Acknowledgements

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We would also like to express thanks to the research administrators, patient engagement specialists, researchers, and patient partners from the organizations represented in this catalogue for giving their time and so generously sharing their insights through surveys and qualitative interviews.

Disclaimer:

Please note that this catalogue is not an exhaustive list of organizations who have incorporated patient engagement in research in Ontario. There may be organizations not included in this catalogue that successfully engage patients as partners in research and we welcome any suggestions about how this catalogue can be updated or expanded.

Contact

For questions about this catalogue, please contact:

Eddy Nason
Assistant Director
Ontario SPOR SUPPORT Unit
661 University Ave. St 405
Toronto, Ontario, Canada

✉ eddynason@ossu.ca
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**Catalogue of Organizations in Ontario**

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Definitions

Patient engagement
Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Patient engagement activities can include: reviewing & giving feedback on grant & funding applications, providing feedback & input on the research agenda (e.g., topic selection), assisting in framing the research questions, being involved with developing the study design and plan, helping collect data, assisting in interpreting data, helping develop tools and publications, reading and providing feedback on drafts of written reports, sharing research findings at conferences and being members on a committee. [1]

Patient-oriented research
A continuum of research that engages patients as partners focusses on patient-identified priorities and improves patient outcomes. It aims to apply the knowledge generated to improve healthcare systems and practices. [1]

Patient partner
Individuals with personal experience of a health issue and their informal caregivers (i.e. family and friends) who are actively involved in the planning or conduct of research. [1]

Spectrum of patient engagement in research:

<table>
<thead>
<tr>
<th>Inform</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Lead</th>
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<tbody>
<tr>
<td>To provide with information</td>
<td>To obtain feedback</td>
<td>To work with to develop alternatives</td>
<td>To partner in each aspect of decision-making</td>
<td>To decide</td>
</tr>
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</table>

Increasing impact on decisions

Adapted from the International Association of Public Participation (IAP2). [2]
The purpose of this catalogue is to provide patients, researchers, and organizational employees with information on the variety of patient engagement in research activities and policies in organizations across Ontario.

From March to August 2019, we collected information regarding patient engagement through surveys, semi-structured interviews, and document reviews. This first edition includes 14 entries that represent diverse organizational processes for patient engagement in research including their objectives, research activities, engagement methods, and successful outcomes. We are aware that there are many other organizations and patient engagement activities not currently identified in this catalogue and welcome suggestions about how this catalogue can be expanded. Please send any suggestions or comments to: ossu@ossu.ca

We encourage you to share this document with others who are interested in patient engagement in research.

Ontario has a large and complex health care and health research system, which is increasingly becoming aware of the need to engage patients, caregivers, and family members in their activities. The objective of partnering with patients is to improve the relevance and translation of research into practice and policy and ensure that the research reflects their needs. Patient engagement in research is now a part of many types of organizations including: research institutions, health care centres, government organizations and not-for-profit organizations.
Within Ontario, there are numerous institutions that focus on research excellence and innovation. Research institutions are establishments founded for performing research and may specialize in basic research, applied research, or may be discipline-based or interdisciplinary in nature. The two principal objectives of research institutions are to pursue excellence in research and maintain high-level teaching programs. Many research institutes are affiliated with hospitals or post-secondary institutions (colleges or universities) and are designed to bring together researchers, clinicians, regional partners, and industry.
Centre for Rural and Northern Health Research

The Centre for Rural and Northern Health Research (CRaNHR) is an academic and applied research Centre at Laurentian University. CRaNHR’s mandate is to conduct interdisciplinary research on rural health with a view to improving health services, access to health care, particularly in rural and northern communities, and enhancing understanding of the health care system. CRaNHR is part of Canada’s Strategy for Patient Oriented Research (SPOR) and is one of 13 Ontario SPOR Support Unit (OSSU) Research Centres. The Centre has over 30 faculty and affiliated investigators at Laurentian and the Northern Ontario School of Medicine, and has employed 15 full-time grant-funded employees over the past fiscal year.

Patient engagement (PE) at a glance

| ✔️ Organizational policy on PE |
| ✔️ Training for patient partners for research activities |
| ✔️ Training for researcher for PE activities |
| ✔️ Evaluation of the PE experience |
| ✔️ Level of patient engagement: Learn, Consult, Involve, Collaborate |
| ✔️ 6 years of experience engaging patients in research |

What are their research themes?

CRaNHR conducts studies on the organization, delivery, and effectiveness of rural and northern health services, as well as on various health workforce issues.

Areas of focus for research and evaluation include:

- Child Health
- Francophone Health
- Health Services Research
- Indigenous Health
- Northern Ontario School of Medicine-Integrated Impact Investigations
- Virtual Care Research

CRaNHR also provides research consultation support and services to stakeholders, and collaborates with partners to engage the perspectives of rural and northern populations. CRaNHR facilitates data access and use as part of its mandate, by leading local analyses in partnership with existing data platforms, and involvement in the ICES North Satellite.
CRaNHR aims to improve the research process and health outcomes for northern and rural populations through engaged research. 

By partnering with patients and communities, they hope to:

- Respond to patient and community health needs and priorities
- Enhance the relevance of research questions
- Build mutual relationships and trust
- Improve the credibility of research and evaluation
- Improve the translation of research findings into practice
- Improve quality of life and strengthen the health care system
- Develop more effective and culturally-safe programs, services and products

Engagement methods include: Email, phone, and video-conference communications; individual and team meetings; individual interviews and focus groups; and Indigenous engagement methods, such as sharing circles, offering tobacco, smudging and prayer, meal-sharing.

Training includes orientation, meetings with team and community members, on-site learning with research team members, and handouts that provide information about their role in the research or evaluation project.

Evaluation of engagement occurs by way of individual interviews, focus groups and debriefing/discussion sessions.
Highlights/Success factors of engaging patients in research

• CRaNHR’s engagement with patients and communities has resulted in strong and authentic partnerships. This has enhanced the design and conduct of research with northern and rural populations.

• CRaNHR has been approached by Indigenous communities, and this is extremely important to ensure that the research addresses community needs and is driven by the community.

• The involvement of patients and community partners has strengthened organizational and community capacity for evaluation and research.

Patient engagement contact:

Diana Urajnik, Director, CRaNHR
durajnik@laurentian.ca

Centre for Rural and Northern Health Research contact

935 Ramsey Lake Road
Sudbury, Ontario, Canada
P3E 2C6

705-675-1151 ext. 4342
Toll-Free: 1-800-461-4030
705-671-3876
Toll-Free: 1-855-512-4321
cranhr@laurentian.ca / cranhr@laurentienne.ca
https://www.cranhr.ca or http://www.cresrn.ca
Children’s Hospital of Eastern Ontario Research Institute

Children’s Hospital of Eastern Ontario (CHEO) Research Institute is associated with the Children’s Hospital of Eastern Ontario (CHEO) and the University of Ottawa. The CHEO Research Institute works to create new knowledge and evidence to help provide the best pediatric health care for children and youth from Eastern Ontario, Western Quebec, Nunavut and Northern Ontario. All basic science and clinical research projects at the CHEO Research Institute fall into one or more research programs (Molecular Biomedicine, Health Information Technologies, or Evidence to Practice). There are 249 researchers at the CHEO Research Institute conducting leading-edge pediatric research, attracting nearly $28 million in funding yearly.

Patient engagement (PE) at a glance

- Organizational policy on PE
- Training provided for patient partner for research activities
- Training provided for researcher for PE activities
- Evaluation of the PE experience
- Level of PE: Learn, Consult, Involve, Collaborate
- 2—3 years of experience engaging patients in research

What are their research themes?

Research at CHEO covers a full spectrum of pediatric topics, but is focused on those problems that significantly affect the health of children, including:

- Cancer
- Diabetes
- Emergency Medicine
- Genetic Conditions
- Mental Health
- Musculoskeletal Health
- Obesity

What are their objectives for engaging patients in research?

CHEO Research Institute believes that patients can make an impact on the discoveries they are making every day and that will lead to healthier children and youth in their community and beyond. Enhancing patient engagement is a strategic goal of the organization and they are dedicated to moving beyond the model of patients only being involved in research as study participants to a model where all researchers partner with patients at all stages of the research project.
What research activities are patients engaged in?

Patient/family advisors are engaged through the:

01. Participation
   • The CHEO Research Institute recognizes that through study participation many families learn the value of research and then wish to become engaged as grant reviewers or study advisors. The Institute is dedicated to making it easy for families to participate in research and ensuring it is a positive experience for parents and children.

02. Information Sharing
   • Family leaders receive a newsletter every two weeks that highlight any new research and call-to-actions for reviewers and advisors.
   • Patient and Family Advisory Committees meet in-person or via teleconference or videoconference every month.
   • Training for patient partners includes an interview to ensure project fit and the option to do an orientation session online or in-person that outlines the research process, expectations, and roles.
   • A “for patients” section on the CHEO Research Institute external website is updated regularly to provide families with information about research and engaging in research at CHEO.

03. Engagement
   • The family leader program engages families from the grant submission phase through to publication and presentation of study results.

How are patients engaged in research?

The CHEO Research Institute follows the INVOLVE framework of engaging patients in three levels of engagement. They recognize participation, information sharing, and partnering in research as important levels of engagement.

Patient and Family Advisory Committees

Six parents and two youth sit on the Research PFAC. They are consulted and provide a patient perspective on how to move the research forward, overcome barriers, plan future directions, and provide advice on communication strategies.

Family Leader Program where they have the option to join as a Research Project Reviewer or a Research Project Advisor.

Research Project Reviewers review research grant submission summaries and provide feedback on the research relevance, design, and impact and have the opportunity to provide letters of support for grant submissions.

Research Project Advisors have the opportunity to be part of the study team and provide regular feedback on the project and help problem-solve issues.

Patient and Family Advisory Committees meet in-person or via teleconference or videoconference every month.

Training for patient partners includes an interview to ensure project fit and the option to do an orientation session online or in-person that outlines the research process, expectations, and roles.

A “for patients” section on the CHEO Research Institute website is updated regularly to provide families with information about research and engaging in research at CHEO.

Highlights/Successes of engaging patients in research

• At the CHEO Research Institute, patient and family engagement involves both parents and grandparents as partners as well as youth/patients.

• A major factor in the success of patient engagement in research includes the leadership support and strategic plan. Additionally, the commitment to human resources in having a full-time dedicated Research Family Leader Program Coordinator in place.
Partner Perspective

“I think the game changer at CHEO-RI was the choice to place patient engagement as a priority in the strategic plan. Also, the commitment that was made to create a Family Leader Research Program Coordinator role, who can meet with Family Leaders and Researchers, was essential to build and launch the Family Leader Program.”

— Organizational employee

Patient engagement contact

Michelle Quinlan,
Research Family Leader Program Coordinator
mquinlan@cheo.on.ca
(613) 737-7600 ext. 4112

CHEO Research Institute contact:
CHEO Research Institute
(Co-RI Administration Offices
401 Smyth Road
Research Building 2, 2nd floor, Room 2119
Ottawa, Ontario, Canada
K1H 8L1

613-737-7600
613-738-4875
http://www.cheori.org/
Institut du Savoir Montfort (ISM) is a Canadian leader in francophone research and education. It is affiliated with the University of Ottawa and Hôpital Montfort. Its unique model, based on the collaboration between researchers and teachers, facilitates the creation and transmission of knowledge. The ultimate goal at ISM is to improve the health of the population, particularly in Francophone communities. Their collaborative research programs focus on the needs of patients and participants in care, and on health services, such as families, caregivers, health professionals, administrators, and political actors.

**Patient engagement (PE) at a glance**

- Organizational policy on PE
- Training provided for patient partner for research activities
- Training provided for researcher for PE activities
- Evaluation of the PE experience (in development)
- Level of PE: Learn, Consult, Involve, Collaborate
- 4 years of experience engaging patients in research

**What are their research themes?**

- **01.** Information and data platform on the health of Francophones, health care human resources and health care services
- **02.** A collaborative research approach centred on patients and participants in health care and services
- **03.** Conduct and supervision of randomized studies both in hospitals and in the community
- **04.** Training opportunities to transfer and mobilize knowledge among health network stakeholders
- **05.** Health care Technologies Platform to improve the management and self-management of patients with multi-morbidities
ISM aims to improve the research process and outcomes for patients and the health care system through engaged and collaborative research.

By partnering with patients and other partners, they hope to:

- Promote collaboration between all partners involved in the project by enhancing professional relationship based on support.
- Enhance the relevance of research questions by enhancing communication and sharing of experiences and expertise.
- Accelerate knowledge mobilization and application of research findings into practice.
- Develop more effective health services and products.
- Improve the health care system and health services (access, quality, security) by focusing on research projects that are centered on the needs of patients and other knowledge users.

**What research activities are patients engaged in?**

**Patient partners are engaged in:**

- Reviewing & giving feedback on grant & funding applications
- Assisting in framing the research question
- Developing the study design and plan (e.g., consent procedures, identifying study population, recruitment, identify/choosing interventions, identifying/choosing outcomes)
- Developing tools and publications
- Reading and providing feedback on drafts of written reports
- Sharing research findings at conferences, within the community, in patient groups, etc.
- Joining committees

**How are patients engaged in research?**

- Engagement methods include: in-person, email, phone, and online web communications with the administrative and research teams.
- Training is provided during the initial orientation process.
- The patient engagement experience is evaluated through informal interviews and de-briefing with study coordinators.

**Highlights/Success factors of engaging patients in research**

- Including a patient partner to lead the patient partner group that is validating the online training module for patients in collaborative research.
- Including patient partners on the advisory group to help develop the Centre of Excellence for patients with multiple chronic diseases: inform on patient pathways, patient assessment, clinic design, research indicators, validate the model and team.
- A patient partner convinced a research team not to submit their grant proposal as it was not fully developed and could put the team's reputation at risk.
Institut du Savoir Montfort contact

Office of Research
745A, Montréal Rd., Suite 202
Ottawa, Ontario, Canada
K1K 0T1

☎ 613-746-4621 ext. 6023
📧 ism-recherche@montfort.on.ca
🌐 savoirmontfort.ca/en
Lawson Health Institute

Lawson Health Research Institute (Lawson) is the research institute of London Health Sciences Centre (LHSC) and St. Joseph’s Health Care London (St. Joseph’s). Lawson employs over 1,500 people including principal investigators, researchers, technicians, support staff and trainees working at 10 sites across London, Ontario. Their scientists undertake more than 500 new clinical trials and partner on over 600 research projects annually.

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<th>Patient engagement (PE) at a glance</th>
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<td>Training for researcher for PE activities</td>
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<tr>
<td>Evaluation of the PE experience</td>
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<tr>
<td>Level of PE: Learn, Consult, Involve</td>
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<tr>
<td>1–2 years of experience engaging patients in research</td>
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</table>

What are their research themes?

Lawson conducts research that mirrors the clinical areas of LHSC and St. Joseph’s, including:

- Cancer
- Cardiology and vascular disease
- Children’s health
- Critical illness
- Diabetes and endocrinology
- Imaging
- Infectious disease
- Mental health
- Microbiome and probiotics
- Nephrology
- Neurological disorders
- Ophthalmology
- Orthopaedics
- Personalized medicine
- Surgery
- Transplantation

Lawson also includes the Parkwood Institute Research program that conducts research in the fields of cognitive vitality and brain health, mobility and activity, and mental health.

What are their objectives for engaging patients in research?

Lawson aims to improve the interface between patients and the health care system through engaged research. By partnering patients with Lawson staff and researchers, they hope to improve the quality and relevance of research and ultimately achieve benefits that matter to patients, such as:

- Improved health outcomes for patients
- Improved mutual trust between patients and researchers
- Increased transparency and credibility of research
- More effective dissemination of research findings
- More relevant and applicable research findings

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Catalogue of Organizations in Ontario

Page: 16
<table>
<thead>
<tr>
<th>What research activities are patients engaged in?</th>
<th>How are patients engaged in research?</th>
<th>Highlights/Successes of engaging patients in research</th>
<th>Partner Perspective</th>
</tr>
</thead>
</table>
| Reviewing and providing feedback on two to five grant proposals twice a year. | Engagement methods include in-person, email, and phone communications with the administrative and research teams. Patients are connected to an administrator who provides guidance, orientation, and internal training opportunities. Training includes information on the research competition, their role as a Patient Advisor in the review process, and the evaluation/review that is expected from them based on their patient/caregiver experience. | Each individual's experience is seen as unique and patients provide valuable input on how research is designed and conducted. Grant proposals identified by Patient Advisors as being highly ranked and important were successful in receiving funding. | “...when [name] interviewed them, a common concern they had was that they had no experience in research and they don’t know what they can bring forward... and when [name] last explained very carefully that’s exactly what we need. We need people with different backgrounds and you always have something to bring.”  
– Organizational employee |
Lawson Health Research Institute contact:
Lawson Health Research Institute Administration Team Office
750 Base Line Road East
Suite 300
London, Ontario,
Canada N6C2R5

☎ 519-667-6649
☎ 519-432-7367
✉ info@lawsonresearch.com
🌐 lawsonresearch.ca

Lawson Health Institute
Thunder Bay Regional Health Research Institute

Thunder Bay Regional Health Research Institute (TBRHRI) is the research arm of Thunder Bay Health Sciences Centre (TBRHSC) and is affiliated with Lakehead University and the Northern Ontario School of Medicine. TBRHRI facilitates clinical research in the area of imaging and related fields – strategic to regional health care needs. It also supports over 150 clinical research studies originating from TBRHSC, an academic health care centre that is responsive to the needs of the population of Northwestern Ontario.

Patient engagement (PE) at a glance

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<tbody>
<tr>
<td>✗</td>
<td>Organizational policy on PE</td>
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<tr>
<td>✗</td>
<td>Training provided for patient partner for research activities</td>
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<tr>
<td>✗</td>
<td>Training provided for researchers for PE activities</td>
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<td>Evaluation of the PE experience</td>
</tr>
<tr>
<td>✓</td>
<td>Level of PE: Learn, Consult, Involve</td>
</tr>
<tr>
<td>✓</td>
<td>1–2 years of experience engaging patients in research</td>
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</tbody>
</table>

What are their research themes?

The TBRHRI promotes patient-centred research that focuses on finding treatments and techniques to solve health care challenges most prevalent in Northwestern Ontario. There is research in various areas ranging from medical imaging to smart health technology.

Clinical research fields include:

- Cancer
- Cardiac Disease
- Indigenous Health
- Lung Disease
- Orthopaedics
- Stroke

What are their objectives for engaging patients in research?

TBRHRI follows TBRHSC’s patient and family-centred care model which is currently expanding how it conducts its research. Although objectives for patient engagement in research are still in development, the aim is to have it as a greater focus and mandate for the organization.
<table>
<thead>
<tr>
<th>What research activities are patients engaged in?</th>
<th>• Identifying the research question, developing protocols, and collaborating on the project from start to finish as part of the research team in seed grant funding competitions.</th>
<th>• Creating dissemination tools and attending research events in the oncology division.</th>
</tr>
</thead>
<tbody>
<tr>
<td>How are patients engaged in research?</td>
<td>• Engagement methods include phone and email communications and in-person meetings at an ad hoc basis with the administrative team and patient representatives. • Patient representatives are engaged through the organization’s Patient and Family Advisory Council and connected to the research arm of the organization.</td>
<td>• Currently, there isn’t a defined training plan for patients or researchers on patient engagement in research activities. TBRHSC provides orientation to volunteers to ensure they have the proper tools to be successful.</td>
</tr>
<tr>
<td>Highlights/Successes of engaging patients in research</td>
<td></td>
<td>• Organizational support and endorsement of patient engagement in research initiatives. • Co-development of patient partner role, training needs and areas of interest.</td>
</tr>
<tr>
<td>Partner Perspective</td>
<td>“The expectation would be that the input would be meaningful and valuable. So, not just checking off a box, for example.”</td>
<td>– Organizational employee</td>
</tr>
</tbody>
</table>
Patient engagement contact

Daniel Horne
Manager, Clinical Research Services Department
✉ horned@tbh.net

Thunder Bay Regional Health Research Institute

contact:
Thunder Bay Regional Health Research Institute
980 Oliver Rd
Thunder Bay, Ontario,
Canada P7B 6V4

Thunder Bay Regional Health Research Institute
The University of Ottawa Heart Institute (UOHI) is a heart health centre dedicated to understanding, treating, and preventing heart disease. They provide medical care to patients, conduct cardiac research, and train medical, graduate, and post-graduate students. The research at UOHI is closely integrated with clinical care and is performed by over 60 principal investigators and 130 research staff. UOHI has over $10 million dollars in research funding for the 2019 year and regularly conducts over 100 clinical trials. The UOHI is closely affiliated with The Ottawa Hospital, the University of Ottawa, and Carleton University. Additionally, it is designated under the Ontario French Language Services Act and the majority of their services are offered in both official languages.

**Patient engagement (PE) at a glance**

<table>
<thead>
<tr>
<th><strong>Organizational policy on PE</strong></th>
<th><strong>pending</strong></th>
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<tr>
<td><strong>Training provided for patient partner for research activities</strong></td>
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<td><strong>Training provided for researcher for PE activities</strong></td>
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<tr>
<td><strong>Evaluation of the PE experience</strong></td>
<td><strong>in development</strong></td>
</tr>
<tr>
<td><strong>Level of PE: Learn, Consult, Involve</strong></td>
<td>✔️</td>
</tr>
<tr>
<td><strong>4–5 years of experience engaging patients in research</strong></td>
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</table>

**What are their research themes?**

UOHI has major research programs in cardiovascular biology, imaging, regenerative medicine, and diseases such as heart failure, arrhythmias and vascular disease.

_They also have five Innovation Hubs of interdisciplinary research teams:_

1. Atherosclerosis and cardiometabolic diseases
2. Arrhythmias
3. Brain and heart
4. Heart failure
5. Valvular heart disease

**What are their objectives for engaging patients in research?**

UOHI aims to improve patient relevant outcomes for research by encouraging their researchers to incorporate the patient perspective into their research proposals. Patient and family engagement in research is used to leverage patient experience to improve the quality and relevance of research from a patient perspective. The following principles are integral to this goal:

*(continued)*
What are their objectives for engaging patients in research?

Patient engagement activities are driven by the Patient Engagement in Research Strategy, and led by the Patient Engagement in Research Advisory Council (PERAC).

- The mandate of PERAC is to advise the Chief Scientific Officer (CSO) and the Scientific Advisory Committee (SAC) of the University of Ottawa Heart Institute, and the Ottawa Heart Institute Research Corporation Board of Directors on strategies and activities related to the engagement of the Institute's patients, public constituencies and communities at large.
- A Patient Partners in Research questionnaire has been launched on UOHI's website for those interested in assisting with research activities at the Institute. Volunteers are contacted when opportunities arise to partner with a research group or advise on research activities.
- A “research” tab has been included within the patient’s portal of their electronic health record, called “MyChart” that will inform patients about partnering opportunities, and provide the link to UOHI website information.
- UOHI’s “Ask Me About Clinical Research” campaign has been fully launched to staff and the general public; the campaign strives to help educate the public about Clinical Research and address any questions or misconceptions they may have.

How are patients engaged in research?

- All patients of UOHI are automatically included as alumni members and added to a mailing list. The mailing list is used as a tool to inform patients of opportunities to engage in research activities.
- Patient partners assist in establishing performance indicators on the clinical research strategies.
- Patient partners provide input on individual research project material (e.g., surveys).
- Patient partners assist with review of internal funding competition applications by:
  - Considering incorporation of patient engagement and/or patient-relevant outcomes
  - Evaluating overall quality of the application
  - Reporting scores back to the scientific review committee
- Patient partners serve alongside researchers in our “innovation hub” meetings held annually. These meetings strive to drive research priorities and questions within specific disease areas.
Highlights/Sucesses of engaging patients in research

- Inclusion of patient engagement as a main goal in the Institute's Research Strategic Plan
- Successful partnering with researchers
- The launch of the *Patient Partners in Research* campaign
- Positive feedback from the Scientific Review Committee with regards to input on internal funding applications

Partner Perspective

“One of the most interesting things that we’ve actually done was to see the kind of research that’s being done and to figure how that research is fitting into a bigger picture.”

– Patient Partner

Patient engagement contact

✉ patientpartners@ottawaheart.ca
☎ 613-696-7000 x 18686

The University of Ottawa Heart Institute contact:
The University of Ottawa Heart Institute
40 Ruskin Street
Ottawa, Ontario, Canada
K1Y 4W7
☎ 613-696-7000
✉ ottawaheart.ca
Ontario has a network of 147 public health care centres that include community hospitals, teaching hospitals, chronic care and rehabilitation hospitals, and specialty psychiatric hospitals. They provide medical treatment and nursing care for sick or injured people and play a unique and vital role in the province’s health care system. Health care centres are well-positioned to combine care, research and education through a range of disciplines and expertise. Many centres focus on accelerating the translation of research into clinical practice to improve patient well-being and access to the latest advances in care.
The Centre for Addictions and Mental Health

The Centre for Addiction and Mental Health (CAMH) is a mental health teaching hospital that provides clinical care, conducts research and policy development and is fully affiliated with the University of Toronto. CAMH operates central clinical and research facilities in Toronto and has 10 locations throughout the province that provide communities with education and support for program development, health promotion and prevention. There are over 130 research scientists at CAMH, who work in a diverse range of disciplines in basic, clinical and social sciences.

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What are their research themes?

Research at CAMH focuses on mental health and addictions across the lifespan. There are three overarching research themes of: brain science, clinical and applied health services research, and social and epidemiological research and policy. Additionally, CAMH includes multiple research centres, each with their own specific research priorities:

- Campbell Family Mental Health Research Institute
- Institute for Mental Health Policy Research
- Clinical Academic Divisions
- Azrieli Adult Neurodevelopmental Centre
- Azrieli Centre for Neuro-Radiochemistry
- Cundill Centre for Child and Youth Depression
- Krembil Centre for Neuroinformatics
- The Margaret and Wallace McCain Centre for Child Youth & Family Mental Health
- Research Imaging Centre
- Slaitgh Family Centre for Youth in Transition
- Tanenbaum Centre for Pharmacogenetics
- Temerty Centre for Therapeutic Brain Intervention
CAMH aims to engage patients to improve and increase the relevance and uptake of new knowledge. By partnering with patients, CAMH hopes to:

- Enrich the research projects by making research objectives and outputs more meaningful to service users.
- Develop and use outcome measures that will be more impactful to service users.
- Develop projects that are focused on patient-identified priorities which is more likely to lead to better patient outcomes.
- Integrate knowledge translation from the beginning of each research project.
- Enhance the uptake and dissemination of new knowledge so that results are implemented and used in the public domain more quickly.

“In one of our projects the primary outcome was symptom reduction, and the youth actually said, “We’re not really interested in symptom reduction. That’s important, yes, but we want the primary outcome to be functioning.” – Research lead

Patient and family advisors are engaged in various initiatives and projects. For example, the Youth Engagement Initiative at CAMH facilitates collaboration between young people who have lived experience of mental health and/or substance use challenges and clinicians, researchers and other decision-makers at CAMH and in the broader community. Supported by the Margaret and Wallace McCain Centre for Child, Youth and Family Mental Health and the Child, Youth and Emerging Adult Program, this initiative has a far-reaching approach to youth engagement, where partners are engaged:

- As co-researchers and equal partners who may be involved at various stages of a research project, from the conception of an idea, to the determination of research objectives and study design, to the dissemination of knowledge.
- As youth advisors who are paid honoraria and are engaged in various projects (co-facilitate focus groups, perform recruitment activities).
- As youth engagement facilitators who are on staff at CAMH.
- In the National Youth Action Council (NYAC), an online network of over 100 youth across Canada. Youth on NYAC are able to view available opportunities for collaboration in research activities, service planning and education, or connect with other youth to initiate their own youth-led projects.
- Through youth advisory committees that allow for a broader group of youth to provide input and direction on research agendas.
What research activities are patients/caregivers engaged in? (continued)

Patients and families are also engaged in additional research centres, including the Azrieli Adult Neurodevelopmental Centre, Cundill Centre for Child and Youth Depression, Slait Family Centre for Youth in Transition and Temerty Centre for Therapeutic Brain Intervention. In these centres patients and families play a key role in various research activities, where they are engaged:

- In peer support and service user/family advisor roles where they are involved in developing and reviewing research materials, collaborating on intervention design and delivery, and supporting the experience of participants in research projects.

As part of CAMH’s newly launched 3 year Patient and Family Engagement Roadmap, an initiative is currently underway to increase patient and family engagement in research across CAMH research initiatives.

“It makes their work stronger when we work together with the scientists. And I think that, working with the scientists, you get to learn more, but the scientists also learn about the disabilities, and it can be a collaborative team.”

– Service User Partner

How are patients engaged in research?

- A formal hiring process exists for engagement facilitators and peer support workers. Additional patient and family advisors may be recruited through advertisements and referrals made by staff at CAMH, partner organizations as well as other service users.

- Engagement methods with patients and family members may include regular in-person meetings, virtual meetings, email and phone communication and social media engagement.

- Areas of patient and family engagement in research at CAMH have been captured through an internal environmental scan to identify opportunities for further growth and development for the patient and family engagement process.

- Preparation for meetings with patients and family members may include a pre-brief with a CAMH coordinator, who reviews the agenda with patients and caregivers and prepares them for meeting discussions. The coordinator is also responsible for providing other supports that enable participation.

- For every meeting with an advisor, an identified project ally may also be present for support if needed.

- Patient and family engagement has been evaluated across several research projects, a more formal evaluation strategy for engagement exists within the Youth Engagement Initiative, and a more robust evaluation strategy across CAMH research initiatives is being developed.

- Training includes an onboarding and matching process for patient and family partners and regular skill-building trainings and educational sessions.

- CAMH has also developed opportunities for researchers to attend workshops, one-hour lunch and learns and webinars on patient engagement.
Highlights/Successes of engaging patients in research

At CAMH, key success factors have included:

- Taking the time to develop relationships.
- Respecting different kinds of expertise and knowledge.
- Training/orientation and ongoing support and mentorship for the patient partners as well as the research team.
- Considering what accommodations and supports need to be in place for each partner.
- Matching interests and abilities of patient partners to research partners/projects

“What I lack in formal clinical training does not need to be a limitation as an ACT facilitator. It is more important for me to bring authenticity to the role and to recognize that my vulnerability is one of my greatest strengths. My own journey, as a person and a parent, with all my mistakes and limitations, is the foundation I need to draw upon to listen and respond to others with compassion.”

– Family Advisor

Some recent highlights include:

- Being recognized as a leading practice by Accreditation Canada for the Youth Engagement Initiative.
- Building a model of family leadership and parents training other parents to deliver a research protocol.
- Having a large impact on the success of research projects in the form of recruitment and retention of participants.

Partner Perspective

“I think one of our big highlights has been co-designing roles within the Youth Engagement Initiative with young people to make sure that it is actually reflecting their interests and their needs and their schedules. So, making sure that we’re creating opportunities for people to build the skill sets that they’re interested in and that we’re thinking ahead with them about where they want to land and how we can best support that.”

– Youth Partner
Patient/family engagement in research contact:

Lina Chiuccariello
Senior Manager, Clinical Research Operations
mail lina.chiuccariello@camh.ca

CAMH contact:
Queen Street Site
1001 Queen Street West
Toronto, Ontario, Canada
M6J 1H4

https://www.camh.ca/
Holland Bloorview Kids Rehabilitation Hospital is a top 40 Canadian research hospital that is fully affiliated with the University of Toronto and serves over 7500 families annually. Holland Bloorview supports children and youth living with disability, medical complexity, illness, and injury. Housed within Holland Bloorview Kids Rehabilitation Hospital is the Bloorview Research Institute. Established in 2004, the internationally recognized Bloorview Research Institute is dedicated to improving the lives of children with disabilities through client and family-centred rehabilitation research. The Research Institute brings together a multi-disciplinary team of scientists who work collaboratively with clinical staff, clients, and families to generate clinically-linked and applied pediatric rehabilitation research.

**Patient engagement (PE) at a glance**

- Organizational policy on PE
- Training provided for patient partner for research activities
- Training provided for researcher for PE activities
- Evaluation of the PE experience
- Level of PE: Learn, Consult, Involve, Collaborate, Lead
- 4–5 years of experience engaging patients in research

**What are their research themes?**

Holland Bloorview aligns its research with the hospital's Centres for Leadership. The Centres for Leadership advance the leadership, structure, and processes required to bridge clinical excellence with research and education with a framework of interdisciplinary collaboration. The Centres generate programs to improve outcomes for children with disabilities and their families in the following areas:

- Acquired Brain Injury
- Applied Innovation
- Child Development
- Participation and Inclusion

**What are their objectives for engaging patients in research?**

Holland Bloorview highlights several objectives of engaging patients and their families from the researcher perspective, including:

- Assistance obtaining funding
- Expanded research networks
- Improved knowledge translation
- Improved research
- Positive influence on new scientists
What research activities are patients engaged in?

Patient partners are engaged through four different roles within the Family Leadership Program:

1. As a research reviewer that is a one-time consultative role aligned with the grant reviewing part of the research process.

2. As a research adviser, who acts as a partner on the research team and may be involved in many different roles and activities along the research process.

3. As a research communicator that aligns with the dissemination (presentations, co-authoring papers, media outreach) of information or results of the research process.

4. As part of the Research Family Engagement Committee who meets once a month to advise and consult on research practices and current/future studies.

How are patients engaged in research?

- Engagement methods include: in-person meetings, email, and telephone correspondence.
- Patients are recruited through a variety of methods (clinicians, existing relationships with researchers, internet outreach, etc.). Patients and families are provided with an application and go through a reference process with the volunteer services department.

- Training includes a formal Family Leadership onboarding and orientation meeting with a Family Partnership Specialist. Candidates that become family leaders then complete online training modules through our volunteer Resources Department. Project by project training is provided as Family Leaders are matched to different research projects.

Highlights/Successes of engaging patients in research

In 2016, the patient engagement experience was evaluated through an external evaluation including: a literature review, interviews with scientists and families, and an organizational scan. Results from the evaluation were used to improve and expand the patient engagement experience.
Partner Perspective

“I think it is important for everybody to understand what they bring to the table and the equal value of it all. We know interest driven partnerships are so critical. There’s a really intrinsic motivation when you’re doing something that you’re really interested in and is meaningful to you.”

– Organizational employee

Patient engagement contact

Beth Dangerfield,
Family Partnership Specialist
✉️ bdangerfield@holland-bloorview.ca

Holland Bloorview Kids Rehabilitation Hospital
contact:
Holland Bloorview Kids Rehabilitation Hospital
150 Kilgour Road
Toronto, Ontario, Canada
M4G 1R8
☎️ 416-425-6220 | 1-800-363-2440
🌐 hollandbloorview.ca

Holland-Bloorview Kids Rehabilitation Hospital

Catalogue of Organizations in Ontario  Page: 33
Sunnybrook Health Sciences Centre is an academic teaching hospital affiliated with the University of Toronto. Sunnybrook has three campuses and conducts research at the Sunnybrook Research Institute (SRI). They have over 300 scientists and clinician-scientists conducting more than $100 million of research each year on three scientific platforms: biological sciences, evaluative clinical sciences, and physical sciences.

**Patient engagement (PE) at a glance**

| ✔ | Organizational policy on PE |
| ✔ | Training provided for researcher for PE activities |
| ✔ | Evaluation of the PE experience |
| ✔ | Level of PE: Learn, Consult, Involve, Collaborate |
| ✔ | 1–2 years of experience engaging patients in research |

**What are their research themes?**

Sunnybrook Health Sciences Centre conducts research within nine clinical programs:

- DAN Women and Babies
- Holland Bone and Joint
- Hurvitz Brain Sciences
- Integrated Community
- Odette Cancer
- Schulich Heart
- St. John's Rehab
- Tory Trauma
- Veterans

**What are their objectives for engaging patients in research?**

Sunnybrook Health Sciences Centre has a strategic priority in engaging patients in research. It aims to:

- Improve the research process and outcomes that are important to patients and their families.
- Include patient engagement in the research prioritization or study design of 100% of Sunnybrook investigator-initiated studies in a three year timeframe.
- Develop a framework specifically for engagement in research.
- Develop capacity building on patient engagement in research, both for patient partners and researchers.
- Establish centralized institutional support for patient engagement activities.
What research activities are patients engaged in?

Patient/caregiver advisors may be engaged at multiple stages of the research cycle such as:

- Setting and developing the patient-oriented research agenda
- Designing the study and interventions
- Helping to recruit study participants

How are patients engaged in research?

- Patient partners are engaged through a centralized Patient and Family Partner Program
  
  - A current pool of 150 patient partners working on various committees and groups who are available for research specific activities

- New patient partners are interviewed by a member of the Patient Engagement and Health Equity team to identify their skills and interest. Patients are then matched with researchers who are looking to engage with someone about the patient experience. A key contact is then appointed for the patient partner to continue the work and the relationship.

- Having patients involved early on and throughout the research process whenever possible.

- Ensuring both researchers and patients are prepared and having clear expectations/roles defined.

Highlights/Successes of engaging patients in research

- Participating as part of the research team
- Reviewing materials (lay summaries, consent forms)

- Training is provided to researchers in the form of a researcher development series or one-hour lectures which run throughout the year.

- Patient engagement is evaluated through surveys that ask the patient partner to identify if they were oriented to the process, felt comfortable sharing their thoughts, felt like their contribution was useful and respected and felt that the topic was appropriate for partnership.

- Training is being developed for patient partners; focus groups are being conducted to help identify the most important factors to include in training modules. Currently, patients are provided with a guidebook that orients them to the hospital, key policies, and other information related to the work they would be partnering on. Recommendations are then provided to the research team in terms of how to orient the patient to the specific project.
“[Patients] completely informed the research that the program conducted in the future... after speaking with patient and family partners there were things, like different outcomes for example, that were identified that maybe the research team hadn’t necessarily thought about.”

— Organizational employee

**Patient engagement contact**

Laurie Legere, Manager of Patient Engagement and Health Equity

Email: laurie.legere@sunnybrook.ca

**Sunnybrook Health Sciences Centre contact:**

416-480-6100

sunnybrook.ca

Bayview Campus

2075 Bayview Avenue

Toronto, Ontario, Canada

M4N 3M5
**Government Organization**

Government organizations are independent agencies that are affiliated and accountable to the Ontario Ministry of Health and Long-term Care. They can be non-board governed, board governed, or advisory [4]. Generally, these agencies work at the system level to improve the health of residents by providing advice, tools, resources and evidence-based data, but do not provide direct patient care. Their main purpose is to plan and integrate health care to improve access to care and the patient experience. Many government organizations conduct research in support of a larger mandate.
An agency of the Ministry of Health and Long-Term Care, **Cancer Care Ontario** (CCO) is the Ontario government’s principal advisor on cancer and chronic kidney disease care, and access to care for key health services. CCO works with patients with cancer and their families, health professionals, organizations and policy-makers in the design, delivery, and evaluation of Ontario’s cancer system. They provide tools, resources and evidence-based data to help health care partners improve the delivery of care.

CCO’s Research Office works with the research community to advance research across the organization (including universities, research institutions, and health granting agencies). By assisting in navigating the many processes associated with undertaking research (legal, financial, data access, privacy) the Research Office facilitates the generation of knowledge and evidence to inform CCO programs and policies. The knowledge generated by CCO scientists and research staff can then be translated into innovations to help improve health care in Ontario.

### Patient engagement (PE) at a glance

- Organizational policy on PE
- Training provided for patient partner for research activities
- Resources provided for researchers for PE activities
- Evaluation of the PE experience
- Level of PE: Learn, Consult, Involve. Collaborate and lead is project dependent.
- Over 10 years of experience engaging patients in research

### What are their research themes?

CCO supports cancer research within the entire care continuum — from prevention to survivorship and end-of-life care in many different types of cancer including:

- **Breast**
- **Central nervous system**
- **Gastrointestinal**
- **Genitourinary**
- **Head and neck**
- **Hematologic**
- **Palliative care**
- **Skin**
- **Thoracic**
What are their objectives for engaging patients in research?

*To advance the Person Centred Care approach in health care research, so that:*

- Patients have a voice in the design, delivery and evaluation of the care they receive, including the outcomes of research-based activities
- Patient/family advisors are engaged in:
  - CCO partners with over 100 patient and family advisors across the province who participate in all levels of research design and implementation.
  - Invitations to participate in research-related opportunities (including opportunities to attend CCO’s annual Research Day, develop or endorse priorities, sit on working groups, as stated above) with our advisor community.
- Virtual and in person opportunities, including the use of our advisor social network platform.
- Evaluation of patient partners’ experience through surveys and de-briefing sessions.

What research activities are patients engaged in?

*Patient/family advisors are engaged in:*

- Reviewing research proposals
- Identifying research priorities
- Disseminating activities (attending and presenting at conferences)
- Participating in research strategy working groups
- Participating in research study committees
- Patient and Family Advisors were critical in developing patient-centred research priorities for the organization.

How are patients engaged in research?

- Invitations to participate in research-related opportunities (including opportunities to attend CCO’s annual Research Day, develop or endorse priorities, sit on working groups, as stated above) with our advisor community.
- Virtual and in person opportunities, including the use of our advisor social network platform.
- Orientation sessions to CCO and its activities (including the Research Office).
- Evaluation of patient partners’ experience through surveys and de-briefing sessions.

Highlights/Successes of engaging patients in research

- CCO partners with over 100 patient and family advisors across the province who participate in all levels of research design and implementation.
Partner Perspective

“The point is that what you are contributing comes from your experience as a patient so you don’t have to have a research background. What you have to have is patient experience and the knowledge that comes from that.”

– Patient Partner

“I think a lot of their success, quite frankly, comes from the top down. [Leadership] is fully participatory.”

– Patient Partner

“You know, it’s people sitting around a table with equal respect for one another and you know you can feel that.”

– Patient Partner

Patient engagement contact
Ashley Farrelly, Lead, Engagement and Experience
ashley.farrelly@cancer-care.on.ca

Cancer Care Ontario contact:
Cancer Care Ontario
620 University Avenue
Toronto, Ontario, Canada
M5G 2L7

1-888 939-3333
info@cis.cancer.ca
cancercareontario.ca/en
Clinical Trials Ontario

Clinical Trials Ontario (CTO) is a leading organization in the clinical trials community dedicated to strengthening, promoting, and capitalizing on Ontario’s competitive advantages for conducting high-quality clinical trials. They work collaboratively with industry, research institutes, the public, and other health innovation organizations to improve the clinical trials environment and attract investment to the province, while supporting the highest ethical and quality standards.

What are their research themes?

While CTO does not directly carry out clinical trials, it is committed to developing ways to engage patients with clinical trials. They do this by encouraging active involvement of patients in CTO programming, raising patient awareness of clinical trials, and supporting researchers and health care providers in their interactions with patients around clinical trials. CTO works with a range of health charities and patient organizations that are interested in clinical trials including:

- Brain Tumour Foundation of Canada
- Canadian Arthritis Patient Alliance
- Canadian Breast Cancer Network
- Canadian Cancer Survivor Network
- Canadian Skin Patient Alliance
- Colorectal Cancer Canada
- Cystic Fibrosis Canada
- Foundation Fighting Blindness
- Huntington Society of Canada
- The Leukemia & Lymphoma Society of Canada
- Myeloma Canada
- Sickle Cell Awareness Group of Ontario

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<tr>
<td>✓ Level of PE: Learn, Consult, Involve, Collaborate, Lead</td>
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<tr>
<td>✓ 2–3 years of experience engaging patients in research</td>
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What research activities are patients engaged in?

Patients are engaged at CTO through their Patient and Public Advisory Group (P2AG). This group advises CTO on current topics and issues regarding clinical trials for which patient and public input is invaluable and ensures that the patient and public perspective is respected and incorporated into relevant CTO activities. P2AG members also act as ambassadors for clinical trials and for the organization.

**Patient advisors are also engaged in:**

- Reviewing and providing feedback on grant and funding applications to which CTO applies
- Collecting data
- Helping to develop tools and publications
- Reading and providing feedback on drafts of written reports/publications
- Sharing research findings at conferences within
- Establishing patient and researcher partnerships: creating roles, setting expectations, and time commitments.
- Participating in committees to provide input in the strategic direction
- The patient partner experience for P2AG members is evaluated after every workshop. The results of those evaluations are integrated into the design of future workshops or meetings.
- Having honest and transparent channels of communication that make room for open and respectful dialogue amongst all stakeholders.
- Establishing patient and researcher partnerships: creating roles, setting expectations, and time commitments.

Additionally, the organizations CTO supports may include opportunities to: collaborate in research projects; apply to become a community representative on a research ethics board or part of an advisory group; attend conferences or events related to research and clinical trials; and learn about new clinical trials resources.

How are patients engaged in research?

- Engagement methods include: in-person meetings and workshops, online web conferences, email, Google Docs, and phone communications with the CTO team.
- Patient partners have been recruited through other public speaking events, social media, and word-of-mouth avenues.
- Training includes formal conversations with subject area experts and written resources (terms of reference, patient partner expectations, etc.)
- Patient advisors are also engaged in:

Highlights/Successes of engaging patients in research

- Having honest and transparent channels of communication that make room for open and respectful dialogue amongst all stakeholders.
- Establishing patient and researcher partnerships: creating roles, setting expectations, and time commitments.
Partner Perspective

“I think one of the biggest highlights is being on the advisory committee. Being a member of the board of directors has been a wonderful and fulfilling opportunity and now being able to also work with other patients has been very valuable. I love the collaborative environment that has been created with other patients and with our director of patient and public engagement. Being able to come together and share our lived experiences and patient perspectives has been very rewarding.”

– Patient Partner

Patient engagement contact

Dawn Richards,
Director of Patient and Public Engagement
✉ dawn.richards@ctontario.ca
📞 416.358.5877

Clinical Trials Ontario

contact:
MaRS Centre, West Tower
661 University Avenue,
Suite 460
Toronto, Ontario, Canada
M5G 1M1

📞 416.673.6684
✉ info@ctontario.ca
🌐 ctontario.ca
Not-for-profit organizations are clubs, societies, or associations that are organized and operate for the purpose of either social welfare, civic improvement, recreation, or any other purpose except for profit. Not-for-profit organizations can include health charities who advocate for patients to improve their quality of life through awareness, education, and research. Many organizations possess funding capacity to invest in medical research and support the health and well-being of Ontarians.
The Arthritis Society is a national health charity, fueled by donors and volunteers, with a vision to live in a world where people are free from the devastating effects that arthritis has on lives. Founded in 1948 with one very clear goal – to alleviate the suffering of people crippled by arthritis – that same volunteer-led passion carries on today in communities across Canada. Through the trust and support of donors and sponsors, the Arthritis Society is Canada’s largest charitable source of investments in cutting-edge arthritis research, proactive advocacy and information and support that will deliver better health outcomes for people affected by arthritis. The Arthritis Society has funded more than $200 million in research projects since its founding – projects that have led to breakthroughs in the diagnosis, treatment and care of people with arthritis.

Patient engagement (PE) at a glance

| ✓ Organizational policy on PE |
| ✓ Training provided for patient partner for research activities |
| ✓ Training provided for researcher for PE activities |
| ✓ Evaluation of the PE experience |
| ✓ Level of PE: Learn, Consult |
| ✓ 2–3 years of experience engaging patients in research |

What are their research themes?

The Arthritis Society’s research program is grounded on their goal of finding the causes and cures of arthritis and promoting the best possible treatments and care for those with arthritis. Most importantly, transparency, fairness and accountability remain priorities in their research strategy and programs. The goal of the Arthritis Society’s research program is to have a positive impact on health incomes for people with and at risk of arthritis.

*The Arthritis Society has identified five priority research impact areas:*

01. Arthritis and pain  
02. Arthritis and work  
03. Childhood arthritis  
04. Inflammatory arthritis  
05. Osteoarthritis

The Arthritis Society also has an ongoing interest in women’s health research, given the increased prevalence of arthritis in Canadian women (1 in 4) compared to men (1 in 6).
### What are their objectives for engaging patients in research?

The Arthritis Society aims to improve the research process and outcomes for patients and the arthritis care “ecosystem” through engaged research. By partnering with patients, they hope to ensure that their research is informed by patient priorities.

“The overarching goal of our research program is to fund the most promising research in Canada to have positive health outcomes for people living with arthritis. Pairing this with a strategic focus on patient-identified priorities will drive a meaningful contribution to arthritis research in Canada and beyond.”

— Organizational employee

### What research activities are patients engaged in?

**Patient partners are engaged as:**

- Reviewers in the Arthritis Society grant peer review process:
  - Reviewing grant applications for five different competitions offered by the Arthritis Society

- Strategic advisors during research priority-setting process:
  - Informing the Arthritis Society’s Five Year Research Strategy

- Members of the Online Consumer Panels:
  - Providing input on educational resources and knowledge translation products, including those showcasing the impact of research

### How are patients engaged in research?

- Engagement methods include: in-person meetings, workshops, online surveys, email, phone communications, and online web conferences with the research, knowledge translation, and education teams.

- Partners are recruited through a newsletter as well as partnership organizations such as the Canadian Arthritis Patient’s Alliance.
  - Training includes an orientation session, handouts on the rating scales and reading criteria and resources about the research process and specific roles.
  - The patient engagement experience is evaluated through surveys which ask about the patient and researcher experience.

### Highlights/Successes of engaging patients in research

Patients have informed the research themes in their upcoming 2020–2025 five-year strategic plan and they continue to be involved in every grant funding decision made.
Partner Perspective

“Ensuring that the patient perspective is considered in every conversation we have about the research strategy, the peer review process, how we are communicating externally, and how we’re encouraging our researchers to engage with patients and communicate with them. Keeping patient engagement top of mind and a continuous thread throughout the research process will hopefully increase engagement levels and the quality of engagement with patients. We aim to engage a greater number of patients with different perspectives on an ongoing basis.”

— Organizational employee

Patient engagement contact

Carolyn Goard
cgoard@arthritis.ca
☎ 416-979-7228
ext. 3543

The Arthritis Society
contact:
393 University Avenue
Suite 1700
Toronto, Ontario, Canada
M5G 1E6
☎ 416.979.7228 | 1.800.321.1433
☎ 416.979.8366
✉ info@arthritis.ca
🌐 arthritis.ca
The Ontario Brain Institute (OBI) is a research centre maximizing the impact of neuroscience and establishing Ontario as a world leader in brain research, commercialization and care. The OBI aims to enhance the neuroscience research system, grow the Ontario neurotechnology cluster, and improve brain health for Ontarians. The OBI central database, Brain-CODE, helps more than 240 researchers at over 40 institutions across Ontario share their data.

Patient engagement (PE) at a glance

- Organizational policy on PE
- Informal training provided for patient partners for research activities
- Training provided for researcher for PE activities
- Evaluation of the PE experience
- Level of PE: Learn, Consult, Involve, Collaborate, Lead
- 7–8 years of experience engaging patients in research

What are their research themes?

OBI funds and manages five Integrated Discovery Programs that spans several disciplines, including:

- Cerebral Palsy
- Depression
- Epilepsy
- Neurodegenerative Diseases
- Neurodevelopmental Disorders

What are their objectives for engaging patients/caregivers in research?

From its formation in 2011, OBI recognized the value of integrating the lived experience perspective of patients to improve research outcomes.

*By partnering with patients, they hope to:*

- Ensure research is relevant to the needs of the community.
- Improve translation and uptake of research findings into practice.
- Develop more effective health services and products.
- Promote knowledge exchange between the patient and research community.
- Improve quality of life and strengthen the health care system.
What research activities are patients engaged in?

**Patient partners are engaged in:**

- Providing input on research agenda and assist in framing the research question. (e.g., priority setting)
- Developing the study design (e.g., consent procedures, identifying study population, recruitment, identify/choosing interventions, identifying/choosing outcomes).
- Assisting in interpretation and analysis of data.
- Developing tools and co-authoring publications.
- Reviewing and providing feedback on drafts of written reports.
- Sharing research findings at conferences, within the community, in patient groups, etc.
- Participating in committee membership.

How are patients engaged in research?

- Engagement methods include in-person, email, and phone communications with the administrative and research teams.
- Training includes: orientation, on-boarding package, handouts on the research process, and terms of reference as well as on-going capacity development throughout patient partnership.
- Patients participate in patient and family days for the community to discuss research impacts and to celebrate success stories.
- The patient engagement experience is evaluated through a workshop exercise which asked patient partners to map their engagement on the IAP2 spectrum [2] to assess meaningful engagement levels. Yearly surveys are also administered to assess effective integration of patients into the research programs.
- Inclusion of diverse perspectives and roles for patient partners to be involved in the research process.
- Creation of frequent and regular opportunities for knowledge exchange to occur.
- Continuous communication of the impacts of patient engagement in research.
- Continuous assessment of the strength of partnerships and comfort with degree of engagement.

Highlights/Successes of engaging patients in research:

- "Working with the community to identify the priorities and also having the community there to support us to champion these priorities to help us push for more work and more investment into these areas."

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**Partner Perspective**

"Working with the community to identify the priorities and also having the community there to support us to champion these priorities to help us push for more work and more investment into these areas."

— Organizational employee
Partner Perspective

“We want it to be meaningful engagement and we want to build those strong relationships. In the very beginning there was still a bit of trepidation from the researchers to include patients in some of their scientific discussions and now, where we are at, seven or eight years later, is that it is almost a given. So it took a long time to get there but because there was an established principle that recognized the value of having that lived experience perspective. I think that’s what allowed that trust to occur and we are now starting to see the results of that work.”

— Organizational employee

Patient engagement contact: Jordan Antflick, Manager, Knowledge Translation, jantflick@braininstitute.ca

Ontario Brain Institute contact: 1 Richmond Street West, Suite 400, Toronto, Ontario M5H 3W4, (647) 847-9000 | 1 (866) 637-6301, info@braininstitute.ca, braininstitute.ca

Not-for-profit Organization

Ontario Brain Institute
The Ontario Drug Policy Research Network (ODPRN) is a collaboration of established researchers from across Ontario that was formed to rapidly respond to policymakers’ needs for relevant research to guide and inform their decisions. The ODPRN generates scientifically sound evidence related to real-world drug utilization, safety, effectiveness, and costs of drugs in Ontario, and have developed partnerships that help engage in cross-provincial comparisons of drug safety and utilization. Their researchers have expertise in pharmaceutical utilization, outcomes, economics, and drug-policy research. The ODPRN has published over 90 academic papers in top journals, produced over 160 policy reports, delivered over 150 presentations, and engaged 77 students in their training program.

Patient engagement (PE) at a glance

| ✔️ | Organizational policy on PE |
| ✔️ | Training provided for patient partner for research activities |
| ✗ | Training provided for researcher for PE activities |
| ✔️ | Evaluation of the PE experience |
| ✔️ | Level of PE: Learn, Consult, Involve, Collaborate, Lead |
| ✔️ | 6–7 years of experience engaging patients in research |

What are their research themes?

The ODPRN conducts research in a range of themes from large drug class reviews to distinct rapid response projects that have answered a wide breadth of questions related, but not limited to, drug safety and effectiveness, drug utilization, and access to medications.

In particular, the ODPRN conducts research in core areas of:

- Drug class review
- Drug policy and evaluation
- Drug safety and effectiveness
- Safety and use of opioids
- Self-monitoring of blood glucose

What are their objectives for engaging patients in research?

The ODPRN’s main objective for engaging patients in research is prioritizing the patient-relevant issues and that patient voices are being heard right from the beginning of research to the end. By partnering with patients, they hope to ensure that their research is able to inform the general public as the general public are the ultimate end users of who their research is going to directly impact.
What research activities are patients engaged in?

Patient partners are engaged in two major patient engagement groups within the ODPRN:

The Citizens’ Panel
A group of up to 25 volunteer citizens from across Ontario who ensure that the ODPRN appropriately identifies issues of importance to the public, and incorporates these priorities into all aspects of their research. These individuals are diverse in demographics as they are meant to represent the general public.

The Lived Experience Advisory Group for the Ontario Opioid Drug Observatory
A group of up to 10 individuals with opioid use experience. They are diverse in demographics but specifically have personal experience taking opioids.

How are patients engaged in research?

• The Citizens’ Panel meets bi-monthly for two hours via teleconference. There is also an annual, full day, in-person meeting. The Lived Experience Advisory Group, meet quarterly for about an hour and a half via teleconference.

• Training includes: online training modules, a 1:1 phone call with a staff member, and print resources (terms of reference, previous meeting minutes).

• The patient engagement experience is evaluated through surveys.

Highlights/Successes of engaging patients in research

• Determining research priorities of joint interest to policymakers and the general public.

• Strengthening the relevance of our research and the importance of particular research outcomes.

• Improving the knowledge of public access to certain drugs.

Partner Perspective

“I think that maybe we’ve taken a little bit of a unique approach in co-building the Citizens’ Panel. Like, we went to them from the beginning and said, ‘We don’t know how this panel should be structured. Now that the job class reviews are finished, we don’t know how you should be involved in our work, so what do you think? How do you want to be involved?’. I think having that frank conversation at the beginning and then allowing them to create the role is important.”

– Organizational employee
Patient engagement contact

Dana Shearer, Knowledge Broker
shearerd@smh.ca
416-864-6060 ext. 76205

The Ontario Drug Policy Research Network
contact:
The Ontario Drug Policy Research Network
St. Michael's Hospital, 30 Bond Street
Toronto, ON M5B 1W8, Canada

info@odprn.ca
odprn.ca
The following results were gathered from survey responses completed by both organizational employees and patient partners. Surveys were distributed to organizational employees who agreed to participate in this project and to patient partners within those organizations when possible.

A total of 18 organizational employees and patient partners identified research activities patient partners engage in:

- 78% Review & give feedback on grant & funding applications
- 83% Provide feedback and input on research agenda
- 67% Assist with developing the research question, study design and plan
- 44% Help collect data
- 56% Assist in interpreting data
- 89% Help develop tools and publications
- 78% Read and provide feedback on drafts of written reports
- 61% Share research findings at conferences
- 72% Participate in committee membership

*Please note that there were no significant differences in survey responses from organizational employees and patient partners, therefore results were collated.*
A total of 18 organizational employees and patient partners indicated what level of patient engagement they were involved in according to the IAP2 Spectrum of Patient Engagement [2]:

*Please note that there were no significant differences in survey responses from organizational employees and patient partners, therefore results were collated.

Respondents identified if they had received any training regarding patient engagement:

- Patient Partner (n=4)
  - 50% — Yes
  - 50% — No

- Organizational Employee (n=14)
  - 78% — Yes
  - 22% — No

Patient Partners' Perspectives:

The majority (over 65%, N=4) of patient partners reported that:

- They contribute to research activities.
- They ensure that outcomes important to patients are reported.
- They provide feedback on grant proposals, funding decisions, and patient-related materials.
- They are valued as a contributing member to the research team.
- They understand their role in patient engagement in research.
- They are supported adequately to carry out research tasks.
- They are able to work with researchers in a positive manner.
- Their organization keeps them informed of research results.
- Their organization promotes an environment of mutual respect.

One third of patient partners (N=3) reported that they participate as a member of the research team in the planning, designing and guidance of research objectives. Additionally, 50% (N=4) of patient partners agree that they meaningfully engage with researchers and that they are engaging with researchers using collaborative, inclusive methods.

Organizational Employees' Perspectives:

The majority (over 70%, N=14) of organizational employees reported:

- They meaningfully engage with patients in research-oriented tasks.
- They participate in meaningful conversations about patient engagement with a patient partner.
- They understand their role in patient engagement in research.
- They value patient voices in the research process.
- They work with the patient partners in a positive manner.
- Their organization promotes an environment of mutual respect.
- That patient partners are engaged using collaborative, inclusive methods.
- Their organization informs patient partners of the research results.
Perceived Barriers to Effective Patient Engagement in Research

The following is a list of most frequently mentioned barriers perceived to affect patient engagement collected from the interviewees and survey respondents:

1. Lack of organizational support and protocols for engaging patients
2. Lack of funding to effectively incorporate patient engagement in research
3. Ensuring patient partners are representative of Ontario's diverse population
4. Lack of knowledge and confidence in patient-oriented research concepts for both patients and researcher groups
5. Time, staff and resource constraints limit engagement work
6. Lack of guidance on fair and equitable compensation of patients involved in research
7. Fear of tokenism and inability to provide meaningful and interesting opportunities for patients
Recommendations

The following recommendations were formed by analyzing responses from the interviews and surveys of the participating organizational employees and patient partners. The study team analyzed key factors (barriers and facilitators), the strategies used to mitigate or leverage each factor, and suggestions shared by interviewees to compile recommendations that can be considered when implementing patient engagement approaches.

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| Ensure adequate training, tools and resources are provided to both patient and researcher groups. | This can increase knowledge and confidence to participate in patient engagement in research and foster active and sustainable collaboration between patients and researchers. It allows for individuals to have an equal chance to succeed. | “So, I think that has been a big learning around how much we have to prep everybody; ourselves as professionals and the youth or the service users who are coming into the group to work together and to be able to have open conversations and learn how to have a dialogue where not everybody agrees and has the same views, but understanding that if we talk it through we'll have a richer outcome.”
“So, I just think that the whole patient engagement piece takes a lot more energy and hand-holding and we can't just expect that bringing patient partners onboard is like asking your research colleague down the hall to be part of the team. Like, you have to give them a lot more context, a lot more information and if you don't have the energy to do that, I would say don't bother to do it. It's really disingenuous just to have people be part of the team and not really help them feel part of it or not let them know what's going on.” | OSSU Capacity Building Compendium highlights training courses on patient-oriented research: [https://ossu.ca/for-researchers/training/](https://ossu.ca/for-researchers/training/) |
| Recommendation | Establish patient engagement as an organizational priority to ensure suitable resources are present. This can include creating an organizational role for patient partnership engagement and having leadership buy-in to the patient engagement process. |
| Rationale | Centralized organizational support and formal policies increase accountability, application, and sustainability of engagement between researchers and patients. Designating an employee who patients can connect to allows for a supportive, safe and open environment for patients to relay feedback, concerns and questions throughout their partnership with the research team. |
| Illustrative quotes from participants | “I guess the one big recommendation I would have is that you need to have somebody who can allocate time and energy to doing it. You’ve got to be responsive so you can’t have people’s messages sitting in your inbox or on your voicemail for weeks before you get back to them. You have to have time to really orient them, explain to them.” |

| Recommendation | Be transparent, and ensure open, honest communication and cultural competence to cultivate viable partnerships between patients and researchers. |
| Rationale | Active listening, respectful dialogue and transparency facilitate high-quality relationships between patients and researchers. |
| Illustrative quotes from participants | “I think people need to be honest with each other. That everybody is fairly new to this, right? I always find if you’re really transparent about ‘I’m new to this, you’re new to this, we’re going to kind of fumble our way through it together’, it really helps, I think set the stage for everyone’s learning together, as opposed to not being as transparent and not admitting that maybe you don’t know everything about it. So, I think that’s important.”

“Make sure there are opportunities for frequent knowledge exchange. So bringing people together once a year is not enough. We might overdo it but our patient advisory committee members meet with themselves or research programs or as a whole, you know, between four and six times a year. So there are a lot of opportunities for people to talk and build those relationships. Which I think is the foundation of being able to do this meaningful work.” |
**4**

**Recommendation**
Co-create roles and expectations and be mindful and flexible of individuals’ interest, time commitments and choice of how and when to contribute.

**Rationale**
Co-designing roles that match patients to areas of interest and emphasizing the importance of the patient role in providing lived-experience leads to increased retention and empowerment of patients in ability to impact research.

**Illustrative quotes from participants**
“Really establishing the role that they can play and expectations and time commitments so that they can have the confidence to actually participate in research.”

“Certainly, you need to have a framework in order to onboard anybody and it’s really no different than just having another type of staff member here. We need to have a framework for what they need to be doing, how they’re operating and how we’re interacting with them and we don’t have that developed. So, there’s a time and cost consideration that certainly goes with that.”

“Being really responsive to the skills sets that people are interested in. So, if they’re interested in learning more about facilitation then we might bring in facilitation training. If they’re more interested in learning about interviewing skills then that might be what we work on. So, it’s definitely informed by what they’re interested in and also what we feel they might need to be able to participate in a meaningful and safe way.”

**Resources**
CIHR’s framework for patient engagement:
http://www.cihr-irsc.gc.ca/e/48413.html

**5**

**Recommendation**
Avoid tokenistic engagement of patients and strategically identify opportunities for meaningful and effective engagement.

**Rationale**
Being purposeful and strategically planning to include patient voices in research mitigates the risk of tokenism and will increase impactful patient engagement work.

**Illustrative quotes from participants**
“Just make sure that when you ask for [a patient partner], you know what you’re going to do, you know so you don’t get them down here and waste their time or look at them as tokens and that is very important.”

“You just have to be careful that you’re not just filling a chair. If you are then you either speak up about it or if you’re reluctant to do that then come back and tell us and we’ll do something about it because there is no point in thinking we have all these people involved as collaborators and partnering completely in a project only to find out in the end that all you did was say yes or no.”

**Resources**
Workbook to guide the development of a Patient Engagement In Research (PEIR) Plan – can be used to have conversations with multiple stakeholders to determine what meaningful patient engagement in research can look like:
### Recommendation

Ensure diverse representation and inclusion of patients by engaging with members of marginalized communities, and other under-represented groups in research.

### Rationale

This will make sure that diverse perspectives are heard and understood and that the patients included in research are reflective of relevant patient populations.

### Illustrative quotes from participants

“In terms of finding people that aren’t reaching out to us, we’ve tried different routes such as specifically reaching out to networks that we have that might access that certain population. So, for example, we have some contacts within the Chiefs of Ontario so we had sent them an email in the past asking if they would be interested in helping us look for individuals within the Indigenous population.”

### Resources

- Guidance for engagement and inclusion of diverse patient populations developed by Fraser Health Authority: [https://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/awesome_handbook-fraserhealth.pdf](https://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/awesome_handbook-fraserhealth.pdf)
- Publication titled “Describing the process of ethical conduct of research in an Ontario-wide First Nations diabetes research” by Jennifer D. Walker et al: [http://www.cmaj.ca/content/190/supplement/S19?rss=1f](http://www.cmaj.ca/content/190/supplement/S19?rss=1f)

### Recommendation

Establish organizational compensation policies to provide guidance on how to optimally offer appreciation and acknowledgement for patients involved in the research process.

### Rationale

Patient partner compensation minimizes barriers to participation and facilitates inclusion of diverse individuals. Fair recognition and appreciation of patients’ time and contributions promotes a supportive and equitable environment.

### Illustrative quotes from participants

“The compensation piece is really important and I think it helps patients feel like they are more part of the team. At least offering patients that, I think, is really important.”

“When we’re doing research like that that’s more national in scope or that might require folks to travel. So, really thinking through those barriers that exist too. How we can make sure that if people are spending money out of pocket, how they can be reimbursed as quickly as possible, what costs we can cover up front and making sure that we’re having those conversations throughout the project with participants or advisers about what that might look like and how we can make it accessible for them.”

“just the importance of compensation for family leaders and really making sure that family leaders feel valued...were asking families to really engage in some really important and sometimes time consuming work”
The Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework has been updated to include an appendix that outlines considerations when paying patient partners in research:
http://cihr-irsc.gc.ca/e/51466.html

Recommendations on patient engagement compensation developed by the SPOR Networks in Chronic Diseases and the PICI Network:

Considerations for budgeting for patient engagement developed by George & Faye Yee Centre for Healthcare Innovation:
https://chimb.ca/sub-sites/1-patient-engagement?page=79-budgeting-for-engagement

Recommendation
Engage in proactive collaboration by involving patients from the start of the research process at the priority setting stage and sustain engagement by continuously providing updates, learning opportunities, personal/professional development and new research opportunities.

Rationale
Encouraging long-term and productive engagement by connecting with patient partners on an ongoing basis increases retention and interest in participating in research.

Illustrative quotes from participants
“If it really is a partnership model there needs to be that closing of the loop and that feedback and that understanding of how decisions are made and hopefully that moves towards co-decision making.”

“...one of our stated goals is to ensure that our research is informed by patient priorities and the only way to truly do that is to involve patients up front and really test our assumptions of what is important to them and involve them in a priority setting exercise”

“So, by having service users and families engaged right in the development, you’re more likely to develop something that will be engaging. Where your recruitment will be more successful, where your retention will be more successful”

Resources
Interactive tool that outlines participatory approaches to use in your engagement strategy developed by George & Faye Yee Centre for Healthcare Innovation:
https://chimb.ca/sub-sites/1-patient-engagement?page=75-how-to-engage
**Recommendation**  
Advocate for the benefits of including patient perspectives in research in order to gain buy-in from all stakeholder groups. Identify champions of patient engagement and continuously acknowledge and share successes.

**Rationale**  
Increased buy-in from organizational employees, researchers and patients alike will contribute to the advancement of patient engagement work.

**Illustrative quotes from participants**

- “Demonstrating the value added of patient related outcomes and how those relate to the priorities of researchers. It’s an education process with the researchers and with the patients as to what their involvement is because the patients can’t steer the research because they are not the researchers, they are not the scientific authorities, but they do have a unique perspective that the researchers don’t.”

- “Celebrate success. I think we try to do this all the time. That is one of the reasons we try to bring people together. We usually try to have receptions and try to do fun things and really make sure the patient engagement activities are elevated to the leadership. So that the value of that work can be reflected and awareness can be raised to show how this is actually fundamentally changing research.”

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**Recommendation**  
Proactively identify feasible metrics/indicators and methods to monitor and evaluate engagement practices within the organization.

**Rationale**  
This allows patients and researchers to provide feedback in order to continually improve patient engagement practices. This will also allow organizations to track and report the impact of their approaches on outcomes of interest, which can be shared with funding sources to secure and sustain funding for patient engagement work.

**Illustrative quotes from participants**

- “I do think providing some kind of way to have feedback, whether it’s with an evaluation tool, because I think some people ... I just think it’s important, again, for there to be feedback on both sides.”

- “We survey the people from the committee members and ask them how integrated do you feel or did you see any future opportunities for more integration with the program. So we are always, sort of, assessing the strength of the relationship but we are also, sort of, forcing it to be a strong relationship.”

**Resources**

GRIPP2 reporting checklist for guidance on monitoring engagement activities: [https://www.bmj.com/content/358/bmj3453](https://www.bmj.com/content/358/bmj3453)

*(continued)*
**Recommendations**

**Recommendation**
Network and collaborate with other organizations to share resources, knowledge and lessons learned.

**Rationale**
This ensures that there is no duplication of efforts and that organizations are using resources and tools that are established and validated.

**Illustrative quotes from participants**

“One recommendation would be to collaborate. So, I meet monthly with [a hospital] next door, and then that sort of branched out now to [another], and so for information sharing, or resource sharing, or tools or template sharing, or best practice sharing. Like, doing all of that with the right people has been a really, really good part of it.”

“I honestly believe that this area of activity is relatively new and I don’t think there is a set way to do it best. So people are trying different things and by bringing these groups together and sharing knowledge these ideas spread and they are challenged and I think that’s been the most powerful thing is people begging, borrowing and stealing ideas from each other.”

**Resources**

Publication titled “Patient Engagement in Research and Innovation: A New Framework”, provides an organizational framework for patient engagement developed by Sunnybrook Health Sciences Centre:

Highlight of patient oriented research projects and collaborations:
http://www.cihr-irsc.gc.ca/e/51040.html

Patient Engagement Resource Hub by the Canadian Foundation for Healthcare Improvement:
https://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub.aspx

Patient engagement research evidence library developed by INVOLVE UK:
https://www.invo.org.uk/resource-centre/libraries/evidence-library/
Limitations

The development of this catalogue had a few key limitations worthy of mentioning. First, this catalogue is not an exhaustive list of organizations conducting patient engagement in research across Ontario. Those organizations that are included in this catalogue are the organizations who responded to a call to participate from the Ontario SPOR Support Unit and the Knowledge Translation (KT) Program of St. Michael's Hospital-Unity Health Toronto.

Additionally, this catalogue only highlights organizations that conduct patient engagement at an organizational level. Currently, there are many research programs and research teams in Ontario that are carrying out patient engagement independently at a program level. These research programs and research teams were not eligible to be included in this catalogue despite the meaningful patient engagement they conduct.

Conclusions

This catalogue is designed to showcase organizations in Ontario that have effectively integrated patient engagement in research at the organizational level (i.e., providing oversight across an organization). It provides patients, researchers, and organizational employees with information on the wide variety of patient engagement activities and policies being undertaken throughout the province. While patient engagement in research is being approached in different ways, the goals of patient engagement in research are the same: to improve the relevance and translation of research into practice and policy and to ensure that research reflects the needs of patients. Participating organizations have demonstrated their commitment to those goals by incorporating patient engagement initiatives at an organizational level.

Participating organizations have also highlighted several challenges that limit the effectiveness of meaningful engagement and its implementation at an organizational level. One example of a challenge is the resource intensive nature of patient engagement which may be a significant barrier for many organizations in Ontario due to resource constraints specifically lack of funds, time and staff.

Participating organizations have also highlighted several recommendations for successful patient engagement, including: ensuring adequate training, tools and resources are provided to both patient and researcher groups and establishing patient engagement as an organizational priority by evoking support from the organizations’ leadership.

This catalogue, along with other existing resources from the Ontario SPOR Support Unit, can be used to guide and further inform patient engagement in research initiatives in Ontario.
References

2. International Association for Public Participation (IAP2).
3. The University of Ottawa. https://research.uottawa.ca/centres-institutes
Map of organizations

1. Centre for Rural and Northern Health Research
2. Children’s Hospital of Eastern Ontario Research Institute
3. Institut du Savoir Montfort
4. Lawson Health Research Institute
5. Thunder Bay Regional Health Research Institute
6. University of Ottawa Heart Institute
7. Centre for Addictions and Mental Health
8. Holland-Bloorview Kids Rehabilitation Hospital
9. Sunnybrook Health Sciences Centre
10. Cancer Care Ontario
11. Clinical Trials Ontario
12. Arthritis Society
13. Ontario Brain Institute