groups to be members of the panel. This composition ranges between 15% and 60% depending on the committee subject matter.</p>	<p>Panel members serve 3-year terms.</p>	<p>Interested participants can submit and application during the nomination cycle which will be reviewed to appoint new panel members by the Board of Governors</p>
		<p><b>Become an Ambassador</b></p> <p>PCORI ambassadors can participate in a variety of activities including sharing research findings and patient centred outcomes research opportunities with their communities and engaging with PCORI activities</p>	<p>Variable based on the availability of the participant.</p>	<p>Interested participants can submit and application online.</p>

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
		<p><b>Become a Peer or Merit Reviewer</b></p> <p>Patients or caregivers with experience related to a related disease or condition can review PCORI research reports to comment on the study's relevance and usefulness and determine if patients' and caregivers values and perspectives were considered adequately during the research and writing process. They can also contribute to the assessment of applications to PCORI for funding as a merit reviewer.</p>	Not Specified	Interested patients can register online for the peer reviewer pool or apply online to become a merit reviewer.
		<p><b>Suggest a Research Question</b></p> <p>Members of the public can submit their suggestions for research questions online</p>	Not Specified	Questions can be submitted at any time online through a portal on the PCORI website.
		<p><b>Participate in Events</b></p> <p>Patients and caregivers are invited to participate in several activities aimed at co-learning and partnership building including:</p> <ul style="list-style-type: none"> <li>• Webinars</li> <li>• Workshops</li> <li>• Roundtables</li> <li>• Workgroups</li> </ul>	Not Specified	Interested participants can sign up for email alerts to be informed of upcoming opportunities to participate.

Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
<b>Institut National D'Excellence en Santé et en Services Sociaux (INESSS)</b>	<ul style="list-style-type: none"> <li>Montreal Model</li> </ul>	<b>Administrative Board Member</b> The administrative board is designed to include at least one patient/public member to contribute their perspective.	Not Specified	An open application call is posted on social media, the organization website, and through existing data banks of patients, users and caregivers. Interviews are used to select patients to participate
		<b>Consultation Table Member</b> This table has 5 patient/caregiver/citizen seats, 5 management seats and 5 seats for health care professionals. The purpose of this table is to prioritize topics to be investigated and aid in the implementation of recommendations.	Not Specified	
		<b>Standing Deliberative Committee Member</b> Two members of the public are part of the deliberative committees that decides on recommendations to be implemented in 3 different evaluation groups: health service interventions, medical drugs and social health services.	Not Specified	
		<b>User Group Panel</b> The Social Services section has a user group panel that provides patient and user perspectives to projects.	Not Specified	



Organization	Framework(s) Used	Engagement Activities	Time Commitment	Recruitment Strategies
		<p><b>Scientific Advisory Panel Member</b></p> <p>Patients may also be involved in the advisory committee for specific project depending on the needs of the project and the patients.</p>	<p>A project typically runs for about 1 year and a committee may meet 4-5 times during that year.</p>	

**Table 6. Summary of Identified Models for Patient and Public Engagement and Governance**

Model Name & Reference	Overview	Strengths/ Advantages	Weaknesses/ Limitation
<p><b>IAP2 Spectrum of Public Participation (4)</b></p> <p><a href="#">Figure (Appendix F)</a></p>	<p>The IAP2 articulates 5 levels of public engagement each with their own participation goal and public promise. This framework can help determine the level to which an organization wants to involve members of the public in their activities. The five levels of this spectrum are:</p> <ul style="list-style-type: none"> <li>• <b>Inform</b> – provide the public with balanced, objective information to assist with their personal decision-making</li> <li>• <b>Consult</b> – obtain feedback from the public on options, alternatives or decisions</li> <li>• <b>Involve</b> – work with the public throughout a process. Decision-making does not generally include the public at this phase</li> <li>• <b>Collaborate</b> – partner with the public in each aspect of decision-making</li> <li>• <b>Empower</b> – Commit to implementing final decisions which are made by the public</li> </ul>	<ul style="list-style-type: none"> <li>• Easy to understand visualization of the level of involvement of members of the public.</li> <li>• Provides users with a variety of general options for implementing public participation in their activities. Users could select varying levels of participation for different projects.</li> </ul>	<ul style="list-style-type: none"> <li>• Does not provide practical guidance for implementation participation in activities at each level</li> </ul>

<p><b>Carman Multidimensional Framework (5)</b></p> <p><a href="#">Figure (Appendix F)</a></p>	<p>The Carman Multidimensional Framework describes 3 levels of increasing patient engagement and provides examples of this engagement for direct care environments, organizational design and governance, and policymaking. It also describes several factors that may influence engagement at the patient, organizational and societal levels.</p> <p>The 3 levels of engagement are:</p> <ul style="list-style-type: none"> <li>• <b>Consultation:</b> This is the lowest level of engagement and examples involve giving patients information and gathering perspectives from patients using surveys and focus groups</li> <li>• <b>Involvement:</b> This is the middle level of engagement. Examples include asking patients about their treatment preferences, and gathering recommendations from patients to be used by decision-making groups</li> <li>• <b>Partnership and Shared Leadership:</b> The highest level of engagement. Examples here include making treatment decisions that include patient preferences, and having patients be equally represented in decision-making roles</li> </ul>	<ul style="list-style-type: none"> <li>• Provides specific examples of each level of engagement in multiple environments</li> <li>• Provides users with a variety of general options for implementing public participation in their activities. Users could select varying levels of participation for different projects.</li> <li>• Notes specific influences on patient engagement. These factors can be considered to help plan activities.</li> </ul>	<ul style="list-style-type: none"> <li>• Framework figure is hard to understand</li> </ul>
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Model Name & Reference	Overview	Strengths/ Advantages	Weaknesses/ Limitation
<p><b>Health Canada and the Public Health Agency of Canada Guidelines on Public Engagement (6)</b></p> <p><a href="#">Figure (Appendix F)</a></p>	<p>This model notes 4 levels of increasing engagement with patients. These 4 levels are:</p> <ul style="list-style-type: none"> <li>• <b>Inform:</b> Providing information to affected or interested parties</li> <li>• <b>Listen:</b> Gathering feedback on proposed policies from affected parties</li> <li>• <b>Discuss:</b> Exchanging information with interested groups to understand their perspectives on issues</li> <li>• <b>Dialogue:</b> Engage with interested parties to deepen an understanding of views and shape decisions</li> </ul>	<ul style="list-style-type: none"> <li>• This model contains a practical guide to assist users with implementing a patient/public engagement process</li> <li>• Provides specific examples of engagement activities</li> <li>• Easy to understand framework figure</li> </ul>	<ul style="list-style-type: none"> <li>• Created from the perspective of a Government. This term may need to be altered for different user groups that may not be “Government.”</li> </ul>
<p><b>CADTH Framework for Patient Engagement in Health Technology Assessment (9)</b></p> <p>No figure available.</p>	<p>The CADTH Framework uses the Health Technology Assessment international (HTAi) values and standards for health technology assessment, and provides descriptions of how each value and standard is incorporated into CADTH processes for health technology assessments</p>	<ul style="list-style-type: none"> <li>• Links up with established partner organization (HTAi), which may increase buy in for partners who have an HTAi perspective</li> </ul>	<ul style="list-style-type: none"> <li>• No framework figure available.</li> </ul>



Model Name & Reference	Overview	Strengths/ Advantages	Weaknesses/ Limitation
<p><b>Montréal Model (7)</b></p> <p><i>Pomey, Marie-Pascale, et al. « Le « Montreal model » : enjeux du partenariat relationnel entre patients et professionnels de la santé », Santé Publique, vol. 1, no. HS, 2015, pp. 41-50.</i></p> <p><i>Translated Title: The Montreal Model: issues in the relational partnership between patients and health professionals</i></p> <p><a href="#">Figure (Appendix F)</a></p>	<p>The Montreal Model is multidimensional model of the continuum of patient engagement and looks to form partnerships at the:</p> <ul style="list-style-type: none"> <li>• Patient level (direct care)</li> <li>• Organizational level</li> <li>• Health system level</li> </ul> <p>Outlines challenges of forming successful patient-provider partnerships and highlights the importance of patient and provider education and as well as patient partnerships in research.</p>	<ul style="list-style-type: none"> <li>• The model clearly distinguishes 3 contexts for patient engagement (care level, organizational level, &amp; policy/system level) as well as 2 avenues (education/training and research), where patient engagement efforts can be useful.</li> </ul>	<ul style="list-style-type: none"> <li>• Does not provide practical guidance on patient engagement, only outlines levels at which initiatives could be implemented.</li> </ul>

## 5. Recommendations

Based on the results of the document review and key informant interviews, the KTP has identified 3 major recommendations to consider when planning for patient engagement in governance activities. These recommendations are:

### **Recommendation 1: Build on existing models of patient engagement**

Overall, there is a limited amount of information regarding formal models of governance involving patients. Participation on boards and committees by patients or members of the public was more commonly found across organizational documents than in key informant interviews. Little information was available on the structures and procedures used to engage patients and members of the public in governance activities.

During the key informant interviews, most participants (n=9) reported their organization engaged patients in non-governance capacities such as, co-leading projects, reviewing documents or publications, and leading presentations. Two participants described strategies used to engage patients in governance activities such as on committees or Boards of Directors; no interview participants reported using a formal models or frameworks for patient-engagement in governance.

Given the lack of formal models used for patient engagement in governance, the KTP suggests the ODTC look to existing models of general patient engagement. There are a number of existing models and frameworks for patient and public engagement that were reportedly used by the organizations (see [Table 6](#)). Leveraging one of these models as a basis on which to design patient and public governance activities for organ donation and transplantation in Canada may be helpful for ensuring successful engagement of patients in governance. For example, using the IAP2 Spectrum of Public Participation could provide general guidance to help the ODTC frame patient engagement in governance, or using the Health Canada and the Public Health Agency of Canada Guidelines on Public Engagement could provide a higher level of guidance through the use of its accompanying guidance questions.

### **Recommendation 2: Employ EDI principles throughout engagement and governance processes**

Themes from the document review as well as all interview participants (n=11), highlighted the importance of using EDI principles when co-designing and implementing activities that involve patients. Employing EDI principles throughout the design and implementation of patient-involved governance structures may mitigate some of the potential risks to patient engagement highlighted by interview participants, such as tokenism, and power imbalances. EDI principles should be considered and incorporated throughout all processes and procedures related to patient participation, including recruitment and governance activities. Recommending specific EDI training or resources is beyond the scope of this environmental scan.

### **Recommendation 3: Create a supportive environment for patients engaging in governance activities**

Creating a supportive environment for patients was highlighted throughout the scan. A supportive environment enables patients to meaningfully engage in governance activities. The scan identified several factors that can contribute to establishing a supportive environment, including:

- **Providing Capacity Building for All Governance Participants**

A key theme noted in the environmental scan was the need to provide capacity building for all parties involved in patient engagement activities. For patients or members of the public involved, capacity building can include providing orientation sessions and specific topic-related training. Other involved people or groups participating in these activities, such as organizational staff members or researchers should also undertake capacity building in topics such as EDI, co-creation, patient partnerships and plain language communications, in order to foster a supportive environment for all governance participants.

- **Providing Access to Services and Supports**

The environmental scan identified several avenues for support that could be provided to patients to assist them in engaging in organizational activities. These suggested supports include:

- Providing environmental supports or accommodations as needed (e.g., considering if a physical meeting place is accessible to all participating patients and providing supports or an alternate venue if needed or providing an option for patients to join virtually)
- Providing child care or financial support for child care, as required
- Providing access to psychological or emotional supports (e.g. grief counselling) if needed
- Providing a framework for peer-peer support between patient participants. This also relates to having many patient partners on a governance group.
- Compensating patients for their time and efforts with a fair wage

- **Creating a clear communications plan**

Another key finding centered on ensuring there was a clear, documented plan for communication with patients involved in engagement activities. This ensures that patients are able to participate in a fully informed manner in activities and can help as a recruitment or screening resource for patients interested in joining governance work. Overall, expectations should be clearly laid out for patients regarding different aspects of their involvement (e.g., time commitment, means of communication, compensation, etc.)

- **Providing Compensation and/or Expense Coverage**

Communicating how compensation and reimbursements will be managed is important. Organizations should describe whether compensation is available and what form it takes. For example, the organization can outline the pay per hour and any non-monetary compensation (e.g., paper authorship). When possible, organizations should involve patients in choosing how they would prefer to be compensated for their participation.

Expense coverage, including processing time for reimbursement, should also be communicated with patients.

- **Creating a Terms of Reference**

Creating a Terms of Reference or other document outlining the roles and responsibilities of all governance participants is a helpful strategy to ensure expectations are clear. By outlining patients' roles and the expectations patients can have of the organization, patients are able to identify if a role will be a good fit for their current level of interest and availability. Further, in the

case of potential conflict or miscommunication, a Terms of Reference is a helpful resource to reference and re-visit parties' responsibilities in fostering an environment for successful patient-involved governance

## 6. Limitations

There are a few limitations to consider when reviewing the contents of this report. First, the time-limited nature of this analysis meant the KTP team could not conduct a comprehensive document review. Further, the small sample size of key informant interviews limits the breadth of information available. However, the selection of specific target organizations, in collaboration with the ODTG, allowed for a tailored approach that met this project's time constraints.

Second, patients' voices were not directly represented in key-informant interviews. Patient partners were a part of the recruitment pool for the project, but the KTP team was unable to engage any patients for interviews within the time available.

Finally, to ensure feasibility within the time and resource constraints of this project, the KT Program limited the document review to documents available in English only.

## 7. Conclusion

In summary, this environmental scan brought together data from document reviews and key informant interviews to describe and summarize patient and public engagement and governance activities currently taking place in a range of health-based organizations, and provides recommendations for key considerations in the development of a patient governance strategy for organ donation and transplantation in Canada.

The document review revealed that patient and public involvement in organizational governance structures exist in the policy, education, research, and service fields. Common suggestions for improving patient/public interactions include: encouraging open communication, allowing for patient/public input, creating an equitable system for populations with described vulnerabilities to fully participate, and raising awareness of systemic racism and Indigenous rights.

The document review also uncovered limitations in existing patient/public governance models including: underrepresentation of equity-seeking groups, tokenism, and power imbalances. Patients may not be aware of opportunities to become involved in an organization's governance structure. Even when patients joined in governance activities, they are often not provided the appropriate training nor are they provided clarity on the organization's expectations of their involvement. Conversely, fostering patient engagement in all stages of the research process, encouraging inclusivity and diversity in patient/public representatives, and building partnerships with patients/public are key facilitators to good governance engagement.

All interview participants emphasized the importance of the patient partner's voice in every stage of a research and decision making process. This is done by encouraging co-development/co-leading with patient partners to ensure their lived experiences within the healthcare system are represented and informing project focus or decision-making. Furthermore, many participants highlighted suggestions for increasing patient engagement activities within governance models, including: encouraging co-



development of engagement activities; providing capacity building opportunities; increasing EDI and accessibility; and promoting trust and openness with patient partners.

Similar to the document review, interview participants flagged power imbalances, tokenism, non-meaningful engagement, and lack of EDI as challenges to patient engagement in governance models. Participants also highlighted the importance of open communication with patients, which can be accomplished by using a readily accessible Terms of References to outline the rules and responsibilities of patient partners and clear and transparent communications.

All participants highlighted that their organizations provide capacity-building opportunities to patient partners once they join the organization; organizations also provide varied supports including psychological/emotional supports to ensure patients can successfully participate in engagement activities. Organizations also employ tailored compensation and reimbursement strategies to ensure patients are appropriately compensated for their time.

Based on the results of the document review and key informant interviews, recommendations have been provided for key elements to consider when designing a patient governance strategy for organ donation and transplantation in Canada including: building on existing models for patient engagement, employing EDI principles to governance activities, and creating a supportive engagement environment for patients.

The findings contained in the report will allow knowledge users to consider existing models and activities for patient engagement and governance in similar healthcare sectors and gain insight on recommendations for these activities as they design a model for patient engagement and governance in organ donation and transplantation in Canada.

## 8. References

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- (8) SPOR Networks in Chronic Diseases and the PICHI Network, *Recommendations on Patient Engagement Compensation*, Diabetesaction.ca, 2018, [https://diabetesaction.ca/wp-content/uploads/2018/07/TASK-FORCE-IN-PATIENT-ENGAGEMENT-COMPENSATION-REPORT\\_FINAL-1.pdf](https://diabetesaction.ca/wp-content/uploads/2018/07/TASK-FORCE-IN-PATIENT-ENGAGEMENT-COMPENSATION-REPORT_FINAL-1.pdf).
- (9) Canadian Agency for Drugs and Technologies in Health. *CADTH Framework for Patient Engagement in Health Technology Assessment*. Canadian Agency for Drugs and Technologies in Health, 2022. <https://www.cadth.ca/cadth-framework-patient-engagement-health-technology-assessment>

## Appendix A: Organization List for Document Review & Document Review Inclusion and Exclusion Criteria

### Organization List

The following table outlines organizations pre-determined to be included in the document review and their associated websites.

Organization Name and Location	Website URL
<b>First Nations Health Authority</b> Canada (British Columbia)	<a href="http://www.fnha.ca">www.fnha.ca</a>
<b>Canadian Partnership Against Cancer</b> Canada	<a href="http://www.partnershipagaincancer.ca">www.partnershipagaincancer.ca</a>
<b>Donate Life Australia</b> Australia	<a href="http://www.donatelife.gov.au">www.donatelife.gov.au</a>
<b>Organ Procurement and Transplantation Network</b> United States of America	<a href="http://www.optn.transplant.hrsa.gov">www.optn.transplant.hrsa.gov</a>
<b>National Institute for Health Research</b> United Kingdom	<a href="http://www.nihr.ac.uk">www.nihr.ac.uk</a>
<b>Canada's Drug and Health Technology Agency</b> Canada	<a href="http://www.cadth.ca">www.cadth.ca</a>
<b>SPOR Evidence Alliance</b> Canada	<a href="http://www.sporevidencealliance.ca">www.sporevidencealliance.ca</a>
<b>Patient-Centred Outcomes Research Institute</b> United States of America	<a href="http://www.pcori.org">www.pcori.org</a>
<b>Institut National D'Excellence en Santé et en Services Sociaux</b> Canada (Quebec)	<a href="http://www.inesss.qc.ca">www.inesss.qc.ca</a>
<b>Alberta Health Services Patient and Family Advisory Group</b> Canada (Alberta)	<a href="https://www.albertahealthservices.ca/info/Page6620.aspx">https://www.albertahealthservices.ca/info/Page6620.aspx</a>

## Inclusion/Exclusion Criteria for Documents

The following table outlines inclusion and exclusion criteria for the document review.

Document Review Inclusion and Exclusion Criteria	
Inclusion	Exclusion
<ul style="list-style-type: none"><li>• Published January 2016 or later</li><li>• Available in English</li><li>• Contains details about patient or public engagement activities</li></ul>	<ul style="list-style-type: none"><li>• Published before January 2016</li><li>• Not available in English</li><li>• Does not contain details about patient or public engagement activities</li></ul>



## Appendix B: Organizations Invited to Participate in Key-Informant Interviews

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### Organization List

The following table outlines the organizations invited to participate in key-informant interviews.

Organization Name and Location
<b>First Nations Health Authority</b> Canada (British Columbia)
<b>Canadian Partnership Against Cancer</b> Canada
<b>Donate Life Australia</b> Australia
<b>Organ Procurement and Transplantation Network</b> United States of America
<b>National Institute for Health Research</b> United Kingdom
<b>Canada's Drug and Health Technology Agency</b> Canada
<b>SPOR Evidence Alliance</b> Canada
<b>Patient-Centred Outcomes Research Institute</b> United States of America
<b>Institut National D'Excellence en Santé et en Services Sociaux</b> Canada (Quebec)
<b>Alberta Health Services</b> <b>Patient and Family Advisory Group</b> Canada (Alberta)
<b>Alberta Health Services Strategic Clinical Network (SCN)</b> Canada (Alberta)

## Appendix C: Semi-Structured Interview Guide

Key Informant Interview Guide
Patient Engagement Models
<p><b>1. How are patient-centered governance models defined and/developed at your organization?</b></p> <ul style="list-style-type: none"> <li>• Does your organization have any patient engagement/integration in governance, leadership, and service delivery? (informal or formal)</li> <li>• How is the patient perspective and experience integrated into your organization?</li> <li>• [If yes], can you please describe the goals for this engagement/integration?</li> <li>• How were these goals/objectives developed?</li> <li>• Have these goals/objectives changed over time? If so, how did they change?</li> <li>• What factors contributed to these changes? (e.g., new federal policies? evolving partnerships?)</li> <li>• How do you recruit/appoint patients for engagement/integration (e.g., activities, committees, boards)?</li> <li>• Can you describe patients' role and your expectations with respect to their engagement/integration?</li> <li>• Is the role of patients embedded in Terms of References, Website, or other?</li> <li>• Do you provide compensation to patients? If so, how much and how is the amount determined?</li> <li>• Do you provide support to these patients (e.g., training or other resources)?</li> <li>• Does your model include Secretariat support? If so, please describe this support.</li> <li>• What is the top patient engagement/integration priority for your organization?</li> <li>• Does the organization set priorities based on patient input? How so?</li> <li>• How is the impact of patient input reported back to patients?</li> <li>• For government bodies, what is the proximity of patients to government officials when it comes to decision-making?</li> </ul>
<p><b>2. Which patient-centered governance models are working well your organization?</b></p> <ul style="list-style-type: none"> <li>• Why did this/these work in your organization?</li> <li>• Which models did not work in your organization?</li> <li>• Why did/these not work?</li> <li>• How were these models developed?</li> <li>• Which patient-centered governance models are working well in Canada?</li> <li>• Describe the commonalities and differences in the governance structures that include patient involvement?</li> </ul>

**3. What are considerations when developing patient-centered governance models for your organization?**

- What are some risks? And, what are the strategies your organization has used to mitigate them?
- Are there any barriers? If so, are there any ways to overcome them?
- What are some opportunities?
- How do national organizations ensure diversity in representation, across various identifiers (geography, culture, race, gender etc.) for their patient partners?

**Measuring Engagement**

**4. What are your organization's standards or metrics to measure successful patient-centered governance models?**

- Are there existing methods of evaluating patient models in the Canadian Healthcare sectors?
- Does your organization set goals or targets to measure success?
- What accountability mechanisms are built into your organization's engagement models for patient partners?
- Do you have any recommendations or considerations for a patient governance model for ODT strategic planning?

**Wrap-up**

- Is there anything else that you would like to share today regarding your organization's patient engagement/integration models or otherwise?
- Do you have any documents you feel would be important to share with us for our environmental scan to inform ODT policy makers?

## Appendix D: Document Review Data Abstraction Template

Document Review Abstraction Template	
Abstraction Question	Description or Excerpt from Document
Date of Review	
Name of Reviewer	
Document Description	
Organization	
Document Title	
Author (if applicable)	
Access URL	
Publication Date (if available)	
Type of Document	
Includes Details related to patient/public governance or engagement	Yes (Include)/No (Exclude)
Description of Patient/Public Governance or Engagement	
Type of patient centered governance model or patient engagement activity	
Stakeholders Involved in governance or engagement activities	



Role of Patient/Public Member in governance or engagement activities	
<b>Goals of Patient/Public Governance or Engagement Activities</b>	
Are there goals related to patient/public governance or engagement described	Yes/No
If yes: Goals of patient/public governance or engagement activities	
Are any indicators described to monitor/measure goal progress/achievement?	Yes/No
If yes: List indicators	
<b>Patient/Public Governance or Engagement Strengths and Weaknesses</b>	
Strengths of governance or engagement activities (if any described)	
Weaknesses of governance or engagement activities (if any described)	
<b>Evaluation of Patient/Public Governance or Engagement Activities</b>	
Are any evaluation models/methods for patient/public governance or engagement described?	Yes/No
If yes: List details related to evaluation of patient/public governance or engagement	
<b>Recommendations</b>	



Recommendations related to patient/public governance or engagement activities (if any described)	
<b>Additional Comments</b>	
Additional reviewer notes or comments	

## Appendix E: Rapid Analysis Coding Framework

Parent Node	Description	Child Node	Description
<b>Development of a Patient Engagement Strategy/Model</b>	Participant discusses anything related to the development of patient engagement strategies or models	Initial Process	Participant describes any processes used by their organization to develop their patient engagement strategy or model
		Recommendations for future development	Participant describes any recommendations related to the development of patient engagement strategies or models they have
		EDI Considerations	Participant describes their views on integrating EDI considerations into patient engagement strategies/models
		Lessons Learned	Participant describes lessons learned from before, during, or after the development of a patient engagement strategy/model
<b>Existing Patient Engagement Models</b>	Participant describes any currently existing models of patient engagement. This could be a model used by their organization or a model used by other organizations	Objectives	What was the overall point of using the patient engagement model
		Goals	What things are the organization attempting to achieve with the use of the patient engagement model
		Strategies	The how of the patient engagement (e.g. compensation, supports, descriptions of roles)

		Benefits	Participant highlights any benefits they perceive in existing patient engagement models
		Drawbacks	Participant highlights any drawbacks they perceive in existing patient engagement models
<b>Barriers to Patient Engagement</b>	Participant describes any challenges their organization has faced in patient engagement/using patient engagement models	Mitigation Strategies	Participant describes any strategies/actions they used to overcome a barrier or challenge with patient engagement activities
<b>Facilitators to Patient Engagement</b>	Participant describes any facilitators they have encountered when conducting patient engagement activities within their models	N/A	N/A
<b>Measures</b>	Participant describes ways to track or measure the use of patient engagement activities within their organization	Goals or Targets	Participants describe any goals or targets that they measure as way to track the success of their engagement activities
		Methods	Participants describe any methods used to measure their progress towards goals/targets



## Appendix F: Engagement Model Figures

### IAP2 Spectrum of Public Participation (4)

**iap<sup>2</sup>**  
International Association  
for Public Participation

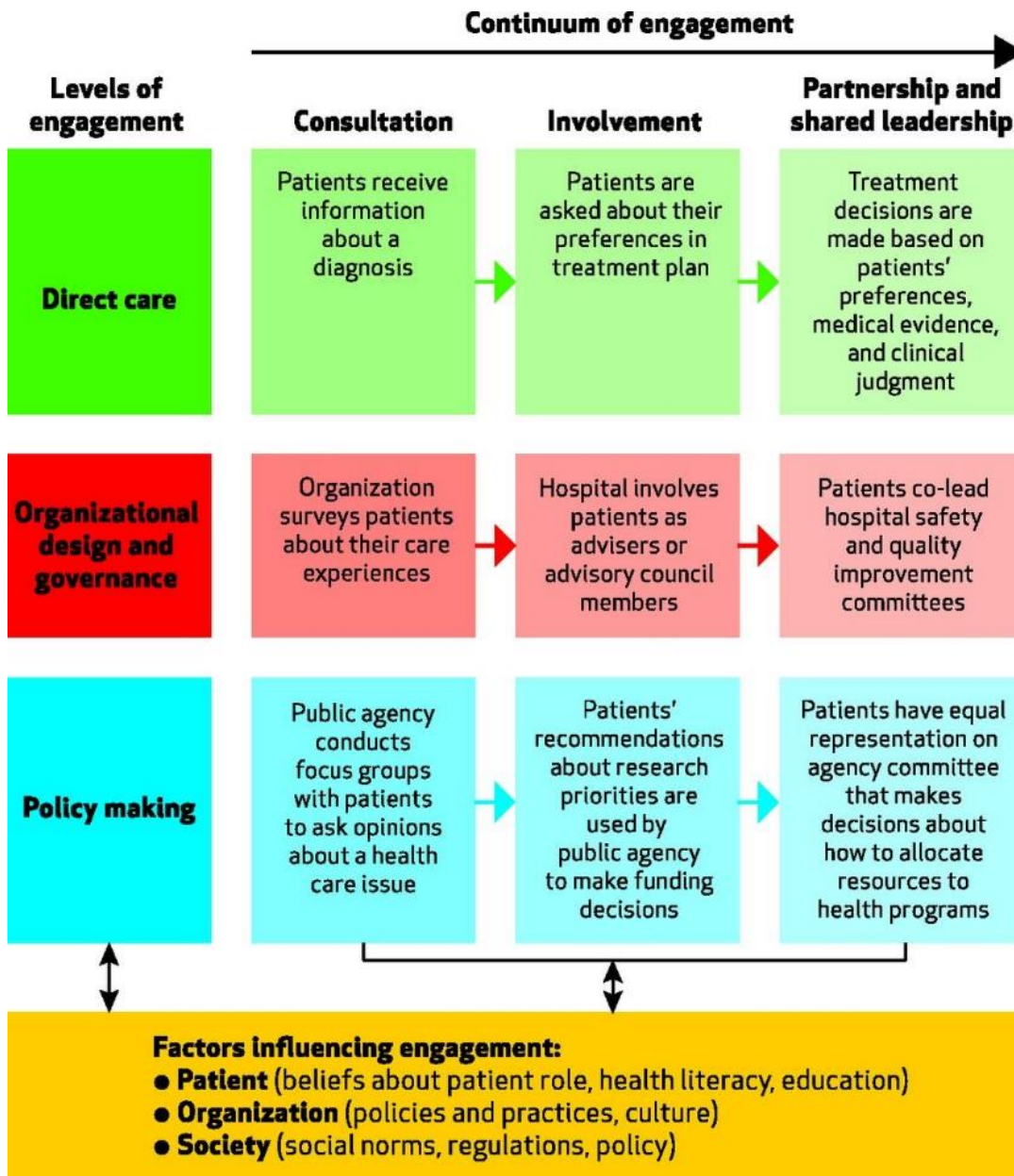
IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

**INCREASING IMPACT ON THE DECISION**

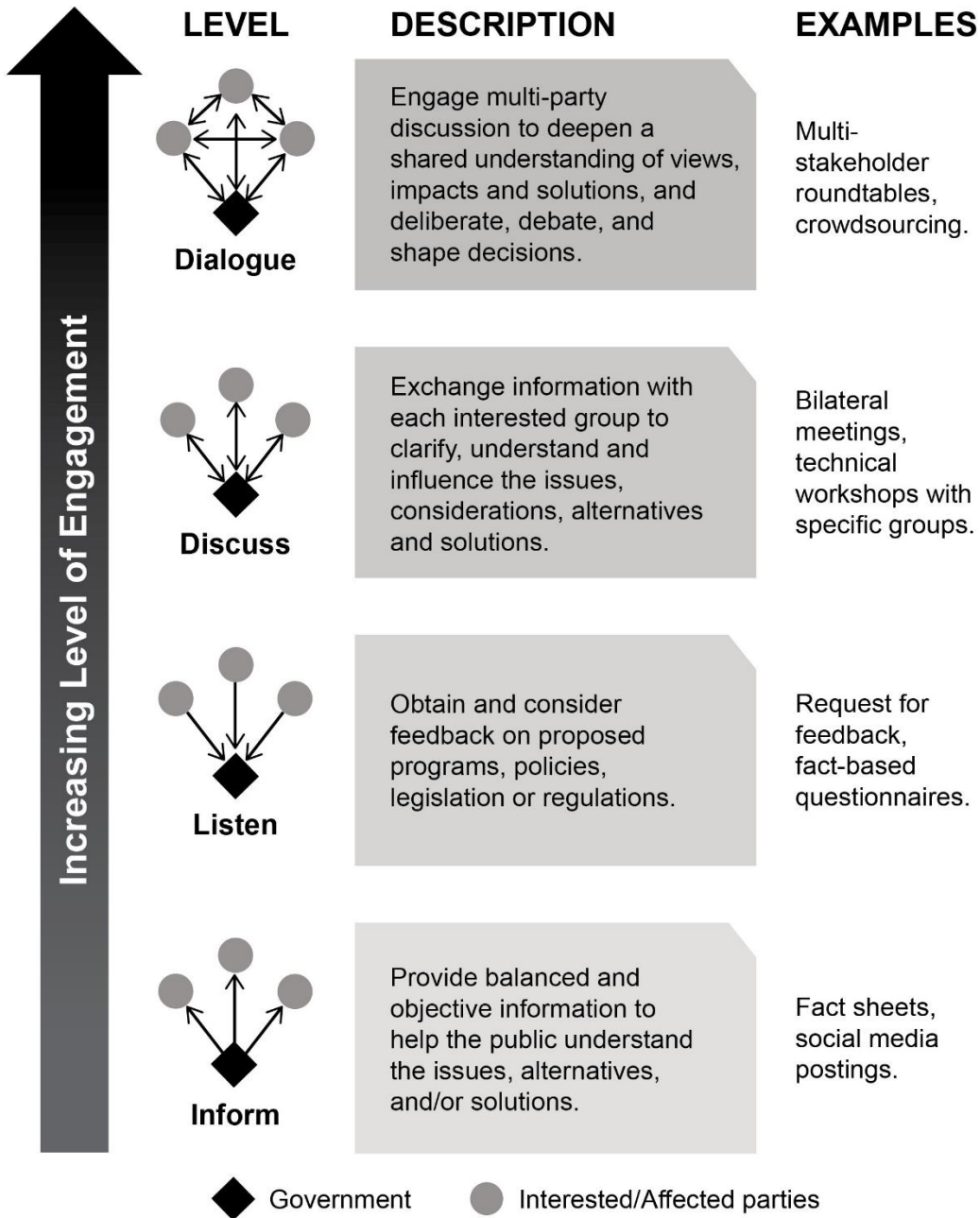
	<b>INFORM</b>	<b>CONSULT</b>	<b>INVOLVE</b>	<b>COLLABORATE</b>	<b>EMPOWER</b>
<b>PUBLIC PARTICIPATION GOAL</b>	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
<b>PROMISE TO THE PUBLIC</b>	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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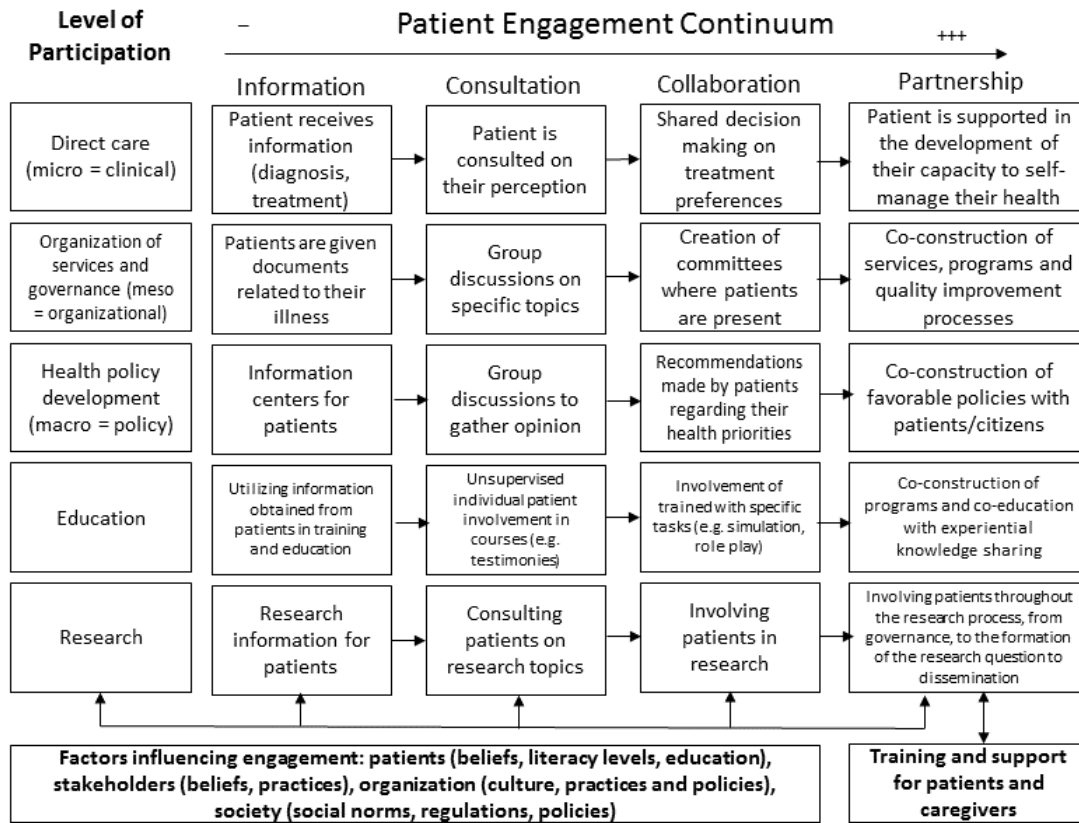
## Carman Multidimensional Framework (5)



## Health Canada and Public Health Agency of Canada Guidelines on Public Engagement (6)



## Montréal Model (7)



*\*Translation of Figure provided by Léah Marsot-Shiffman*