CTTG Community Engagement Working Group

An index of top engagement resources

Organization/ Key Resource	Description
Government Resources to support patient engaged research	
CIHR Strategy for Patient-Oriented Research https://cihr-irsc.gc.ca/e/48413.html	The framework was created in 2014 when the Canadian government's Strategy for Patient-Oriented Research (SPOR) National Steering Committee requested that a framework be developed to outline key opportunities for action. The framework provides rationale, definitions, guideline principles and Core areas for engagement. It also has practical guidance on issues like paying patients for engagement in research.
Ontario SPOR support unit https://ossu.ca/for-researchers/patient-engagement-resources/ Key Resource: The "For Researchers" page of the SPOR support unit lists training opportunities, research centres and patient engagement resources. https://ossu.ca/for-researchers/patient-engagement-resources/	The Ontario SPOR SUPPORT Unit (OSSU) is a network of 14 leading health Research Centres and 8 Research Initiatives, supported by a Coordinating Centre located in Toronto, that engages researchers, patients and other partners in patient-oriented research to improve the health of Ontarians and the health care system.
CIHR's Institute of Musculoskeletal Health and Arthritis (IMHA). Key Resource: Their website features Patient Engagement Research Ambassadors, Patient Engagement Training, Patient Engagement Resources, workshops.	IMHA is the first CIHR institute to actively encourage the research the research community to embrace incorporating patient engagement in the research process and provide the resources to do it. While patient engagement is becoming more familiar – and required – in research projects, many researchers and patients are still unsure why engagement is important. The process

https://cihr-irsc.gc.ca/e/27297.html	can appear daunting and many are uncertain how to begin.
Health Canada Policy Toolkit for Public Involvement in Decision-making Key Resource: The Toolkit includes definitions, policies, guidelines and case studies and techniques. https://www.canada.ca/en/health-canada/corporate/about-health-canada/reports-publications/health-canada-policy-toolkit-public-involvement-decision-making.html	The toolkit was created in 2000 by Health Canada to address a need to improve their ability to consult, engage, listen, persuade and reframe issues so that the results of their work meet citizens expectations and needs. The document was developed at Management Council's request to respond to the expectations of Canadians and the related needs of Health Canada employees around public involvement, including citizen engagement.
Hospital and Health System resources to support patient engaged research	
UHN Pride in Patient Engagement in Research (PiPER) Key Resource: The PIPER Toolkit https://kite-uhn.com/piper	Pride in Patient Engagement in Research (PiPER) is a strategic research network of Toronto's University Health network. It launched in 2022 as a priority of the UHN Research Strategic Plan under the pillar "Engage every patient to strengthen our learning health system." PiPER supports initiatives that foster an inclusive and collaborative research environment by engaging with people with lived experience (PLEX) as partners in research. PiPER toolkit, PiPER research day, Community of Practice, PLEX Network of Networks, PiPER Coaching and consulting services
McMaster Public and Patient Engagement Key Resource: The "Frameworks and Tools" section of their website features an toolkits, tools and other resources. https://ppe.mcmaster.ca/research/frameworks-and-tools/	The Public and Patient Engagement Collaborative is based in the Faculty of Health Sciences at McMaster University. It works at the interface of research and practice, striving to support high-quality engagement through research, consultation and support activities.
University/Community-based Resources to support community engaged research	

Community-Based Research Canada Key Resource: Their website highlights the goals and activities of the organization https://www.communityresearchcanada.ca/	Community Based Research Canada is an independent pan-Canadian non-profit organization and national champion and facilitator of community-based research excellence. They have a Resource Centre with tools for how to undertake community-based research, e-newsletters, conferences and learning opportunities, and a community of practice which involves monthly gatherings.
Centre for Community Based Research Key Resource: They have a searchable database of resources that includes instructional videos, podcasts, infographics, and toolkits. https://www.communitybasedresearch.ca/our-resources	The Centre for Community Based Research (CCBR) is a Canadian organization that conducts and promotes community-based research. It is a non-profit organization located on the University of Waterloo campus. Their approach to research is community-driven, participatory, and action-oriented.
Ontario Regional Blood Coordinating Network (ORBCON) https://transfusionontario.org/en/category/patients/	The Ontario Regional Blood Coordinating Network (ORBCoN) was launched in 2006 and the program is funded by the Ontario Ministry of Health (MOH) to provide an organized and integrated approach to blood management in Ontario through the engagement of hospitals and Canadian Blood Services. Their website features resources like patient fact sheets, which for instance, offer patients and families basic information about blood transfusion etc. https://transfusionontario.org/en/category/patients/

Please contact us if you want to add more resources! Reach out to kelly.holloway@blood.ca

For more questions about any of these resources contact the CTTG community engagement working group.