

Edwin S.H. Leong Centre for Healthy Children Trainee Hub

Building Authentic Partnerships with Patient and Community Partners: Cultivating Communities to Engage in Research

Tuesday January 27, 2026

12:00 – 1:30 PM



Art by Emily Kewageshig

Speaker Introductions



Edwin S.H. Leong Centre for Healthy Children
UNIVERSITY OF TORONTO

SickKids[®] | The Office of
Engagement

SickKids[®] | Research
Training Centre

Building Authentic Partnerships with Patient and Community Partners

RTC-Leong Centre Collaboration Panel Presentation

Colin Macarthur MBChB, PhD
Co-Lead Ontario Child Health SUPPORT Unit (OCHSU)
Senior Scientist, CHES Program, SickKids Research Institute

PUBLIC ENGAGEMENT IS A GLOBAL SOCIAL MOVEMENT

NIHR | National Institute for Health and Care Research



“Research carried out ‘with’ or ‘by’ members of the public, rather than ‘to,’ ‘about,’ or ‘for’ them”

pcori



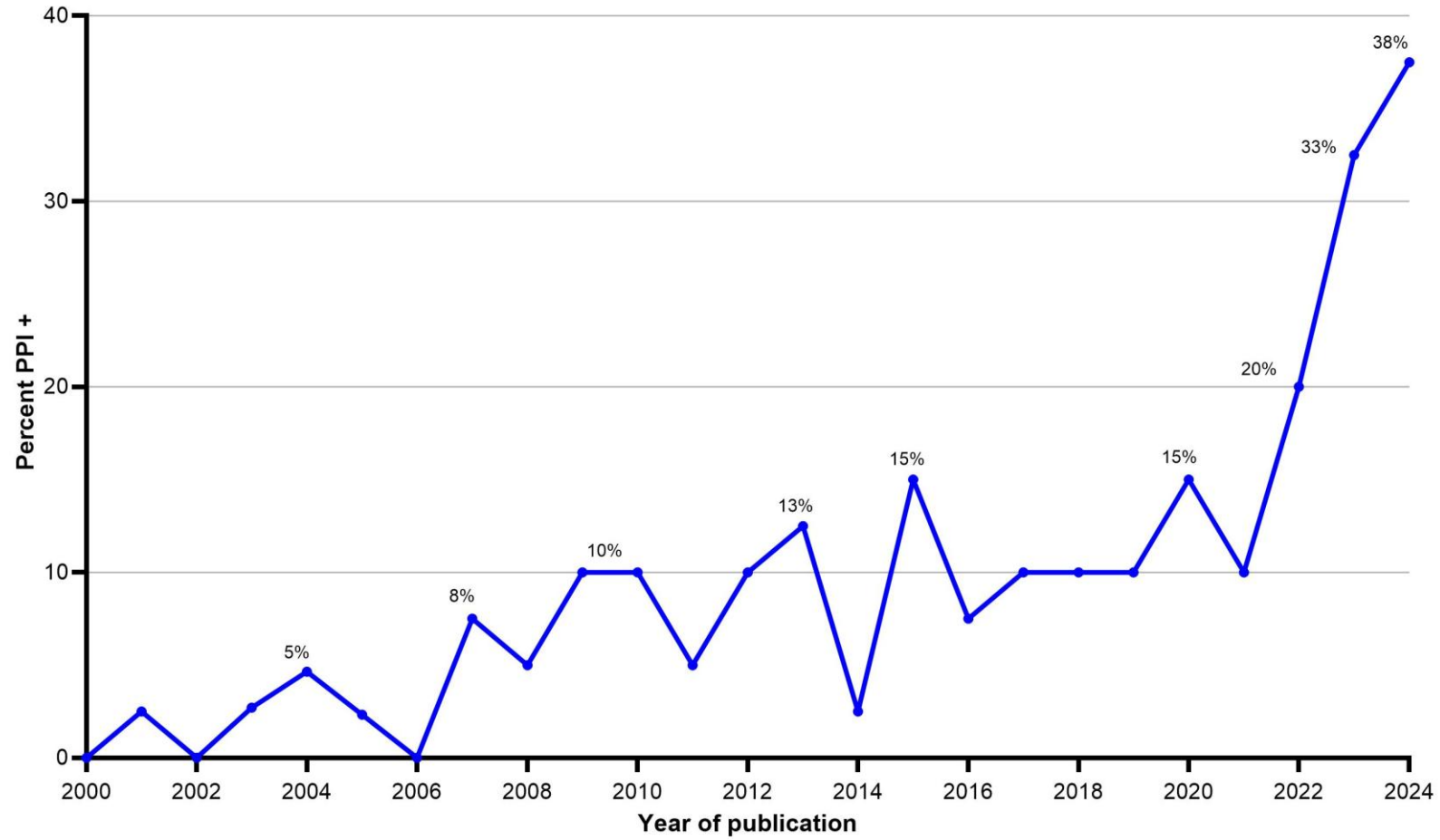
“Research guided by patients, caregivers, and the broader healthcare community... driving U.S. clinical research to be more patient-centered, relevant, and useful.”


CIHR IRSC
Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

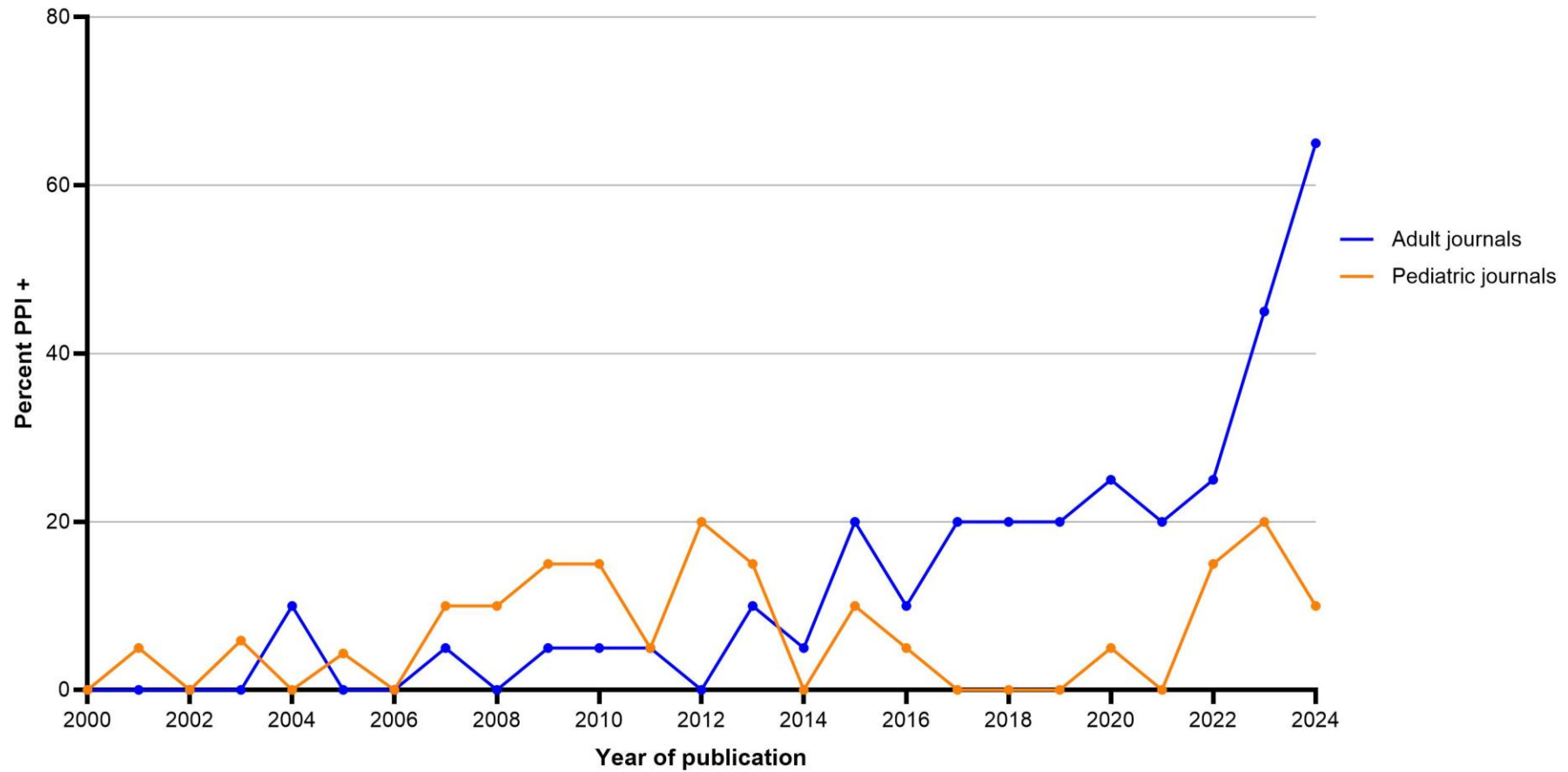
Strategy for Patient-Oriented Research
SPOR
Putting Patients First 

“Patients, researchers, health care providers and decision makers actively collaborate to build a sustainable, accessible, and equitable health care system to bring positive change in the health of people living in Canada”

Trend in PPI reporting in health research 2000 to 2024



Trends in PPI reporting in health research, adult versus paediatric, 2000 to 2024





CIHR IRSC



Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Strategy for Patient-Oriented Research

SPOR

Putting Patients First



SPOR National Research Networks



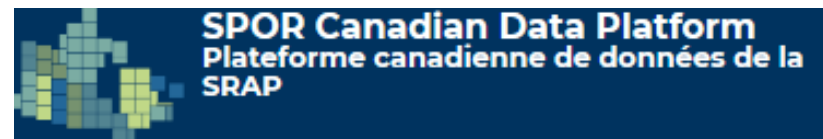


SPOR Enabling Functions



SPOR Evidence Alliance
Strategy for Patient-Oriented Research

Alliance pour des données probantes de la SRAP
Stratégie de recherche axée sur le patient



CCCEC
Centre canadien de coordination des essais cliniques

STRENGTHENING CLINICAL TRIALS FOR CANADIANS
RENFORCEMENT DES ESSAIS CLINIQUES POUR LES CANADIENS

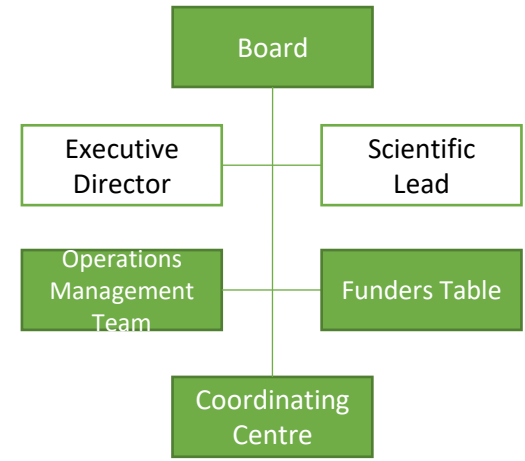
SPOR SUPPORT Units



Support for People and Patient-Oriented Research and Trials (SUPPORT) Units



14 Research Centres



Core Component Working Groups



OSSU Initiatives

- Office of Spread and Scale (Digital Health & Implementation Science Initiative)*
- Fairness is Excellence Initiative (Equity, Diversity and Inclusion)*
- Indigenous (Métis/Inuit) Initiative*
- Mental Health & Addictions Research Initiative*
- Ontario Francophone Communities Research Initiative*
- Public and Patient Engagement Collaborative*
- Sex and Gender Plus Research Support*
- Training and Capacity Building Initiative*

Ontario Child Health Support Unit



OCHSU

ONTARIO CHILD HEALTH SUPPORT UNIT
better research - better care - better outcomes



OCHSU Support to PIs and Trainees

METHODOLOGICAL SUPPORT (Research and Engagement)

- 793 research methods consultations for patient-oriented research projects
 - \$39 million in new research funding; 220 peer-reviewed publications
- Research Family Advisory Committee at SickKids and Patient and Family Advisory Committee at CHEO
 - 40 patient/family research advisors at SickKids, 52 family leaders at CHEO
 - 270 consultations with researchers on patient engagement in research

BUILDING CAPACITY IN PATIENT-ORIENTED RESEARCH IN CHILD HEALTH

- Symposia, Seminars, Online Resources on patient-oriented research in child health



Buchanan et al.
Research Involvement and Engagement (2022) 8:2
<https://doi.org/10.1186/s40900-022-00335-z>

Research Involvement
and Engagement

COMMENTARY

Open Access

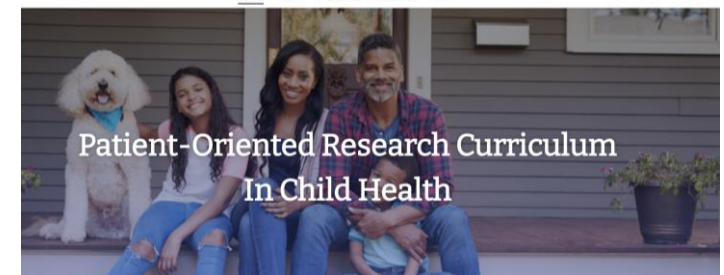
The Research Family Advisory Committee:
the patient and family view of implementing
a research-focused patient engagement
strategy

Francine Buchanan^{1*}, Amy Peasgood¹, Megan Easton¹, Karen Haas¹ and Unni Narayanan^{1,2,3,4}



PORCCH

HOME ABOUT MODULES REGISTER LOGIN



**Over 100
child health
datasets
included**



Child Health Datasets

Are we missing a dataset? [Tell Us](#)

The Child Health Dataset is a searchable inventory of datasets related to child health and health care. The inventory will be updated periodically to ensure the information remains live, pertinent, and a growing resource for researchers interested in child health research. If you know of datasets that are missing, please use the button in the top right to advise us.

Please note that this inventory does not provide access to the data.

Can add multiple search terms (AND/OR/NOT)

Either or (Pan Canadian or Ontario only – single choice)

Clear selections for new search

Search: in Anywhere +

Add Row >>

Refine by:

Categories:

- Acquired Cohorts / Registries
- Health Services Administrative Data
- Population & Demographics
- Care Providers
- ICES-derived cohort
- Registry
- Health Services
- People & Geography
- Survey

Geography:

- Pan Canadian
- Ontario Only

Date Range: Earliest To Present

Ages:

- 0 to 4
- 5 to 9
- 10 to 14
- 15 to 19

Need help getting started?

Search: Anywhere, Title, Description, Keywords (hidden)

Dataset categories (multiple choice)

New In OCHSU: 05/25/2016
Child Health Datasets inventory uploaded

<http://www.ochsu.ca/en/OCHSUDatasets>



PORCCH

<https://porcch.ca/>

Patient-Oriented Research Curriculum in Child Health

The PORCCH modules are free and can be completed by anyone interested in learning more about patient-oriented research. Click on the “Register” tab to create your account. Once you have registered, you can access each module by clicking on the “View Module” button.



Research 101 Part 1: What is Health Research and Who is Involved?

Research 101 provides an overview of key concepts in health research. It is primarily intended for patients and families, or those without a formal background in research. In this module, which is Part 1, we will introduce you to patient-oriented health research and the key players involved. This module will take approximately 30 minutes to complete.

[VIEW MODULE](#)



Research 101 Part 2: Timeline of a Research Study

Research 101 provides an overview of key concepts in health research. It is primarily intended for patients and families, or individuals without a formal background in research. In this module, which is Part 2, we will describe the key stages of a research study, how patients and families can get involved, and the challenges and benefits of patient-oriented child health research. This module will take approximately 30 minutes to complete.

[VIEW MODULE](#)



Patient Engagement 101 Part 1: Foundations of Patient Engagement

Patient Engagement 101 is a summary of the key concepts of effective patient engagement in child health research. It is primarily intended for clinicians and researchers but can be taken by anyone interested in learning more about effective patient engagement. If you are new to research, we recommend completing Research 101 first. In this module, which is Part 1, we describe foundational concepts of patient engagement in child health research. This module will take approximately 30 minutes to complete.

[VIEW MODULE](#)



Patient Engagement 101 Part 2: Patient Engagement in Practice

Patient Engagement 101 is an overview of the key concepts of effective patient engagement in child health research. It is primarily intended for clinicians and researchers but can be taken by anyone interested in learning more about effective patient engagement. If you are new to research, we recommend completing Research 101 first. In this module, which is Part 2, we focus on the practical aspects of patient engagement in child health research. This module will take approximately 30 minutes to complete.

[VIEW MODULE](#)



Research Ethics 101

Research Ethics 101 is a general introduction to research ethics and highlights ethical issues in patient-oriented research in child health. It is primarily intended for patients and families but can be taken by anyone interested in learning more about ethics and patient-oriented research. This module will take approximately 30 minutes to complete.

[VIEW MODULE](#)

Institutional Support for Engagement

SickKids[®]



Commit to Patients & Families as Partners

- Enable patients and families to guide research design and priority setting
- Increase equitable participation of patients, families and communities in research
- Improve the connection between clinical care and clinical research
- Facilitate research dissemination and integration into patient care to maximize benefit



Advance Safety, Quality & Accountability

- Establish an institution-wide approach to management and oversight
- Enhance operations to uphold and continuously improve regulatory, clinical and compliance standards
- Elevate robust monitoring and auditing mechanisms
- Deliver education and training to build expertise in responsible clinical research practices



Develop & Support a Skilled Clinical Research Workforce

- Partner to attract and retain top clinical research talent
- Broaden research mentorship, training and credentialing opportunities across roles and career stages
- Foster and incentivize a collaborative culture for discovery and research-care integration
- Streamline the clinical research appointment and evaluation process
- Build a cohesive clinical research community



Enable a Seamless Clinical Research Ecosystem

- Enhance operational support, simplify processes and promote clarity throughout the clinical research lifecycle
- Foster collaborative partnerships with service providers for workflow, financial and capacity planning
- Plan and invest in integrated infrastructure, services and space to support clinical research activities



Adopt Innovative Digital Solutions

- Expand technology to support the research study lifecycle and strengthen compliance, risk monitoring and oversight
- Enhance and broaden patient-facing digital tools to enhance engagement and participation
- Invest in digital systems to support decentralized trials and advanced research methods
- Leverage electronic medical record systems to enable seamless research and care integration



Ensure Sustained Impact of Clinical Research

- Promote the integration of implementation science into planning, design and execution
- Increase access to interventions and innovations
- Advance advocacy efforts with regulatory bodies
- Build a national and international presence to champion paediatric discovery and innovation
- Measure our impact on patient outcomes, scientific advancement and organizational performance

Core Drivers

Patient Partnership

Integration

Impact

As leaders in child health, we partner locally and globally to improve the health of children through the integration of care, research and education.

Compassion

Integrity

Collaboration

Inclusion

Innovation

Excellence



COMMIT TO PATIENTS & FAMILIES AS PARTNERS



Our objectives:

- Enable patients and families to guide research design and priority setting
- Increase equitable participation of patients, families and communities in research
- Improve the connection between clinical care and clinical research
- Facilitate research dissemination and integration into patient care to maximize benefit

How can we partner with patients and families across the clinical research lifecycle?

To advance world-class clinical research, we will actively partner with patients and families in shaping the questions we ask and the solutions we seek. We will integrate research and care to enhance accessibility, reduce burden on patients, and boost engagement and participation in clinical research.

By applying patient-centred frameworks and models, we will prioritize patients' needs, preferences and experiences. This approach aims to support equitable and inclusive representation, and outcomes that are meaningful across diverse communities. We will close the gap between research and care by supporting the translation of fundamental discoveries into clinical settings and continue learning from bedside experiences to inform and drive new research.

OUR STRATEGY IN THE YOUTH VOICE

Developed in collaboration with the SickKids Children's Council



Include Patients and Families Along Every Step

Include patients and families throughout the clinical research process. Make it easy to inform and be part of clinical research. Ensure clinical research leads to answers that improve the lives of youth everywhere.



Keep Clinical Research Safe and Honest

Make sure clinical research is done in a way that is fair, honest, and easy to understand. Help teams follow the rules, keep everyone safe, and be responsible for the work they do.



Support the People that Make Clinical Research Happen

Help doctors, nurses, researchers and staff deliver innovative clinical care and research to benefit patients. Make SickKids a great place for discovery and learning through clinical research.



Make it Easier to Do Great Clinical Research

Give clinical research teams the tools, space and support they need. Fix the tricky parts so that clinical research is easy to do. Make clinical research more of a part of what the hospital does every day.



Use Tech to Make Clinical Research Better

Put smart tools to keep clinical research safe, organized, and easy to follow. Use helpful technology so patients and families can be part of clinical research, ask questions, and learn what is happening.



Make a Difference That Lasts

Make sure clinical research helps patients feel better and live healthier lives. Share what we learn so other hospitals and kids around the world can benefit too.

Core Drivers

Patient Partnership

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As leaders in child health, we partner locally and globally to improve the health of children through the integration of care, research and education.

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Integrity

Collaboration

Inclusion

Innovation

Excellence

SickKids[®]

The Office of
Engagement

**Supporting Patient, Family
and Community Engagement
Across SickKids**

SUPPORTS FOR STAFF & RESEARCH TEAMS

The Office of Engagement offers a variety of services and supports to help SickKids staff across the hospital to partner with patients in all we do.



Grants,
Planning &
Methods
Consults



Custom
Engagement
Training &
Education



Advisor
Committee
Consultations
& Document
Reviews



Engagement
Facilitation &
Staffing



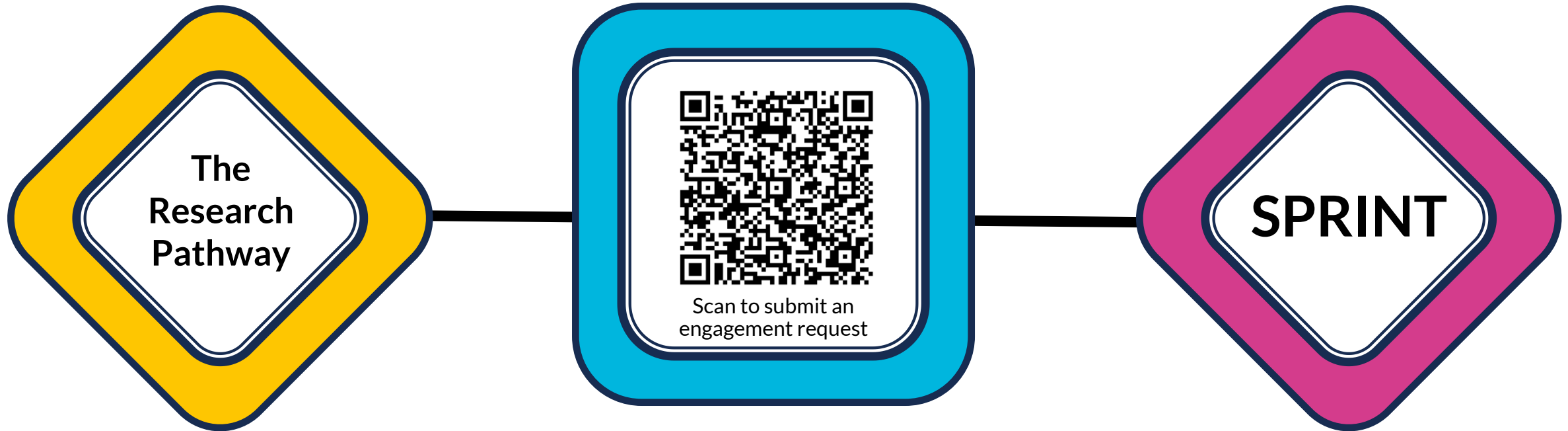
Lived-
Experience
Advisor
Recruitment &
Partnerships



Evaluations &
Surveys

HOW CAN YOU GET SUPPORT?

The Office of Engagement offers support at any stage of your research.
Reach out with any questions



email us at

aSK.Engagement@sickkids.ca

Strategy for Patient-Oriented Research

SPOR

Putting Patients First 

ONLINE RESOURCES

CIHR SPOR: <https://cihr-irsc.gc.ca/e/41204.html>

PASSARELLE: <https://passerelle-nte.ca/en/>

OSSU: <https://ossu.ca/>

OCHSU: <https://www.ochsu.ca/en/OCHSU>

PORCCH: <https://porcch.ca/>

PCORI: <https://www.pcori.org/>

NIHR: <https://www.nihr.ac.uk/>

BIBLIOGRAPHY AND RECOMMENDED READING

Macarthur C, Walsh C, Karoly A, Buchanan F, Jones N. Development of the Patient-Oriented Research Curriculum in Child Health (PORCCH). *Research Involvement and Engagement* 2021;7:27 <https://doi.org/10.1186/s40900-021-00276-z>.

Walsh C, Jones L, McCreath G, Connan V, Pires L, Chen A, Karoly A, Macarthur C. Co-Development and Usability Testing of Research 101: A Patient-Oriented Research Curriculum in Child Health (PORCCH) E-Learning Module for Patients and Families. *Frontiers in Pediatrics* 2022, 10:849959. doi: 10.3389/fped.2022.849959.

Walsh C, Jones L, McCreath G, Connan V, Pires L, Abuloghod L, Buchanan F, Macarthur C. Co-Development and Usability Testing of Patient Engagement 101: A Patient-Oriented Research Curriculum in Child Health (PORCCH) E-Learning Module for Healthcare Professionals, Researchers, and Trainees. *CMAJ Open* 2022;10(4):e872-e881. DOI:10.9778/cmajo.20210336.

Macarthur C, Van Hoorn R, Lavis J, Straus S, Jones N, Bayliss L, Terry A, Law S, Victor C, prud'Homme D, Riley J, Stewart M. Training and Capacity Development in Patient-Oriented Research: Ontario SPOR SUPPORT Unit (OSSU) Initiatives. *Research Involvement & Engagement* 2023;9:5. <https://doi.org/10.1186/s40900-023-00415-8>.

Aubin D, Hebert M, Eurich D. The importance of measuring the impact of patient-oriented research. *CMAJ*. 2019;191:e860-864.

Staniszewska S, Brett J, Simera I, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ* 2017;358:j3453 <http://dx.doi.org/10.1136/bmj.j3453>

Osmond M, Legace E, Gill P, Correll R, Cowan K, Dawson JE, Duncan R, Fox E, Gupta K, Kolstad AT, Langevin LM, Macarthur C, Macklem R, Olszewska K, Reed N, Zemek R. Partnering with patients, caregivers, and clinicians to determine research priorities for concussion. *JAMA Network Open* 2023;6(6):e2316383. doi:10.1001/jamanetworkopen.2023.16383.

Gill PJ, Bayliss A, Sozer A, Buchanan F, Breen-Reid K, De Castris-Garcia K, Green M, Quinlan M, Wong N, Frappier S, Cowan K, Chan C, Arafeh D, Anwar MR, Macarthur C, Parkin P, Cohen E, Mahant S. Patient, caregiver, and clinician participation in prioritization of research questions in pediatric hospital medicine. *JAMA Network Open*. 2022;5(4):e229085. doi:10.1001/jamanetworkopen.2022.9085.

Vanderhout SM, Bhalla M, Van A, Fergusson DA, Potter BK, Karoly A, Ly V, Macarthur C. The impact of patient and family engagement in child health research: A scoping review. *J Pediatrics* 2023;253:115-28. doi.org/10.1016/j.jpeds.2022.09.030.

Authentic patient and community engagement

a paradigm shift in health research

Dalya Kablawi (she/her)
Program Coordinator, Research Engagements
Office of Patient, Family and Community Engagement



DALYA KABLAWI

she/her

Program Coordinator, Research Engagements
Office of Engagement

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session objectives



Background & Evidence



Strategies for Effective Engagement



Tokenism



Evaluation



Resources & Support

background & evidence

what is engagement and why is it important?



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Star Columnists Editorials **Contributors** Letters To The Editor Editorial Cartoons

CONTRIBUTORS **OPINION**

To better help kids with disabilities, Canada should prioritize meaningful 'patient partner' health research

I have been asked to participate in dozens of research projects for children with autism. I became increasingly disappointed by the imbalance.

By **Sharon McCarry** Contributor
Sun., March 13, 2022 | 2 min. read

Teela *et al.*
Journal of Patient-Reported Outcomes (2023) 7:32
<https://doi.org/10.1186/s41687-023-00566-y>

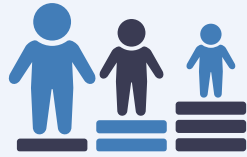
Journal of Patient-Reported Outcomes

REVIEW **Open Access**

Pediatric patient engagement in clinical care, research and intervention development: a scoping review

Lorynn Teela^{1,2,3}, Lieke E. Verhagen¹, Hedy A. van Oers^{1,2,3}, Esmée E. W. Kramer¹, Joost G. Daams⁴, Mariken P. Gruppen⁵, Maria J. Santana^{6,7}, Martha A. Grootenhuis⁸ and Lotte Haverman^{1,2,3*}

VALUE OF ENGAGEMENT



advancing health equity

including and uplifting perspectives of marginalized communities will build trust in research findings and improve historically inequitable health outcomes



increasing relevance & impact

engaging community members ensures research reflects unique experiences, challenges and needs in relevant patient and caregiver population



generating innovative insights

inspiring creative viewpoints to research design, implementation, and interpretation and can lead to innovative solutions that may not emerge from traditional research approaches

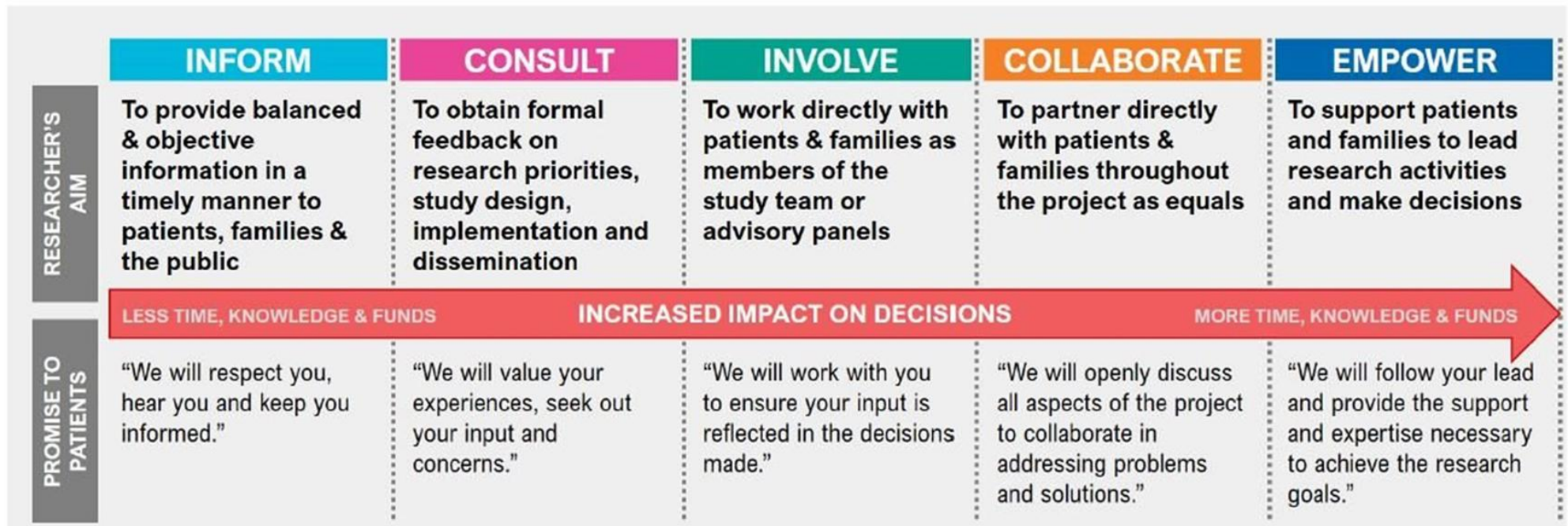
IAP2 spectrum of public participation

INCREASING IMPACT ON THE DECISION

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

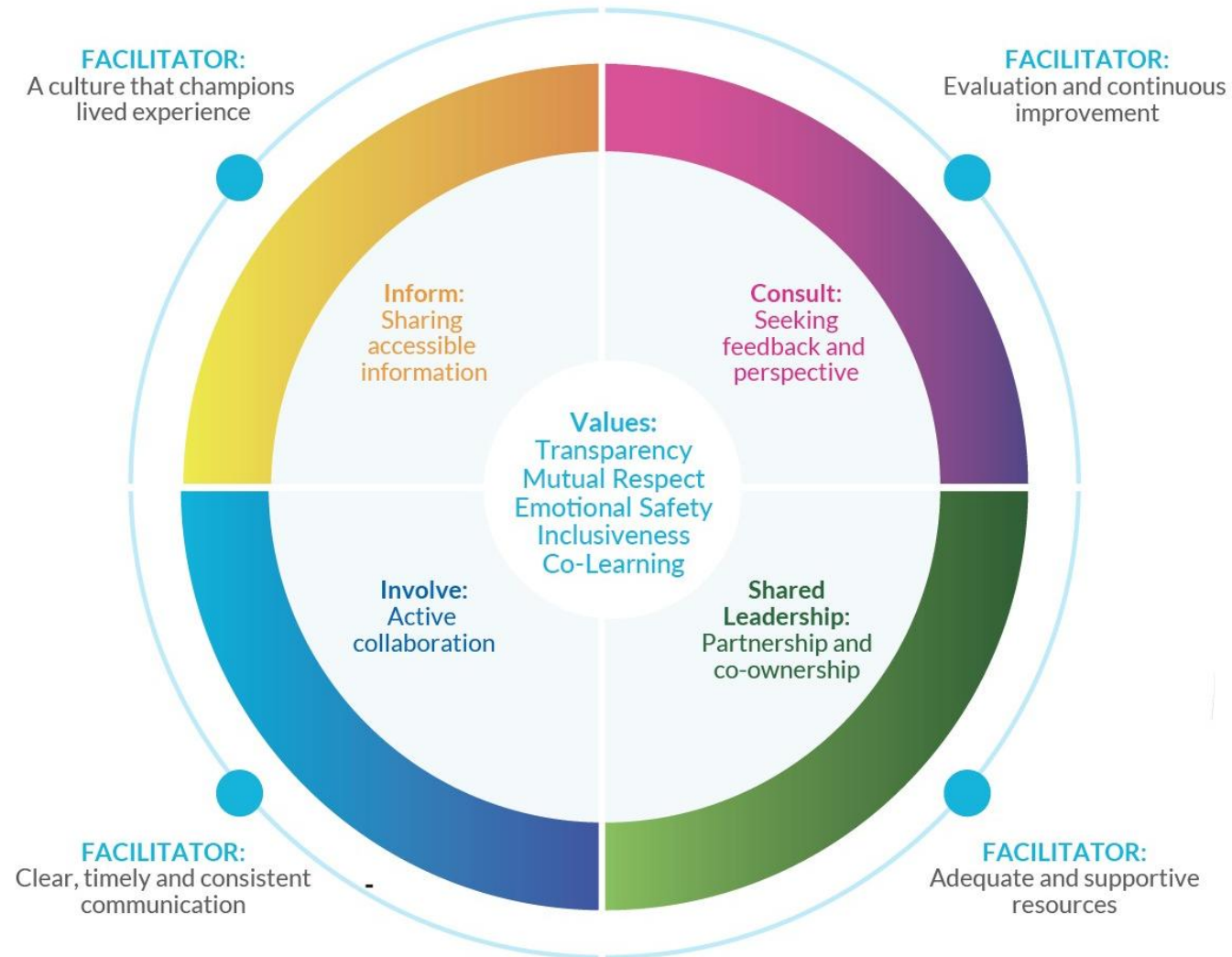
ADAPTATION: HEALTH RESEARCH ENGAGEMENTS

SPECTRUM OF PATIENT AND FAMILY ENGAGEMENT IN HEALTH RESEARCH



Adapted from IAP2 (2007) and Amirav I, Vandall-walker V, Rasiah J, Saunders L. (2017)

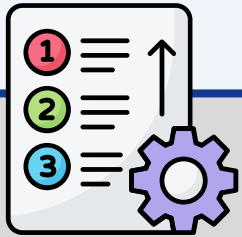
SICKKIDS FRAMEWORK FOR ENGAGEMENT



strategies for effective engagement

when and how to engage patient and community partners

IDENTIFYING OPPORTUNITIES FOR ENGAGEMENT



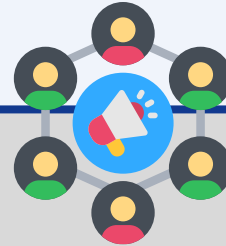
priority setting

- James Lind Alliance priority setting exercise



document review

- Consent/assent forms
- Study protocols



knowledge dissemination

- Conference presentation
- Co-authorship in publications



data analysis

- Coding and thematic analysis
- Co-interpretation of data



participant interviews

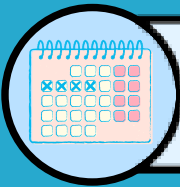
- Co-development of interview questions



participant recruitment strategies

- Co-designing and validating digital material for recruitment
- Sharing research participation opportunities in local networks

connection & communication



Investment of time and capacity



Diverse outreach efforts



Accessible language and mutual respect



Transparency around research process



Regular updates and touchpoints



Feedback loops and grievance processes



accountability & governance

DATA ACCESS & GOVERNANCE



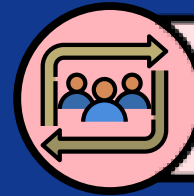
Clear agreements about data privacy and usage



OCAP principles of data sovereignty



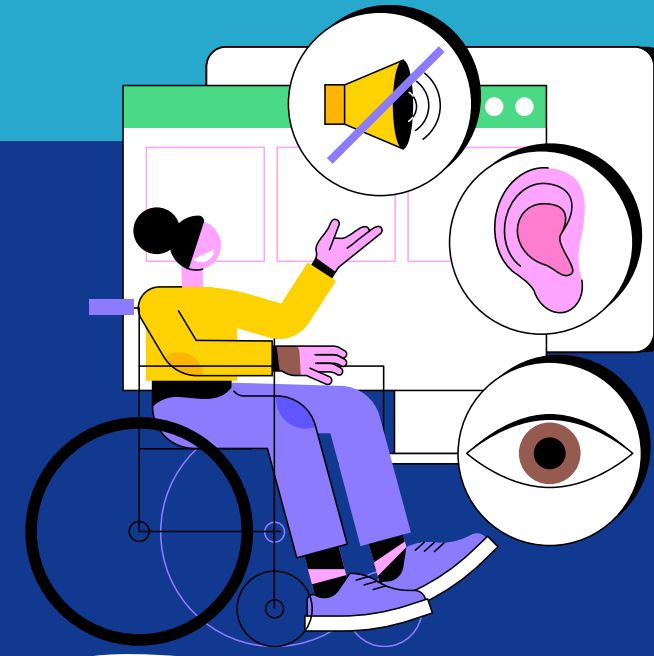
Accommodations to reduce participation barriers



Patient & community partner retention



Compensation & recognition



ACCESSIBILITY

recruitment



Gap analysis - who isn't around the table?



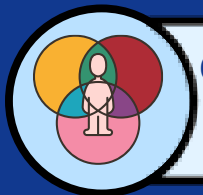
Planning ahead



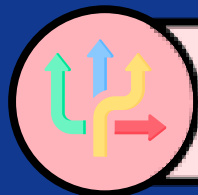
Diverse outreach strategies



Some communities may harbor mistrust or resentment towards research/medical institutions due to discriminatory historical practices. This may create a barrier to equitable representation in research and may lead to poorer health outcomes.



Consider intersectionality



Flexible engagement opportunities



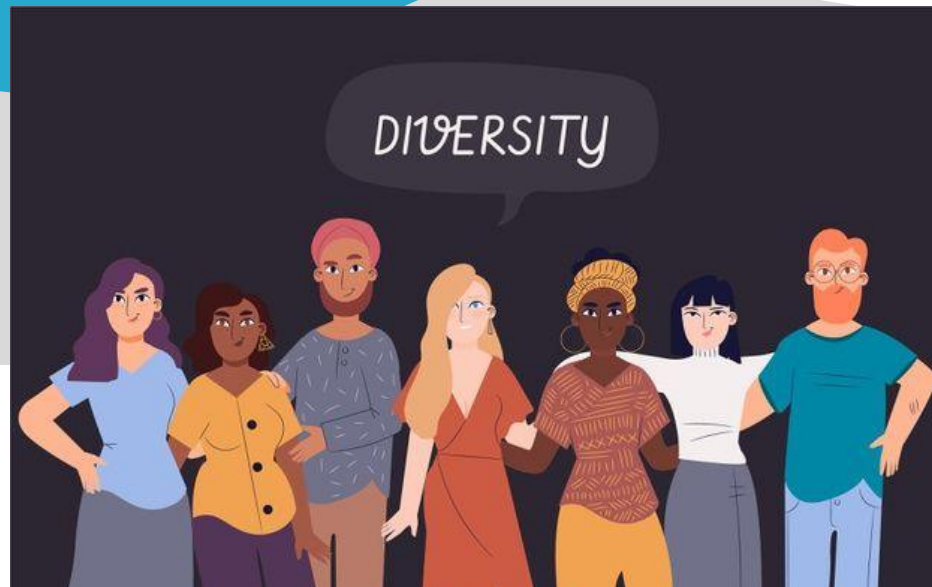
EQUITY, DIVERSITY AND INCLUSION

tokenism

distinguishing between extractive and meaningful engagement

What does tokenism look like in engagement?

- Often well-intentioned efforts to represent diversity of identity, background or opinion around the table.
- Symbolic representation with minimal investment of time to build relationships.



TOKENISM

OR

taking it
seriously

You are recruiting participants from the South Asian community for a study. You approach a patient partner to request their support translating some of the recruitment materials into Urdu.

TOKENISM

Translation of materials does not solicit or incorporate patient partner feedback or input into content, design or dissemination of materials.



TOKENISM

OR

taking it
seriously

You recruit two patient and community members to a Steering Committee. One of them is assigned a co-chair role alongside the PI of the study. The co-chair is invited to co-develop the meeting agenda and Steering Committee activities.

taking it
seriously

Partners are offered decision-making authority with co-chair assignment. Partner has a chance to inform direction of discussion and review agenda items ahead of meetings, giving way to meaningful partnership with significant opportunity for influence.



evaluation

measuring impact and learning lessons

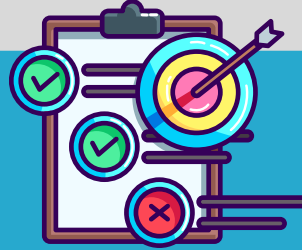
evaluation



process evaluation

assessing methods, activities
and structures

example metrics may include
number of partners, diversity of
partner group, nature of
engagements



outcome evaluation

assessing partner and staff
experience to enhance safety
and impact of future
engagements

qualitative methods may be
used to evaluate outcomes
(surveys, interviews, focus
groups)



evaluation tools

existing tools and resources to
support evaluation of engagements
include Public and Patient
Engagement Evaluation Tool (PPEET)
and Patient Engagement In Research
Scale (PEIRS-22)

resources & support

for staff and partners

TRAINING & EDUCATION

PATIENT ENGAGEMENT IN RESEARCH

- ◆>> **Family Engagement in Research (Course/Leadership Academy)**
McMaster's University Continuing Education
- ◆>> **Patient-Oriented Research Curriculum in Child Health (PORRCH)**
Online, self-paced
- ◆>> **Engagement and Partnering for People-Centred Care Microcredential**
McMaster's University Faculty of Health Sciences Continuing Professional Development Office
- ◆>> **Patient-Oriented Research Training and Learning – Primary Health Care**
Ontario SPOR SUPPORT Unit (OSSU)
Online, self-paced
- ◆>> **Patient Engagement in Research Training Program**
Canadian Institutes of Health Research's (CIHR) Institute of Musculoskeletal Health and Arthritis (IMHA)



THANK YOU!

Please feel free to reach out for any engagement support at ask.Engagement@sickkids.ca or scan the following QR code to fill out the engagement support request form.



SickKids | The Office of Engagement





Canadian
Cancer
Society

Building Authentic Partnerships with Patient and Community Partners

Edwin S.H. Leong Centre for Healthy Children Trainee Hub in collaboration with the SickKids Research Training Centre – January 27, 2026

Stephanie Bazinet, Manager, Research Partnerships and Engagement, CCS – stephanie.bazinet@cancer.ca / research@cancer.ca

CANCER.CA

1. Our research strategy and patient engagement plan
2. How we include people with lived experience (PWLE) in our work
3. What we're looking for when we engage PWLE and how we train and support them
4. Focus areas of engagement
5. Challenges in Patient Engagement and how to avoid them
6. Connecting with a charitable funding agency as a trainee



Canadian Cancer Society Research Strategy Principles

To provide a foundation for our strategy and set an ambitious path forward, we have identified **5 grounding principles**.

1

PERSON-CENTRED

Involve people from diverse communities, including those with lived cancer experience, in every step of the research process

2

DIVERSIFIED

Maintain a broad portfolio of research programs that spans across cancer types and across the cancer continuum

3

COLLABORATIVE

Engage external partners from many sectors to expand reach and maximize capacity

5

INNOVATIVE

Push boundaries to support innovative research and explore partnerships with industry and the private sector to accelerate progress

4

IMPACTFUL

Remain outcome-driven to address areas of greatest unmet need and potential for near-term impact





63 activities in the research process identified for PWLE to participate in



We follow a set of 8 guiding principles

Co-creation of a patient engagement strategy in cancer research funding

Michael S. Taccone, Nathalie Baudais, Don Wood, Suzanne Bays, Sasha Frost, Robin Urquhart, Ian D. Graham & Judit Takacs 

Research Involvement and Engagement 9, Article number: 86 (2023) | [Cite this article](#)

2358 Accesses | 15 Altmetric | [Metrics](#)

Abstract

Background

As research teams, networks, and institutes, and health, medical, and scientific communities begin to build consensus on the benefits of patient engagement in cancer research, research funders are increasingly looking to meaningfully incorporate patient partnership within funding processes and research requirements. The Canadian Cancer Society (CCS), the largest non-profit cancer research funder in Canada, set out to co-create a patient engagement in cancer research strategy with patients, survivors, caregivers and researchers. The goal of this strategy was to meaningfully and systematically engage with patients in research funding and research activities.

<https://rdcu.be/d6X1A>

PATIENT ENGAGEMENT IN RESEARCH PLAN

Patients, survivors, thrivers, caregivers and families (collectively, called "patients") make sure people affected by cancer shape the way that research funding and funding decisions are made.



HOW WE WORK Guiding Principles

VISION

The Canadian Cancer Society (CCS) aspires to integrate meaningful patient engagement into research projects and research funding processes to improve impact and relevance to CCS's patient community and foster health equity through implementation of social practices. This will ultimately improve patient outcomes.



WHY ENGAGE?

"Involving patients in the review process of research grants brings a perspective that many researchers are not familiar with. The sense of participating in an important program was rewarding. I found the experience invaluable."

Angus, Patient/Survivor/Caregiver (PSC) Reviewer & Advisory Council on Research (ACOR) member

WAYS TO ENGAGE

Lead

We will support patient leadership. Last year CCS welcomed patient members to our Advisory Council on Research (ACOR).

Co-Create

We will identify issues and co-develop solutions with patient partners. Patient partners engage as Program Advisors and Patient / Survivor / Caregiver Reviewers in all of our current research competitions.

Consult

We will seek input and advice from patient partners. For instance, patient partners co-developed our website, reviewed and were featured in our 2022 Research Impact Report.

Inform

We will share information in multiple ways. This includes research competition news and results and patient partner experiences in emails, on our website, by video and other ways.



COMPENSATION

We created a Patient Partner Compensation Policy designed to facilitate patient participation and to support equity, diversity and inclusion. We offer compensation to all of our patient partners in accordance with our policy.



CONTACT US

To learn more about being a patient partner and engaging with patient partners, visit our website: cancer.ca/ENpatientengagement. Have questions or comments? Contact: research@cancer.ca.

PATIENT ENGAGEMENT IN RESEARCH PLAN

Patients, survivors, caregivers and families (collectively, called “patients”) make sure people affected by cancer shape the way that research funding and funding decisions are made.



HOW WE WORK Guiding Principles



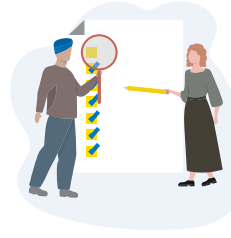
Safety



Co-Build



Clear
Communication



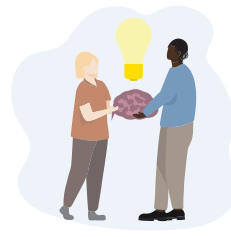
Accountability



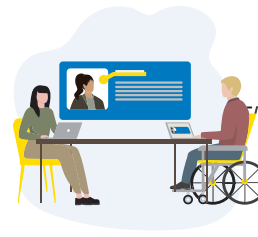
Diversity of
Experiences



Mutual
Respect



Knowledge
Exchange



Personalized &
Progressive

VISION

The Canadian Cancer Society (CCS) aspires to integrate meaningful patient engagement into research projects and research funding processes to improve impact and relevance to CCS's patient community and foster health equity through implementation of social practices. This will ultimately improve patient outcomes.

WAYS TO ENGAGE

Lead

We will support patient leadership. CCS has patient members on our Advisory Council on Research (ACOR) and engages patients to co-lead patient engagement training for researchers and trainees.

Co-Create

We will identify issues and co-develop solutions with patient partners. Patient partners engage as Program Advisors and Patient / Survivor / Caregiver Reviewers in all of our current research competitions.

Consult

We will seek input and advice from patient partners. Patient partners help shape our website and review our Impact Reports.

Inform

We will share information in multiple ways. This includes research competition news and results and patient partner experiences in emails, on our website, by video and other ways.



COMPENSATION

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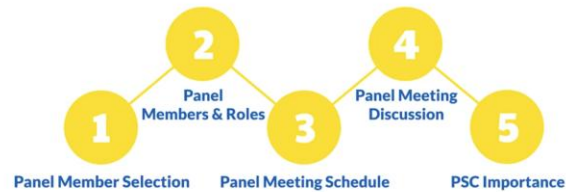
CONTACT US

To learn more about being a patient partner and engaging with patient partners, visit our website: cancer.ca/ENpatientengagement. Have questions or comments? Contact: research@cancer.ca.



Celebrating Diversity in Oncology Table Leads. **Top row:** Greg Mitchell, Dawn Barker, Clare Cruickshank, Michelle Audoin, Lori Thomas, Nate Thomas, Randy Freese. **Bottom row:** Lori Chambers, Katrina Graham, Evaristo Ramos, Dana Bellis, Angelico Obille.

VIDEO TOPICS



Glossary

Home / Cancer information / Resources / Glossary

A B C D E F G H I J K L M N O

Search a glossary term

#

5-HIAA

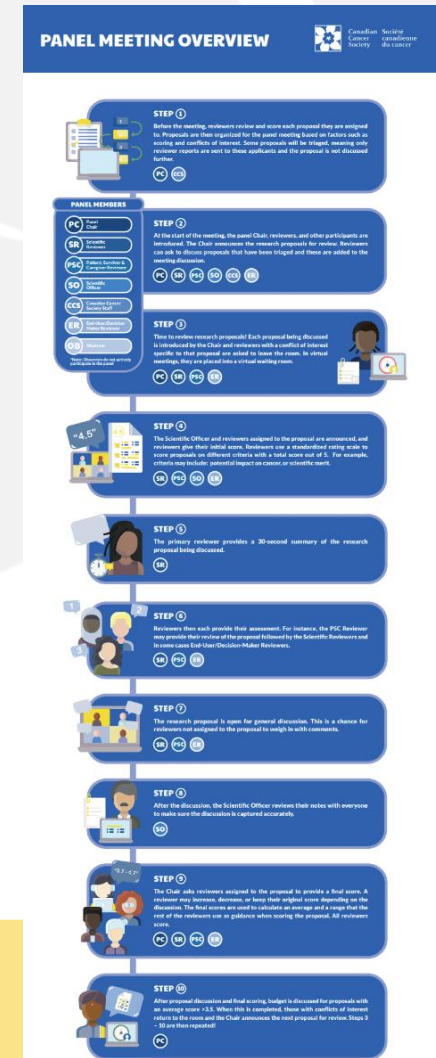
5-hydroxyindoleacetic acid (5-HIAA)

A

abdomen



PANEL MEETING OVERVIEW



STEP 1
Before the meeting, reviewers review and score each proposal they are assigned to. Proposals are then organized for the panel meeting based on factors such as scoring and conflicts of interest. Some proposals will be invited, and some will be rejected. Reviewer reports are sent to these applicants and the proposal is not discussed further.

STEP 2
At the start of the meeting, the panel Chair, reviewers, and other participants are introduced. The Chair announces the research proposals for review. Reviewers can ask to discuss proposals that have been invited and these are added to the meeting discussion.

STEP 3
This is a key research proposal! Each proposal being discussed is introduced by the Chair and reviewers with a conflict of interest specific to that proposal are asked to leave the room. In virtual meetings, they are placed into a virtual waiting room.

STEP 4
The Scientific Officer and reviewers assigned to the proposal are announced, and reviewers give their initial scores. Reviewers use a standardized scale to score proposals on different criteria with a total score out of 5. For example, criteria may include: potential impact on cancer or scientific work.

STEP 5
The primary reviewer provides a 30-second summary of the research proposal being discussed.

STEP 6
Reviewers then each provide their assessment. For instance, the PSC Reviewer may provide their review of the proposal followed by the Scientific Reviewer and the User Decision-Maker Reviewer.

STEP 7
The research proposal is open for general discussion. This is a chance for reviewers not assigned to the proposal to weigh in with comments.

STEP 8
After the discussion, the Scientific Officer reviews their notes with everyone to make sure the discussion is captured accurately.

STEP 9
The Chair asks reviewers assigned to the proposal to provide a final score. A reviewer may discuss, withdraw, or keep their original score depending on the discussion. The final scores are used to calculate an average and a range that the rest of the reviewers use as guidance when scoring the proposal. All reviewers score.

STEP 10
After proposal discussion and final scoring, budget is discussed for proposals with an average score >3.5. When this is completed, those with conflicts of interest return to the room and the Chair announces the final proposal for review. Steps 3-10 can then repeat.



Training resources are self-paced and a compensated activity

CCS Identified Underserved Communities

 **2SLGBTQI+**

 **Communities that don't
speak English or French**

 **Racialized communities**

 **Advanced cancer**

 **Rural and remote
communities**

 **Indigenous communities**

 **Newcomers to Canada**

 **Older adults**

 **Rare cancer**

 **Adolescents and young
adults with cancer**

Building Relationships with Underserved Communities



FNHMA Conference 2023 with friends from the Aundeck Omni Kaning First Nation, Manitoulin Island, the First Nations and Inuit Secretariat in Québec and the First Nations of Québec and Labrador Health and Social Services Commission



Our sponsorship of the conference this year



FNHMA Conference with friends from the Aundeck Omni Kaning First Nation, Manitoulin Island, the First Nations of Québec and Labrador Health and Social Services Commission and some new friends from Big Stone Cree Nation, in Alberta

Challenges in Patient Engagement





Statements Describing Patient Engagement Gone Wrong	Explanation	Questions for the Research Team to Ask Themselves
 <p>Patient Partners as a Check Mark</p>	<p>Also known as tokenism; inviting someone's participation but not wanting them there or listening to their perspectives, and therefore not acknowledging their insights, contributions, or ideas.</p>	<ol style="list-style-type: none"> 1. How do we accept feedback from patient partners and integrate it into our work? 2. How can we ask more thoughtful questions of patient partners about their lived experiences? 3. How can we create safer and more inclusive spaces for real and meaningful discussions? 4. How can we share our power and privilege with patient partners?
 <p>Unconscious Bias Towards Patient Partners</p>	<p>Lived experiences are often not viewed as true expertise and given less credence and respect. This may be unintentional and often relates to ableism. Unconscious bias contributes to power imbalances on the team.</p>	
 <p>Lack of Support to Fully Include Patient Partners</p>	<p>Failure to provide physical and other supports to patient partners so they may fully participate as team members.</p>	
 <p>Lack of Recognizing the Vulnerability of Patient Partners</p>	<p>Failure to appreciate that patient partners often re-live emotional or even traumatic parts of their lives for the sake of a project. This means being vulnerable, sometimes in spaces with people with whom they are not very familiar.</p>	

Fig. 1 Statements and their explanations of patient engagement gone wrong, along with questions for the research team members to ask about how they could improve or prevent these situations

What Patient Engagement Is and Is Not:

What this looks like	What it's not
Patient / caregiver partners	Study participants, PDX models
An exchange – discussion and questions	'Educating' or talking at patients / caregivers
Equal team members	Tokenism
Involvement early	Connecting the day before the grant deadline
Recognition / acknowledgement	Leaving them out

1

Patient and Community Engagement for Researchers

Home / Research / For researchers / Patient and Community Engagement for Researchers




Background

There is building consensus across funders, researchers, clinicians and people with lived experience on the benefits of patient engagement in research. Visit our patient and community engagement resource site to explore a list of literature and resources available for researchers.

CCS currently defines patient engagement as the active partnership with and collaboration between people with lived experience of cancer (patients, survivors, and caregivers) throughout the research or research funding life cycle. CCS's research strategy includes an explicit approach to improve the relevance and impact of research funding outcomes. In response and in partnership with people with lived experience and researchers, CCS has co-created a patient engagement in research funding strategy. You can read more on the back of this strategy [here](#).

One key outcome of the strategy for all researchers, CCS recommends or requires the systematic, meaningful and diverse engagement of people with lived experience in all of our research competitions. This may look different in different competitions and for different however all researchers are required to meet minimum expectations of engagement, below.

Resources

3



COMMUNITY OF PRACTICE
patient engagement
in cancer research

Our Website: www.cancer.ca

2

Research newsletter



Home / Research / Research newsletter



CCS RESEARCH E-MAIL SUBSCRIPTION

4

cancer.ca/en/research-for-researchers/funding-opportunities

Canadian Cancer Society

Cancer information Treatments Living with cancer Research Get involved Ways to give

FOR RESEARCHERS

Funding opportunities

Home / Research / For researchers / Current funding opportunities

Our funding programs All previous funding opportunities

Our funding programs

Status	Program name	Type	Previous Competitions	Next Competition
Open	CCS/AMN Research Grants on Neurofibromatosis and Cancer	Research grant	2023	Open - next competition N/A
Closed	Research Training Awards - PhD, PDF	Trainee stipend + Training budget	2024 2023	Fall/Winter 2025
Open	Research Training Awards - Masters	Trainee stipend + Training budget	2025 2024 2023	Open - next competition fall 2025
Closed	CCS Emerging Scholar Research Grants	Research grant	2023 2021	Spring 2025



- Taccone, M.S., Baudais, N., Wood, D. *et al.* Co-creation of a patient engagement strategy in cancer research funding. *Res Involv Engagem* 9, 86 (2023). <https://doi.org/10.1186/s40900-023-00501-x>
- CCS Patient Engagement Compensation Policy and Procedures: <https://cancer.ca/en/research/for-researchers/managing-your-grant/patient-partner-compensation-policy-and-procedures>
- CIHR Bias in Peer Review: <https://cihr-irsc.gc.ca/lms/e/bias/>
- Health Equity at CCS: <https://cancer.ca/en/about-us/our-health-equity-work>
- Richards et al. Research Involvement and Engagement (2023) 9:41 <https://doi.org/10.1186/s40900-023-00454-1>
- Spears, 2021. Patient engagement in cancer research from the patient's perspective. *Futur Oncol.* 17(28): 3717-28. <https://pubmed.ncbi.nlm.nih.gov/34213358/>
- Patient and Community Engagement Resources for Researchers: <https://cancer.ca/en/research/for-researchers/patient-and-community-engagement-for-researchers>
- Community of Practice in Patient Engagement in Research: <https://cancer.ca/en/research/for-researchers/memberships/patient-engagement-in-cancer-research-cop>
- CCS Research Newsletter: <https://cancer.ca/en/research/research-newsletter>
- CCS Funding Opportunities: <https://cancer.ca/en/research/for-researchers/funding-opportunities>
- CCS IGNITE Trainee Program: <https://cancer.ca/en/research/for-researchers/ignite>

**IT TAKES A
SOCIETY**



**Canadian
Cancer
Society**



Putting the Pieces Together: **Building Authentic Partnerships with Patient & Community Partners**

Francine Buchanan (she/her)

Sr. Man, Patient, Family & Community Engagement

Office of Engagement

francine.buchanan@sickkids.ca



COMMUNITY ENGAGEMENT



a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes

World Health Organization. (2020, October 5). Community engagement: A health promotion guide for universal health coverage in the hands of the people.

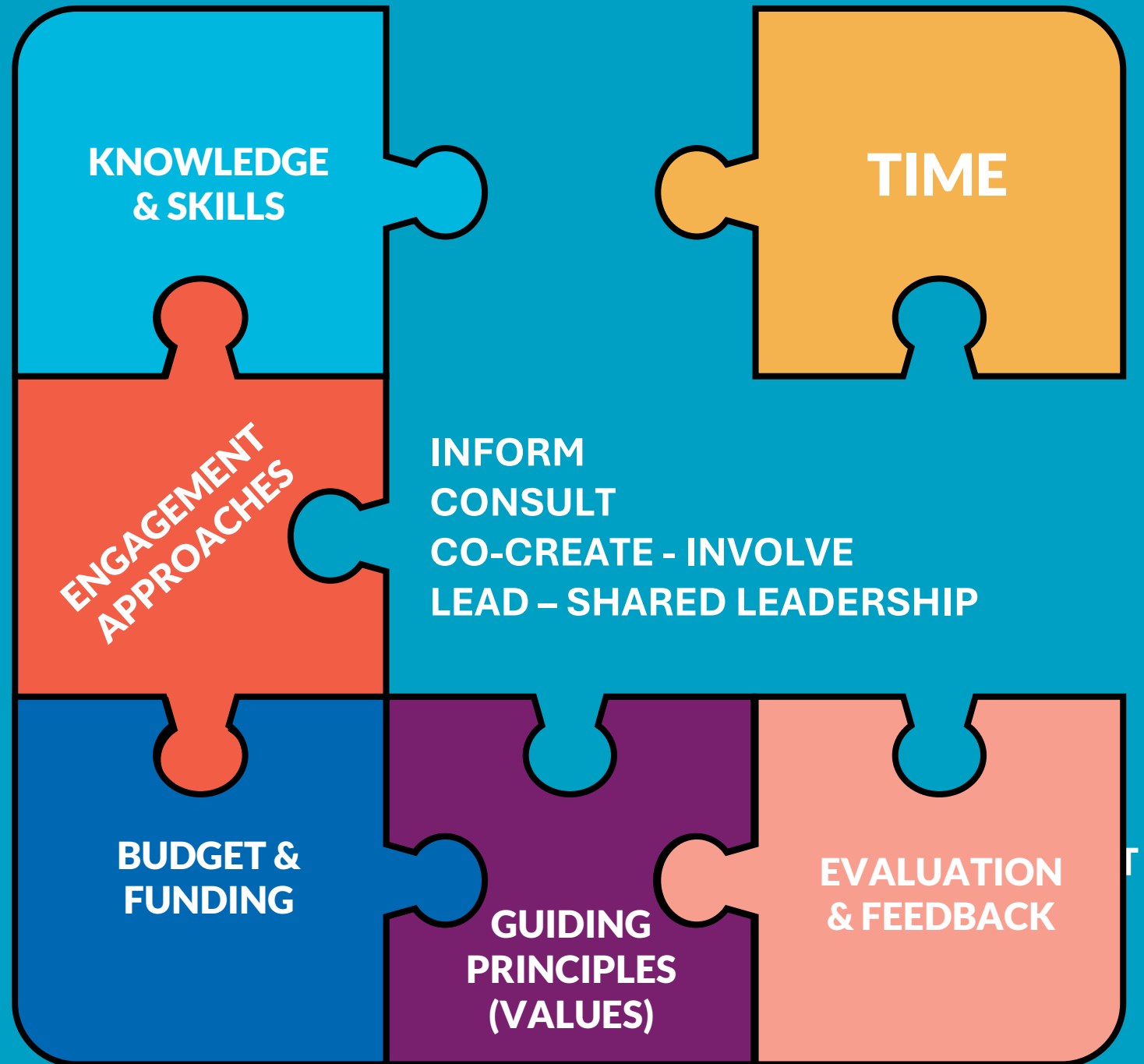
<https://www.who.int/publications/i/item/9789240010529>

developing relationships

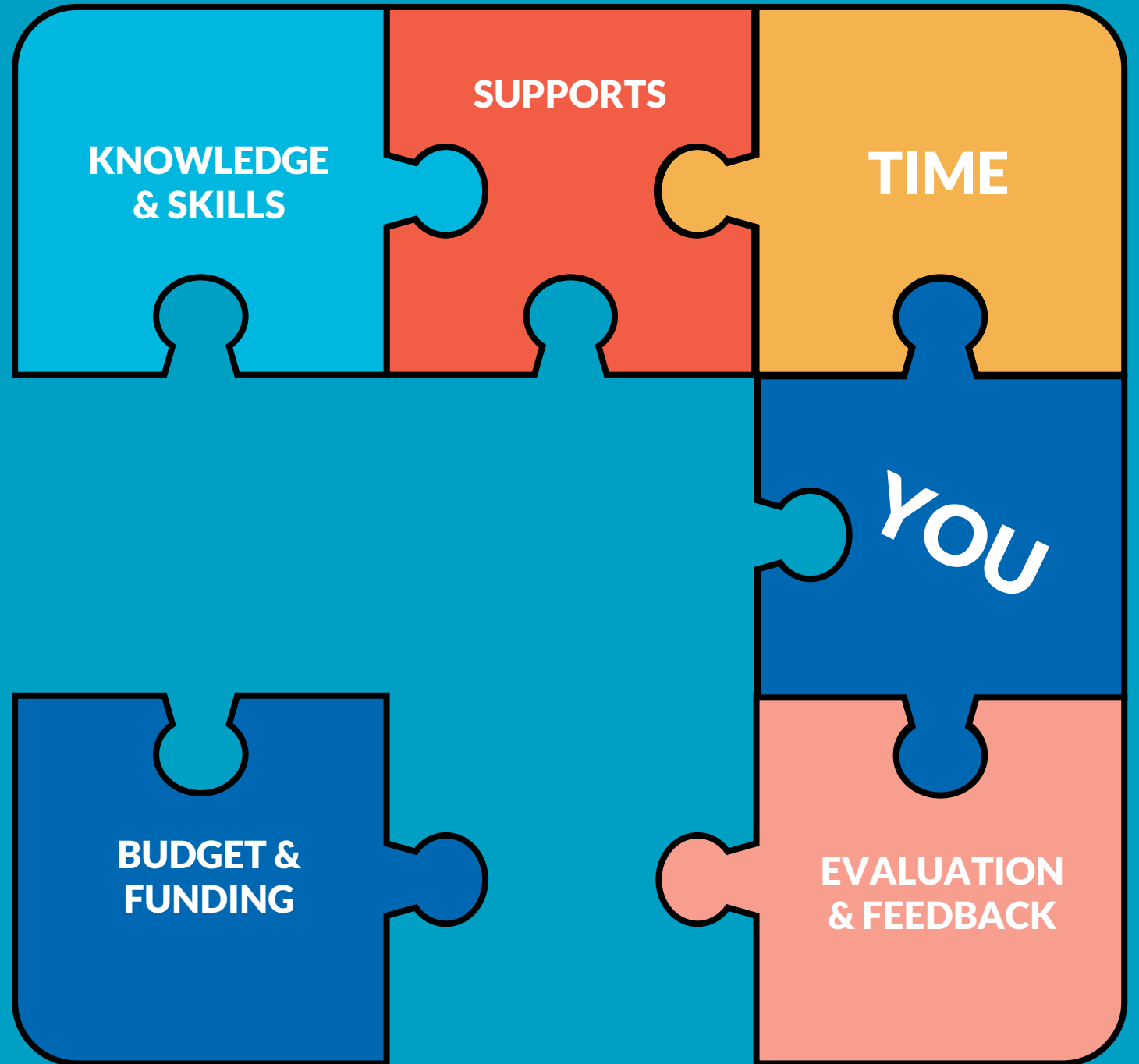


to work together

ALL THE PIECES OF COMMUNITY ENGAGEMENT



ALL THE PIECES OF COMMUNITY ENGAGEMENT



ALL THE PIECES OF COMMUNITY ENGAGEMENT



ALL THE PIECES OF COMMUNITY ENGAGEMENT



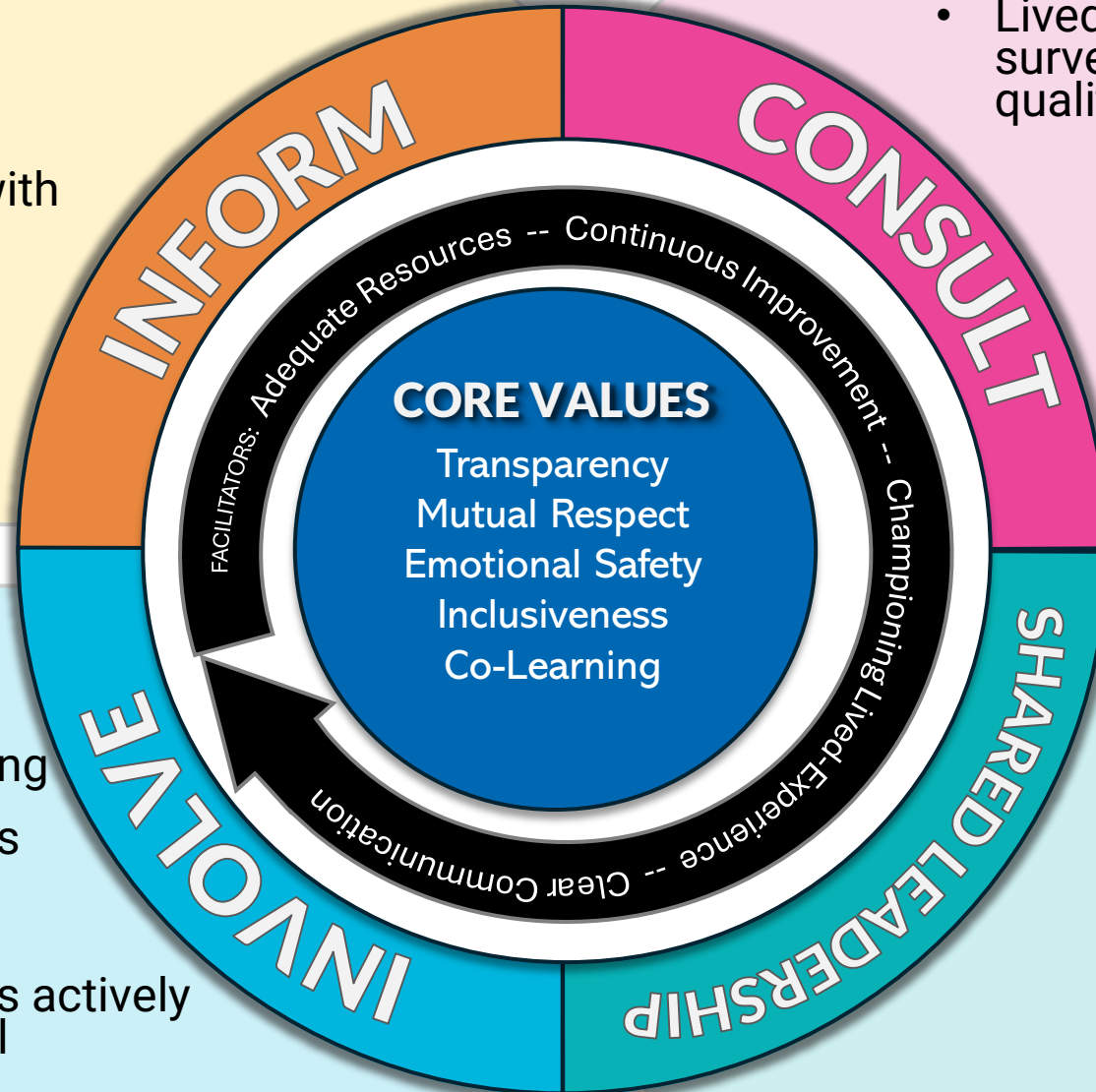
ALL THE PIECES OF COMMUNITY ENGAGEMENT



EXAMPLES OF ENGAGEMENT

EXAMPLES:

- Lay language research summaries are shared with patients & families
- Patients & families are invited to educational and knowledge sharing events
- Lived-experience advisors collaborate on designing a research study and apply for funding
- Lived-experience advisors co-design and co-deliver training for new staff
- Lived-experience advisors actively participate in the hospital accreditation process



- Lived-experience advisors complete surveys or an interview to inform a quality improvement project.
- Lived-experience advisors review an info-graphic to ensure the content is clear and easy for patients to understand
- Lived-experience advisors give general feedback on a grant application
- Lived-experience advisors assume co-investigator roles on research studies or grant applications
- Lived-experience advisors lead the development of an agenda and content for a training and education day event, with the support of hospital staff.

Pandemic Stringency Measures and Hospital Admissions for Eating Disorders

Nadia Roumeliotis, MDCM, PhD; Matthew Carwana, MD, MPH; Katia Charland, PhD; Ofélie Trudeau, MSc; Mike Benigeri, PhD; Mamadou Diop, MSc; Holly Agostino, MD, PhD; Kate Zinszer, PhD; Isra Amsdr, BA; Baudoin Forgeot d'Arc, MD, PhD; Sylvana Côté, PhD; Nicole E. Basta, PhD, MPhil; Patricia Fontela, MD, PhD; Soren Ganttt, MD, PhD, MPH; Terry P. Klassen, MD, MSc; Caroline Quach, MD, MSc; Quynh Doan, MDCM, PhD; for the Pediatric Outcomes Improvement Through Coordination of Research Networks (POPCORN) Investigators

[+ Supplemental content](#)

IMPORTANCE Hospitalizations for eating disorders rose dramatically during the COVID-19 pandemic. Public health restrictions, or stringency, are believed to have played a role in exacerbating eating disorders. Few studies of eating disorders during the pandemic have extended to the period when public health stringency restrictions were lifted.

OBJECTIVE To assess the association between hospitalization rates for eating disorders and public health stringency during the COVID-19 pandemic and after the easing of public health restrictions.

DESIGN, SETTING, AND PARTICIPANTS This Canadian population-based cross-sectional study was performed from April 1, 2016, to March 31, 2023, and was divided into pre-COVID-19 and COVID-19-prevalent periods. Data were provided by the Canadian Institute for Health Information and the Institut National d'Excellence en Santé et Services Sociaux for all Canadian provinces and territories. Participants included all children and adolescents aged 6 to 20 years.

EXPOSURE The exposure was public health stringency, as measured by the Bank of Canada stringency index.

MAIN OUTCOMES AND MEASURES The primary outcome was hospitalizations for a primary diagnosis of eating disorders (*International Statistical Classification of Diseases and Related Health Problems, Tenth Revision* code F50), stratified by region, age group, and sex. Interrupted time series analyses based on Poisson regression were used to estimate the association between the stringency index and the rate of hospitalizations for eating disorders.

RESULTS During the study period, there were 11 289 hospitalizations for eating disorders across Canada, of which 8726 hospitalizations (77%) were for females aged 12 to 17 years. Due to low case counts in other age-sex strata, the time series analysis was limited to females within the 12- to 17-year age range. Among females aged 12 to 17 years, a 10% increase in stringency was associated with a significant increase in hospitalization rates in Quebec (adjusted rate ratio [ARR], 1.05; 95% CI, 1.01-1.07), Ontario (ARR, 1.05; 95% CI, 1.03-1.07), the Prairies (ARR, 1.08; 95% CI, 1.03-1.13), and British Columbia (ARR, 1.11; 95% CI, 1.05-1.16). The excess COVID-19-prevalent period hospitalizations were highest at the 1-year mark, with increases in all regions: Quebec (RR, 2.17), Ontario (RR, 2.44), the Prairies (RR, 2.39), and British Columbia (RR, 2.02).

CONCLUSION AND RELEVANCE In this cross-sectional study of hospitalizations for eating

INFORM

CONSULT

INVOLVE

SHARED
LEADERSHIP

- 5 Advisors
- Met regularly with research teams
- Included in discussions on:
 - Outcomes
 - Variables
 - Interpretation
 - Discussion
- Reviewed & contributed to manuscript writing

Pandemic Stringency for Eating Disorders

Nadia Roumeliotis, MDCM, PhD; Matthew Mike Benigeri, PhD; Mamadou Diop, MSc; Baudoin Forgeot d'Arc, MD, PhD; Sylvana Soren Gantt, MD, PhD, MPH; Terry P. Klassen for the Pediatric Outcomes Improvement

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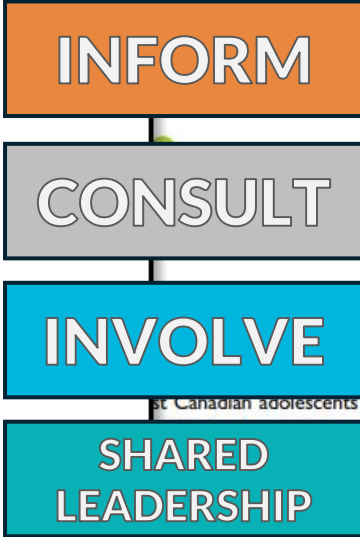
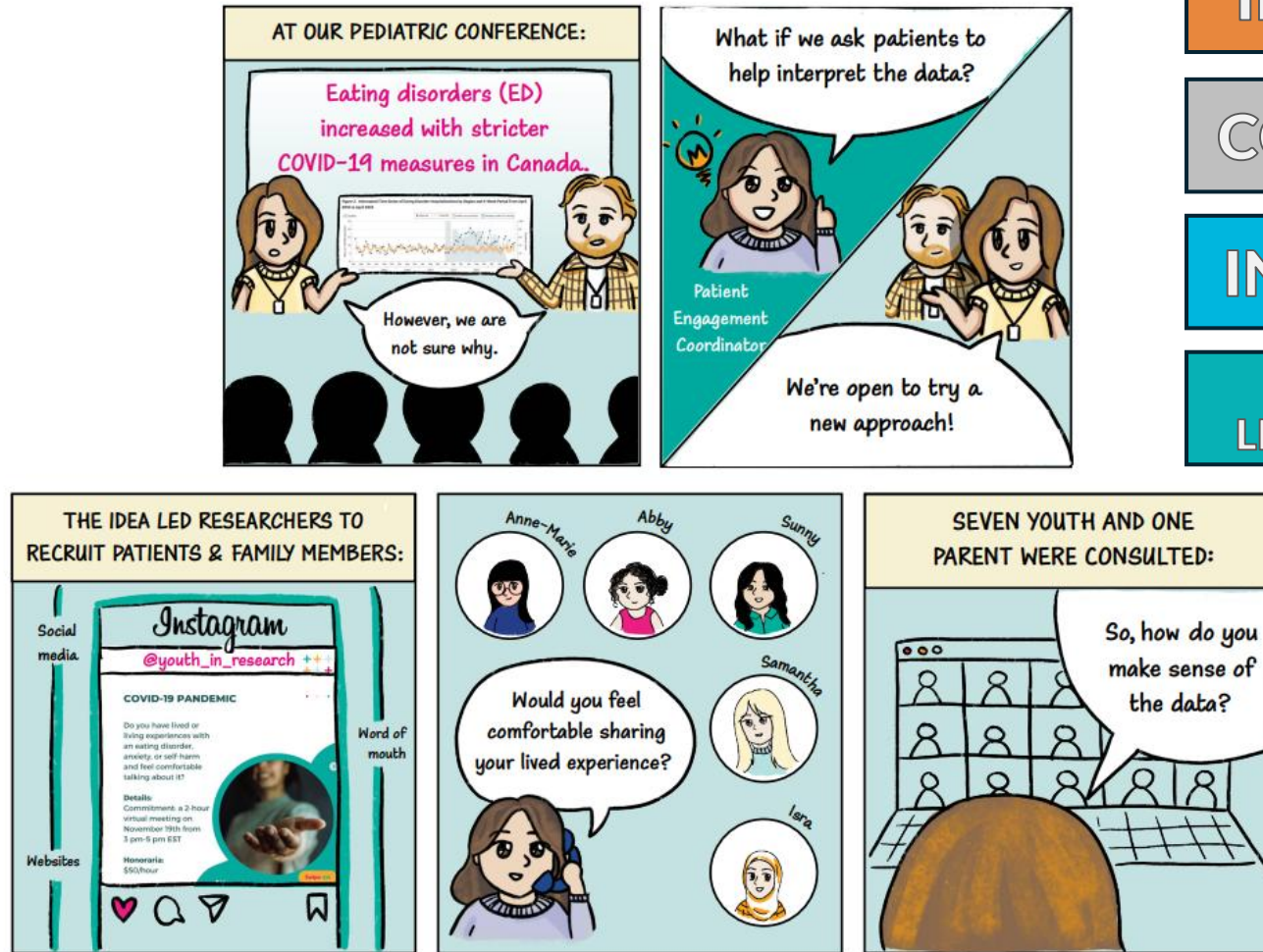
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CONCLUSION AND RELEVANCE In this cross-sectional study of hospitalizations for eating disorders, we found that the excess COVID-19–prevalent p increases in all regions: Quebec (RR, 2.17), Ontario (RR, 2.44), the Prairies (RR, 2.39), and British Columbia (RR, 2.02).

HOW PATIENT PARTNERS MOBILIZED MENTAL HEALTH DATA



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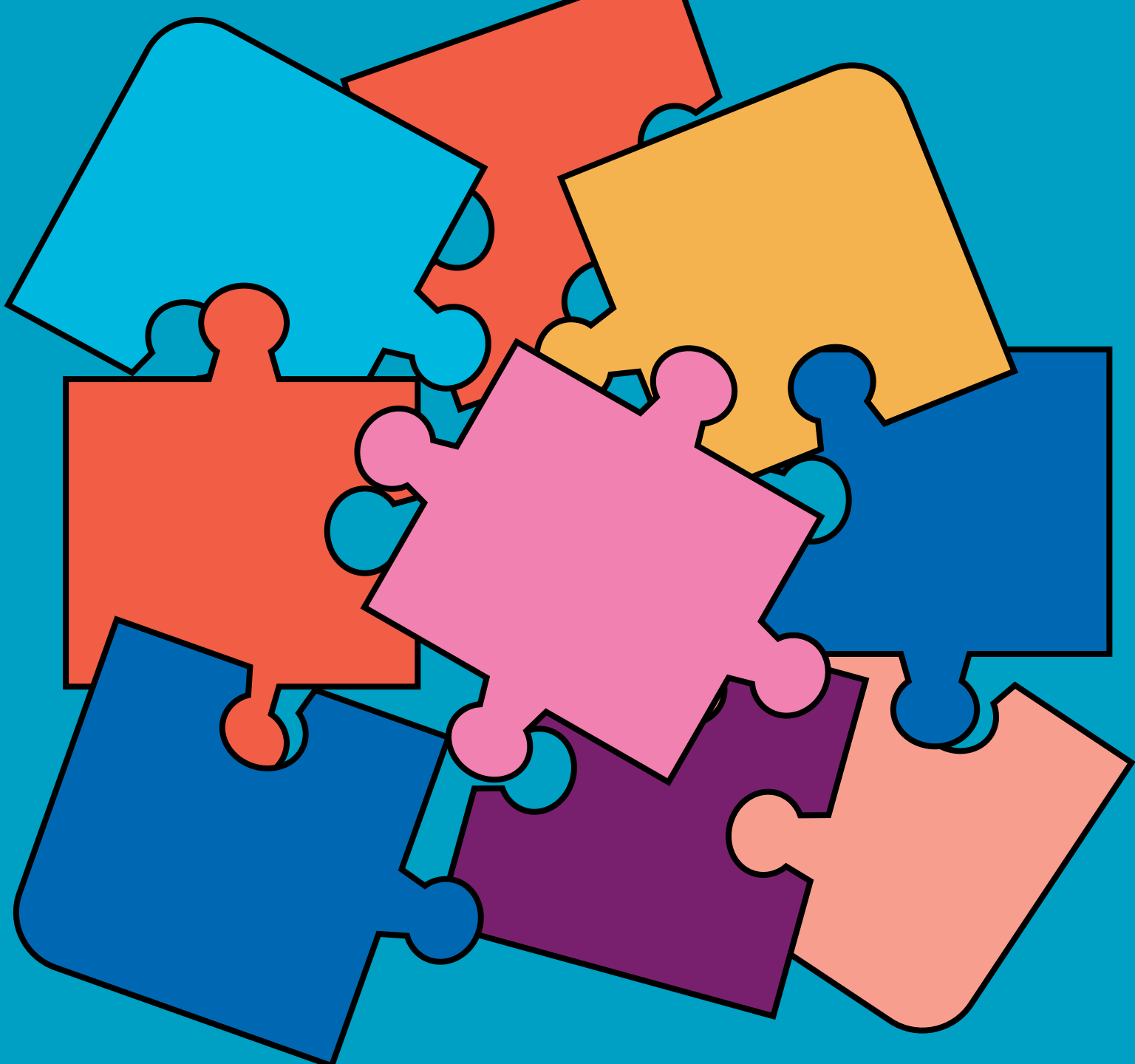
Canadian adolescents during COVID-19 public health of an eating disorder share their insights into how unpredictable have influenced eating disorder ved experience advisory, under- provide suggestions for clinicians, ces in hopes that equitable, accessible, and patient-cent care. This collaboration establishes a precedent for incor- mobilize research. These reflections serve as an example arch, healthcare, and policy to advance care for those

health, pediatrics

anations for this finding included loss of control, disrupted transitions, inaccessible or noninclusive ED treatment, per- ed stigma from clinicians, the harmful influence of social ia during periods of isolation, and reduced treatment capac- Our patient perspectives highlight links between these con- trations to inform future ED research, treatment, and policy.

Hospital for Sick Children, Toronto, ON, Canada
Research Institute, British Columbia Children's Hospital, Vancouver, BC, Canada
Department of Pediatrics, University of British Columbia, Vancouver, BC, Canada

benefit of the original study.

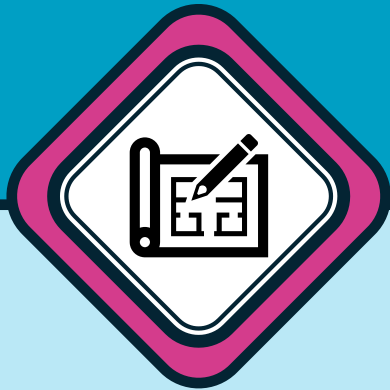


**There is no one
size fit all
engagement
method.**

It is finding the right
approach to promote
the right values, at the
right time, for the
right engagement
goals.

SUPPORTS FOR STAFF & RESEARCH TEAMS

The Office of Engagement offers a variety of services and supports to help SickKids staff across the hospital to partner with patients in all we do.



Grants,
Planning &
Methods
Consults



Custom
Engagement
Training &
Education



Advisor
Committee
Consultations
& Document
Reviews



Engagement
Facilitation &
Staffing



Lived-
Experience
Advisor
Recruitment &
Partnerships



Evaluations &
Surveys

aSK.Engagement@sickkids.ca

Panel Discussion



Edwin S.H. Leong Centre for Healthy Children
UNIVERSITY OF TORONTO

SickKids® | The Office of
Engagement

SickKids® | Research
Training Centre

Thank you for attending!

Share your feedback 



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