January 23, 2025

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

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

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

CIHR IRSC

Canadian Institutes
of Health Research

Instituts de recherche
en santé du Canada

Strategy for Patient-Oriented Research

SPOR

Putting Patients First

CIHR IRSC

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

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

CIHR DEFINITION OF PATIENT-ORIENTED RESEARCH

Engaging patients, caregivers, and families as partners in the research process, leading to meaningful and active collaboration in governance, priority setting, conducting research, and knowledge translation.

‘*Patient’* is an overarching term, inclusive of individuals with personal experience of a health issue as well as caregivers, including family and friends.

Strategy for Patient-Oriented Research

SPOR

Putting Patients First

What is the Strategy for Patient-Oriented Research?

Patient-oriented research transforms patients and their families from **passive recipients** of health services

into **proactive partners** who help shape health research and health care.

To make patient-oriented research a reality, partnerships were formed between:

- Canadian Institutes of Health Research
- Provinces and territories
- Philanthropic organizations
- Academic institutions
- Health charities
- Industry
- Patients
- Clinicians

The result was

What does SPOR do?

It funds research in areas of importance to patients.

It creates hubs of expertise in the provinces and territories that unite patients, caregivers, families, policy-makers, and health care providers.

It builds capacity in patient-oriented research and promotes patient engagement.

What will SPOR achieve?

For patients, it means having a say in which health topics are researched.

For researchers, it means benefiting from the perspectives and experiences of patients.

For the health care system, it means having access to the research evidence that decision-makers and health care providers need to improve care.

For more information on SPOR, please visit cihr-irsc.gc.ca

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

Canada

SPOR National Research Networks

CPN
CHRONIC PAIN NETWORK

ACCESS OPEN MINDS ESPRITS OUVERTS

Diabetes Action Canada
Preventing complications. Transforming lives.

Can-SOLVE
CKD Network

CHILD-BRIGHT
Network

IMAGINE
Inflammation, Microbiome & Alimentation Gastro-Intestinal & Neuropsychiatric Effects

STRATEGY FOR PATIENT-ORIENTED RESEARCH
Primary and Integrated
Health Care Innovations Network

SPOR Enabling Functions

SPOR
Strategy for Patient-Oriented Research
EVIDENCE ALLIANCE

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

SPOR Canadian Data Platform
Plateforme canadienne de données de la SRAP

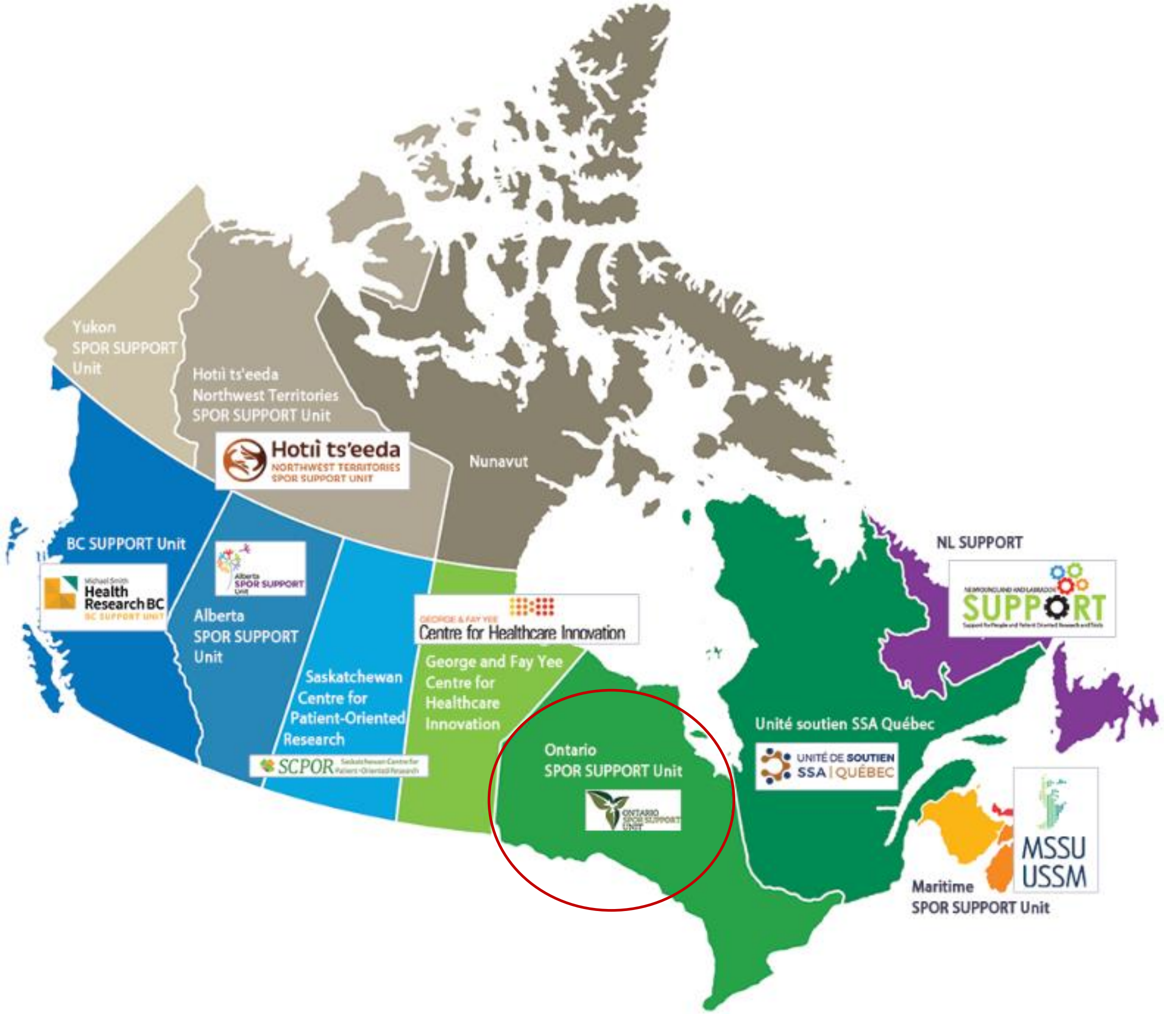
CCTCC
Canadian Clinical Trials Coordinating Centre

CCCEC
Centre canadien de coordination des essais cliniques

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

SPOR National Training Entity

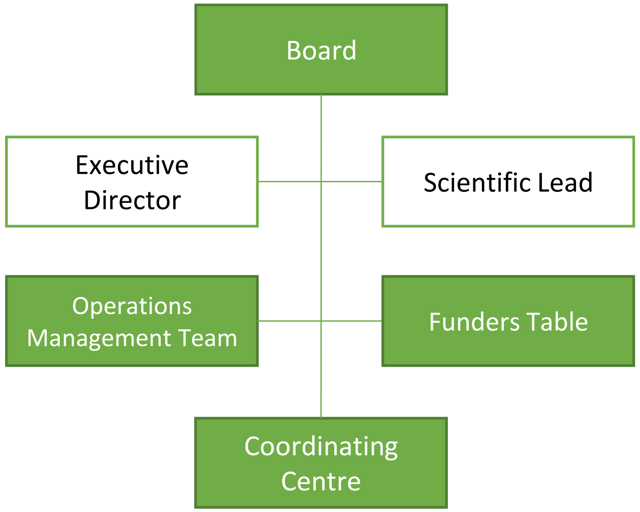
SPOR SUPPORT Units



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

ONTARIO
SPOR SUPPORT
UNIT

OSSU Governance


Board
Executive Director
Scientific Lead
Operations Management Team
Funders Table
Coordinating Centre

Core Component Working Groups


Data Platform and Services
Learning Health System
Capacity Development
Patient Engagement

14 Research Centres

McMaster HEALTH FORUM
HSPRN health system performance research network
KNOWLEDGE TRANSLATION PROGRAM
OCHSU ONTARIO CHILD HEALTH SUPPORT UNIT
McMaster University Institute for Research on Aging
COLLABORATIVE FOR HEALTH & AGING
CENTRE DE MÉTHODES METHODS CENTRE
AHRC APPLIED HEALTH RESEARCH CENTRE
WOMEN'S COLLEGE HOSPITAL women's xchange
ODPRN
IC/ES
INSPIRE-PHC
INnovations Strengthening PrImary Healthcare through REsearch
Centre for Rural and Northern Health Research CRaNHR Centre de recherche en santé dans les milieux ruraux et du nord
CLINICAL TRIALS ONTARIO
ONTARIO BRAIN INSTITUTE

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

CHEO

OCHSU

ONTARIO CHILD HEALTH SUPPORT UNIT

better research - better care - better outcomes

SickKids®

OCHSU Support to PIs and Trainees

1. METHODOLOGICAL SUPPORT

- 793 research methods consultations for patient-oriented research projects
  - $39 million in new research funding; 220 peer-reviewed publications

2. PATIENT AND FAMILY ENGAGEMENT IN CHILD HEALTH RESEARCH

- 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

3. BUILDING CAPACITY IN PATIENT-ORIENTED RESEARCH IN CHILD HEALTH

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

SickKids® | Patient Engagement in Research Program

The Patient Engagement in Research Program is a series of services and supports offered by Clinical Research Services, that will help SickKids research teams efficiently engage with patients & families in the research process.

To find out more about the **Patient Engagement in Research Program**, please email ask.crs@sickkids.ca

ADVISOR MATCHING
Request advisors from the Family Advisory Network (FAN) with lived experience and trained in research advisory

DOCUMENT REVIEWS
Obtain written feedback and comments on grant proposals, consents/assents, recruitment material, and dissemination materials

RFAC CONSULTS
Request support from The Research Family Advisory Committee (RFAC). Obtain input on research studies, grants and proposals from a group of researchers, clinicians, former patients and family members.

EVALUATION SUPPORT
Support is available to help evaluate your current engagement practices

TRAINING
Obtain customized training for research team members and advisors.

CONSULTING SUPPORT
Obtain customized consulting support unique to your teams needs

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

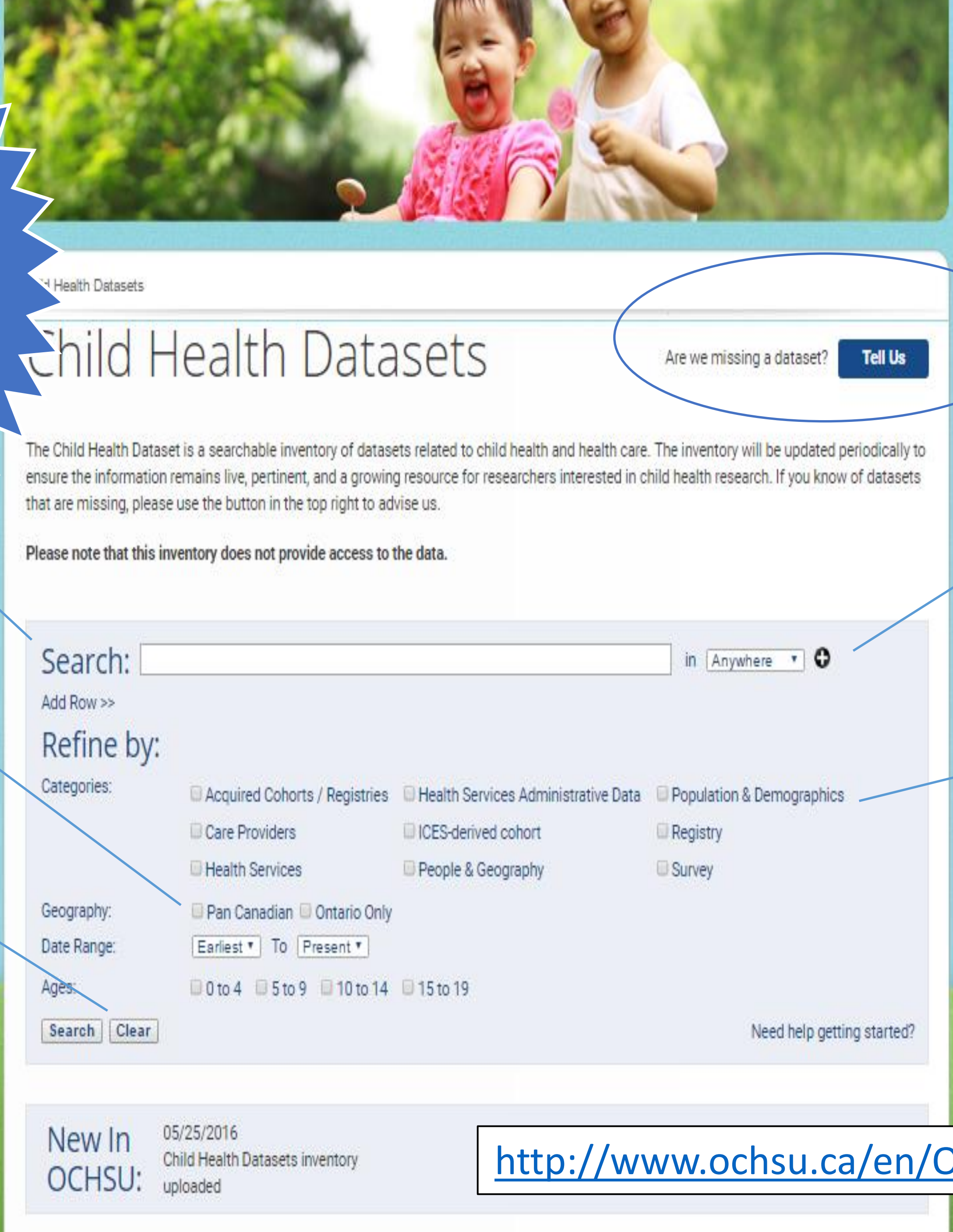
Francine Buchanan[1*], Amy Peasgood[1], Megan Easton[1], Karen Haas[1] and Unni Narayanan[1,2,3,4]

ACTION IN CHILD HEALTH RESEARCH SYMPOSIUM
ADVANCING COLLABORATIVE TRANSFORMATION IN ONTARIO

Patient-Oriented Research Curriculum In Child Health

Over 100 child health datasets included

OCHSU
ONTARIO CHILD HEALTH SUPPORT UNIT



...l Health Datasets

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.

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

Search Clear

Need help getting started?

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

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

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

Clear selections for new search

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

Dataset categories (multiple choice)

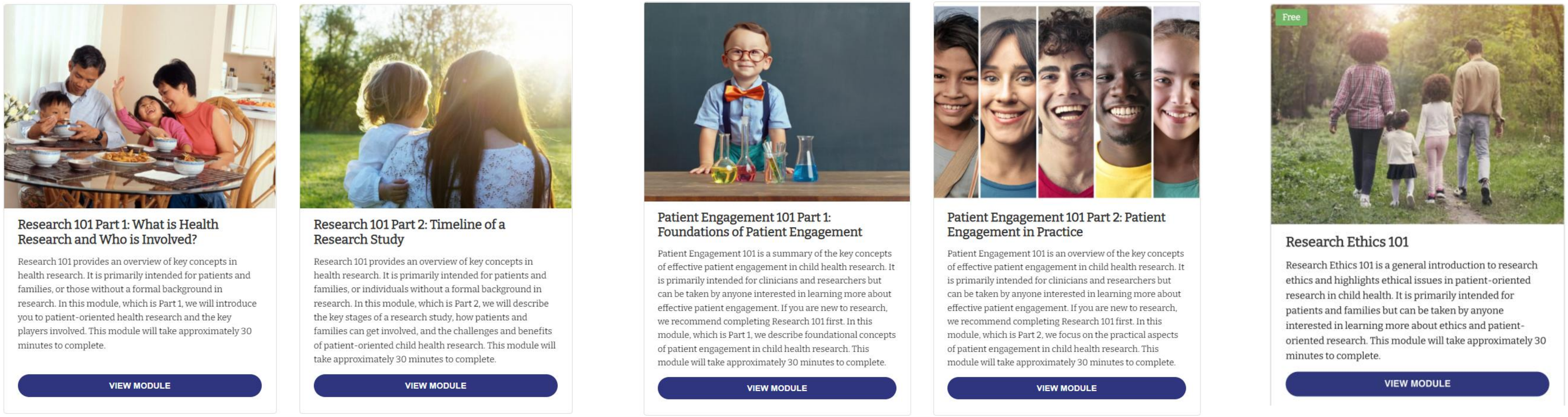
http://www.ochsu.ca/en/OCHSUDatasets

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.

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.

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.

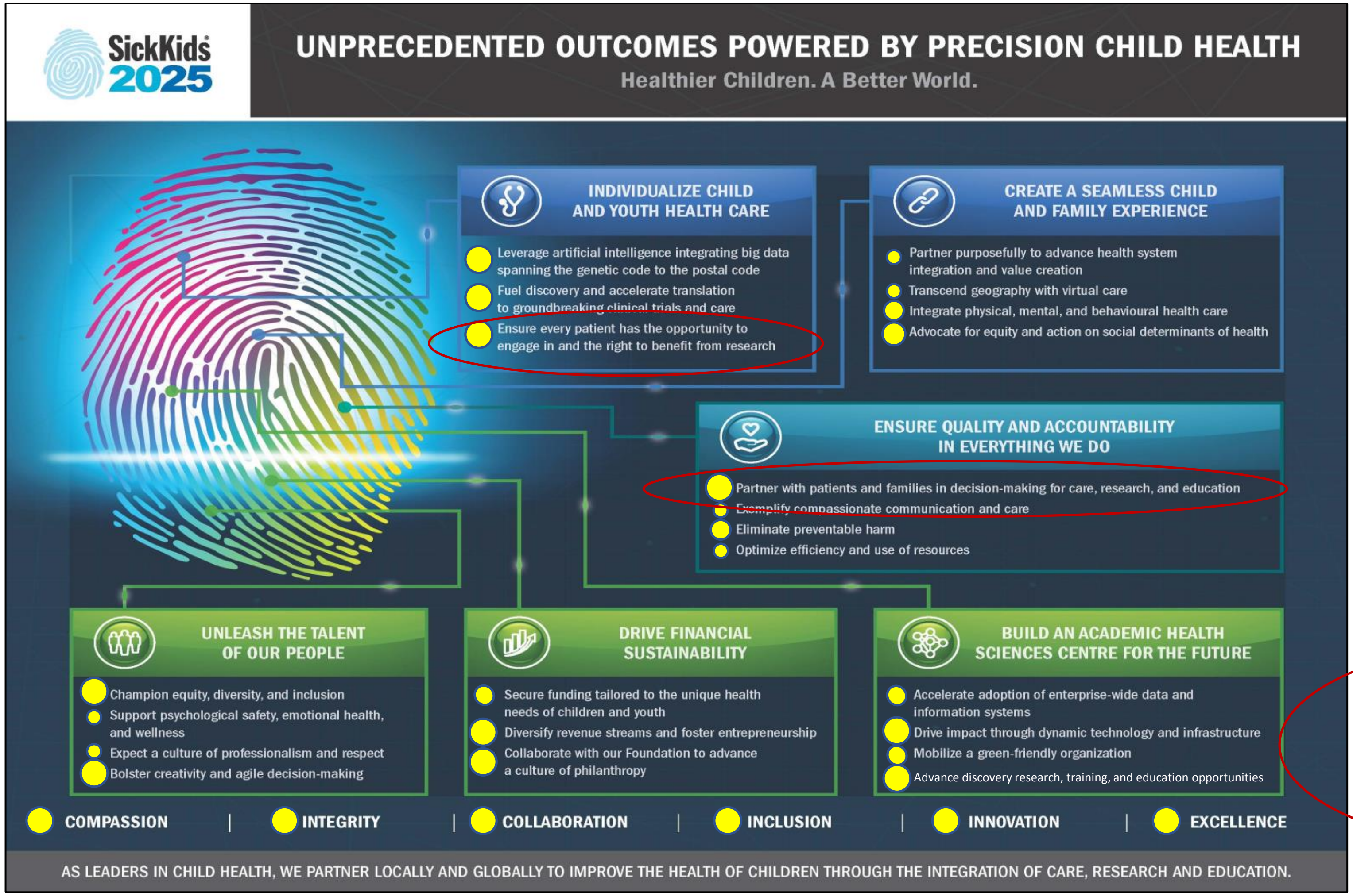
Patient Engagement 101 Part 2: Patient Engagement in Practice

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.

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.

SickKids Strategic Plan – “SickKids 2025”



SickKids 2025

UNPRECEDENTED OUTCOMES POWERED BY PRECISION CHILD HEALTH

Healthier Children. A Better World.

INDIVIDUALIZE CHILD AND YOUTH HEALTH CARE

- Leverage artificial intelligence integrating big data spanning the genetic code to the postal code
- Fuel discovery and accelerate translation to groundbreaking clinical trials and care
- Ensure every patient has the opportunity to engage in and the right to benefit from research

CREATE A SEAMLESS CHILD AND FAMILY EXPERIENCE

- Partner purposefully to advance health system integration and value creation
- Transcend geography with virtual care
- Integrate physical, mental, and behavioural health care
- Advocate for equity and action on social determinants of health

ENSURE QUALITY AND ACCOUNTABILITY IN EVERYTHING WE DO

- Partner with patients and families in decision-making for care, research, and education
- Exemplify compassionate communication and care
- Eliminate preventable harm
- Optimize efficiency and use of resources

UNLEASH THE TALENT OF OUR PEOPLE

- Champion equity, diversity, and inclusion
- Support psychological safety, emotional health, and wellness
- Expect a culture of professionalism and respect
- Bolster creativity and agile decision-making

DRIVE FINANCIAL SUSTAINABILITY

- Secure funding tailored to the unique health needs of children and youth
- Diversify revenue streams and foster entrepreneurship
- Collaborate with our Foundation to advance a culture of philanthropy

BUILD AN ACADEMIC HEALTH SCIENCES CENTRE FOR THE FUTURE

- Accelerate adoption of enterprise-wide data and information systems
- Drive impact through dynamic technology and infrastructure
- Mobilize a green-friendly organization
- Advance discovery research, training, and education opportunities

COMPASSION | INTEGRITY | COLLABORATION | INCLUSION | INNOVATION | EXCELLENCE

AS LEADERS IN CHILD HEALTH, WE PARTNER LOCALLY AND GLOBALLY TO IMPROVE THE HEALTH OF CHILDREN THROUGH THE INTEGRATION OF CARE, RESEARCH AND EDUCATION.

Corporate Scorecard KPI:
# of studies with engagement of patient partners as advisors

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/

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SickKids | Patient Engagement in Research Program

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

AUTHENTIC PATIENT AND COMMUNITY ENGAGEMENT

a paradigm shift in health research

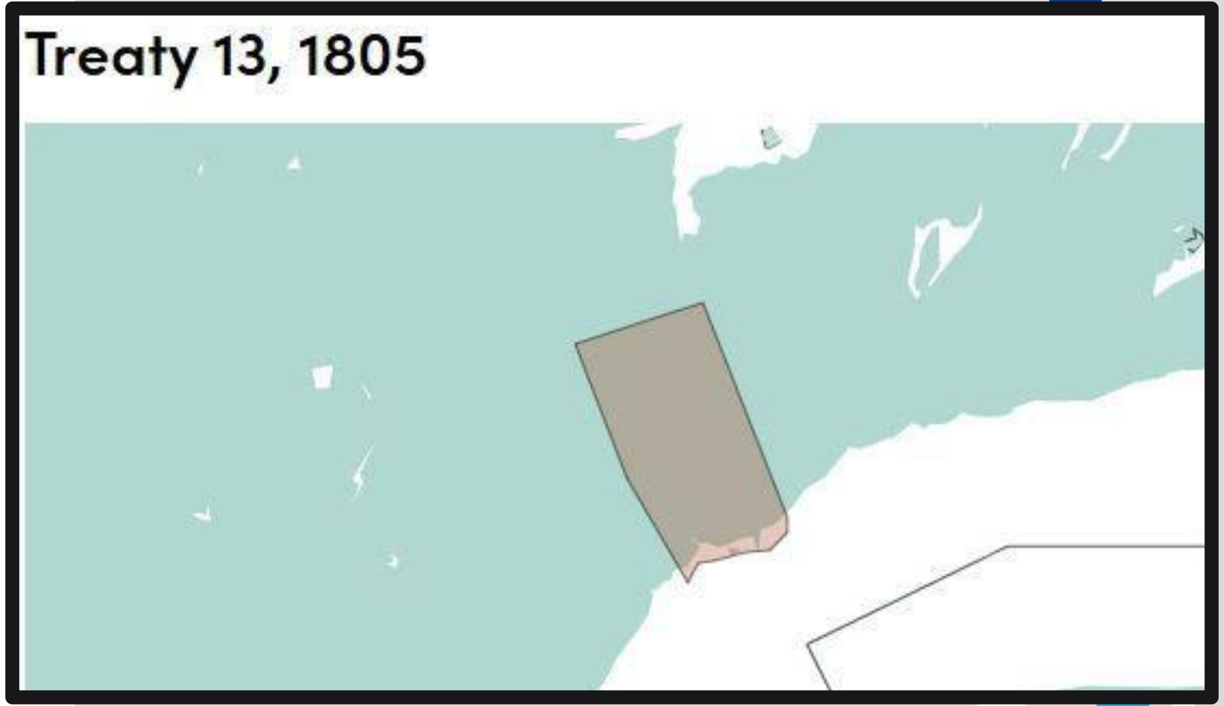
Dalya Kablawi (she/her)
Program Coordinator, Research Engagements
Office of Patient, Family and Community Engagement

23 January, 2025

LAND ACKNOWLEDGEMENT

We acknowledge that we are meeting on the unceded and unsurrendered ancestral territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples.

We also acknowledge that Toronto is covered by Treaty 13 signed with the Mississaugas of the Credit, and the Williams Treaties signed with multiple Mississaugas and Chippewa bands.



DALYA KABLAWI

she/her

Program Coordinator,
Research Engagements

Office of Patient, Family and Community Engagement

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SESSION OBJECTIVES

- Background & Evidence
- Strategies for Effective Engagement
- Avoiding Tokenism
- Evaluation
- Resources & Support

BACKGROUND & EVIDENCE

what is engagement and why is it important?

cmaj

BEST EVIDENCE • BEST PRACTICE • BEST HEALTH

ENGAGING PATIENTS IN HEALTH RESEARCH:

The Ontario Experience

Ontario

CMAJ 2018;190(Suppl 1):S1-S56

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. Verhagen[1], Hedy A. van Oers[1,2,3], Esmée E. W. Kramer[1], Joost G. Daams[4], Mariken P. Gruppen[5], Maria J. Santana[6,7], Martha A. Grootenhuis[8] 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

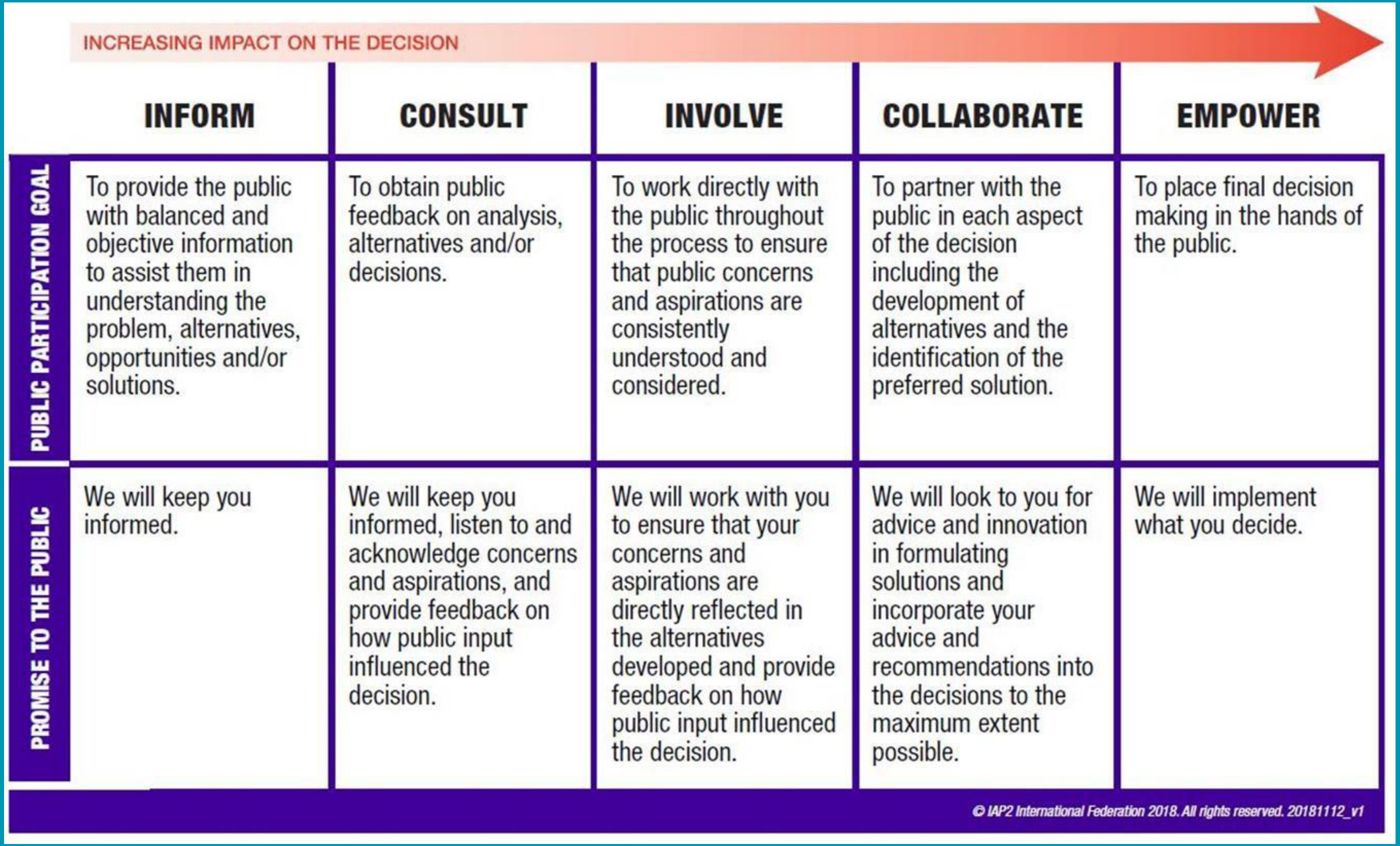
increasing relevance & impact

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

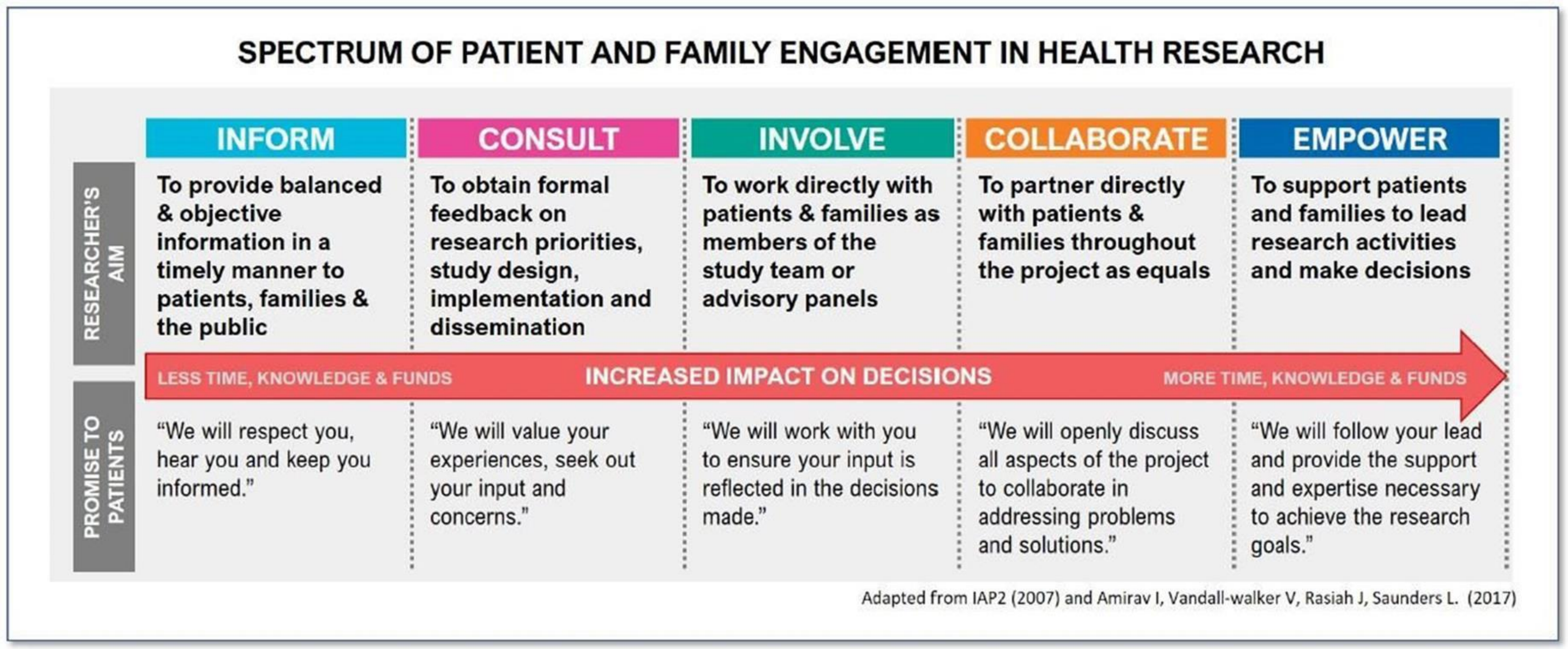
IAP2 SPECTRUM OF PUBLIC PARTICIPATION



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

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
RESEARCHER'S AIM	**To provide balanced & objective information in a timely manner to patients, families & the public**	**To obtain formal feedback on research priorities, study design, implementation and dissemination**	**To work directly with patients & families as members of the study team or advisory panels**	**To partner directly with patients & families throughout the project as equals**	**To support patients and families to lead research activities and make decisions**
	LESS TIME, KNOWLEDGE & FUNDS		INCREASED IMPACT ON DECISIONS		MORE TIME, KNOWLEDGE & FUNDS
PROMISE TO PATIENTS	"We will respect you, hear you and keep you informed."	"We will value your experiences, seek out your input and concerns."	"We will work with you to ensure your input is reflected in the decisions made."	"We will openly discuss all aspects of the project to collaborate in addressing problems and solutions."	"We will follow your lead and provide the support and expertise necessary to achieve the research goals."

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

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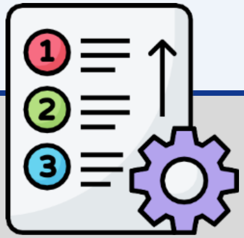
STRATEGIES FOR EFFECTIVE ENGAGEMENT

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

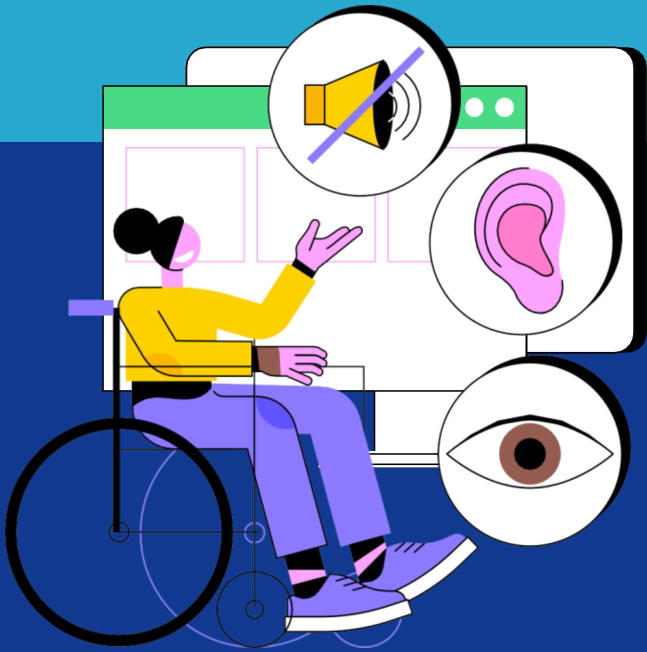
- Transparency around research process
- Regular updates and touchpoints
- Feedback loops and grievance processes

ACCOUNTABILITY & GOVERNANCE

DATA ACCESS & GOVERNANCE

- Clear agreements about data privacy and usage
- OCAP principles of data sovereignty

ACCESSIBILITY



- Accommodations to reduce participation barriers
- Patient & community partner retention
- Compensation & recognition

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

AVOIDING TOKENISM

distinguishing between superficial 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.

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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)

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UNIVERSITY OF TORONTO

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 dalya.kablawi@sickkids.ca or scan the following QR code to fill out the engagement support request form.

SickKids | Patient Engagement in Research Program

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

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 23, 2025

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

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Canadian
Cancer
Society

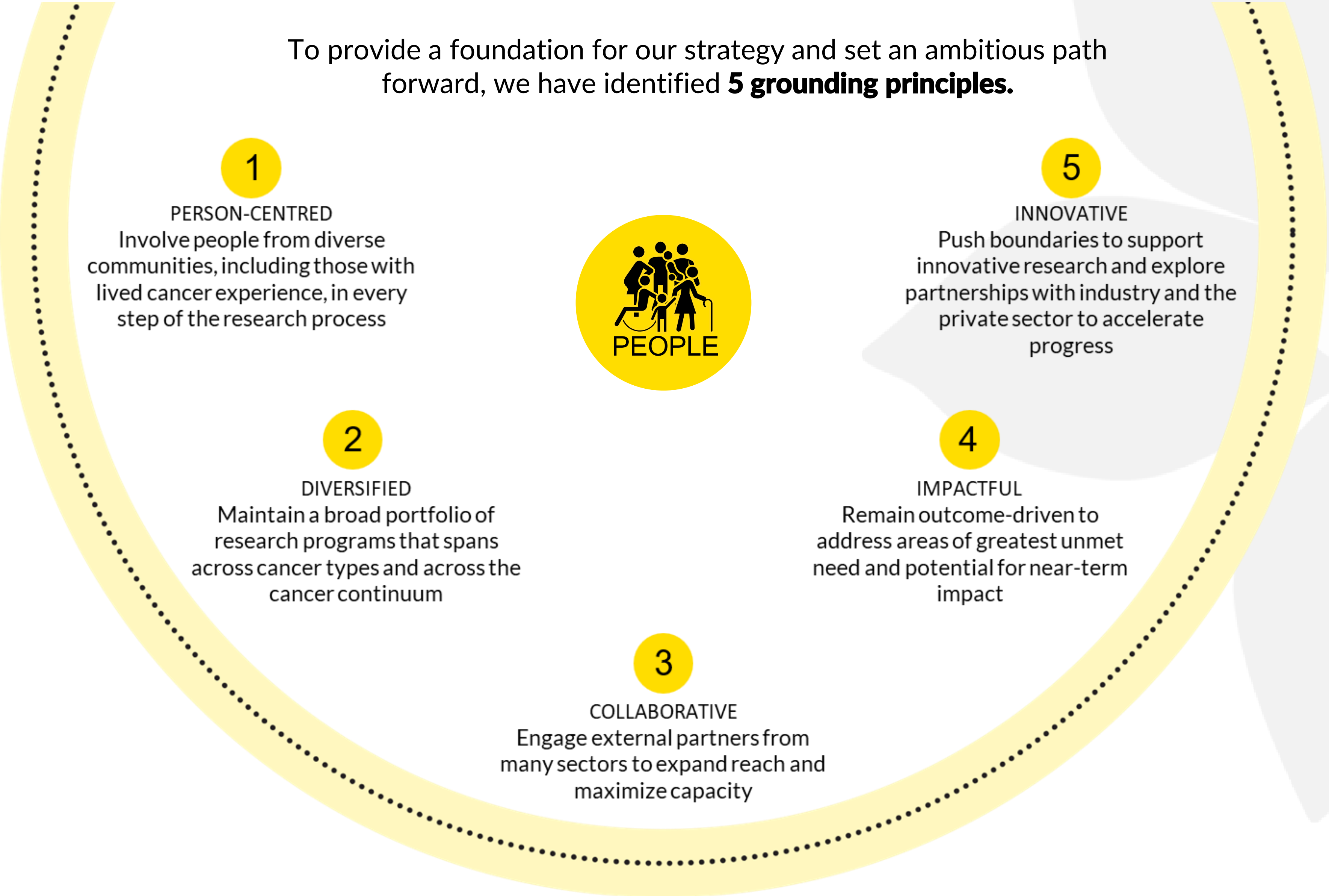
Patient Engagement in Research at the Canadian Cancer Society

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

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.**



PEOPLE

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

4
IMPACTFUL
Remain outcome-driven to address areas of greatest unmet need and potential for near-term impact

5
INNOVATIVE
Push boundaries to support innovative research and explore partnerships with industry and the private sector to accelerate progress

Canadian Cancer Society Patient Engagement in Research Plan

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

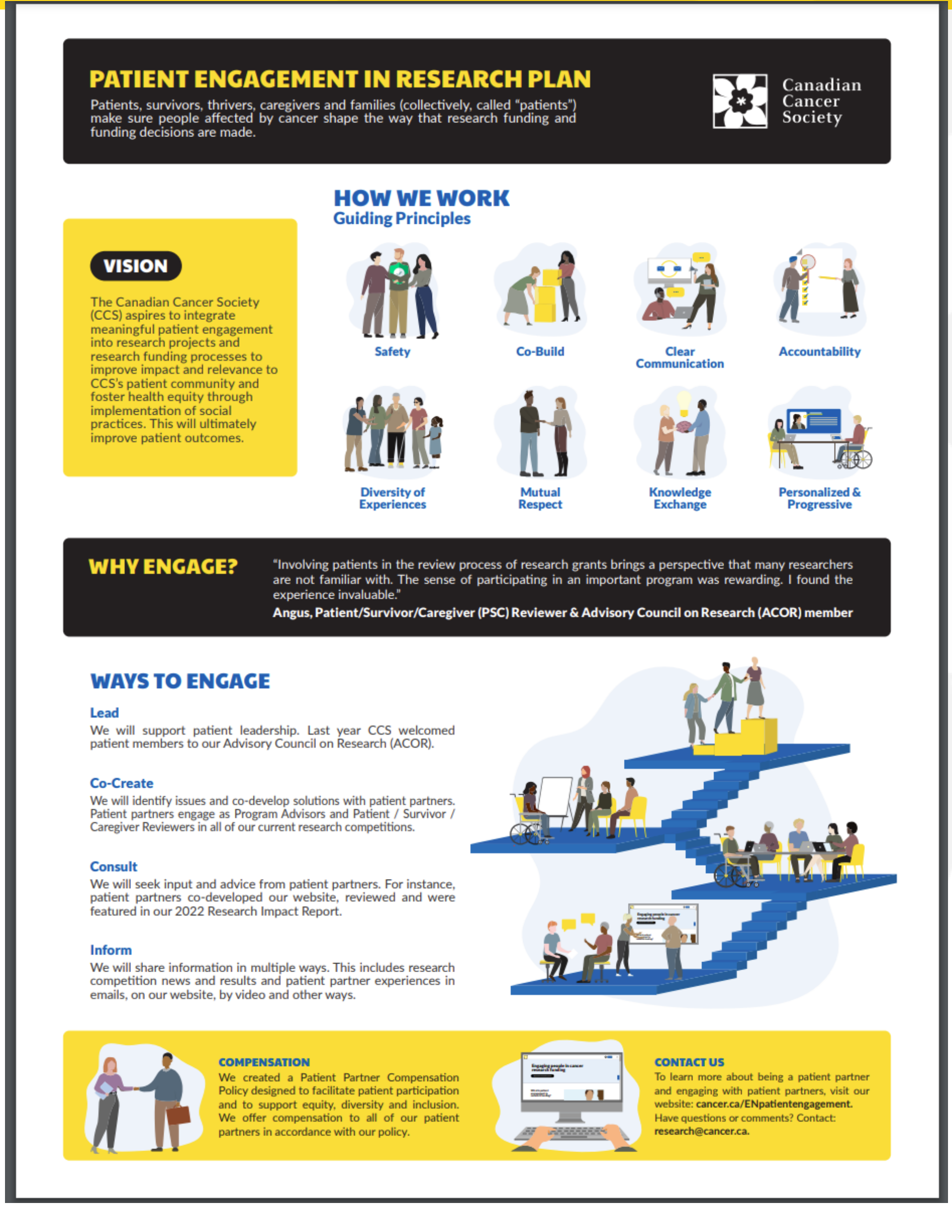
2358 Accesses | **15** Altmetric | Metrics

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.

Canadian Cancer Society

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.

HOW WE WORK
Guiding Principles

- Safety
- Co-Build
- Clear Communication
- Accountability
- Diversity of Experiences
- Mutual Respect
- Knowledge Exchange
- Personalized & Progressive

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.**

How we Work – Guiding Principles

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.

Canadian
Cancer
Society

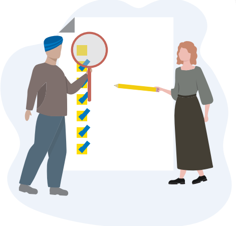
HOW WE WORK

Guiding Principles

Safety

Co-Build

Clear Communication

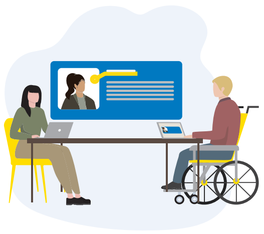


Accountability

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.

Canadian
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Society

Ways we Engage Patient Partners

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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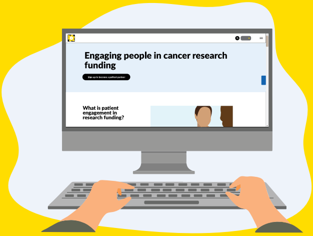

CONTACT US

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.**

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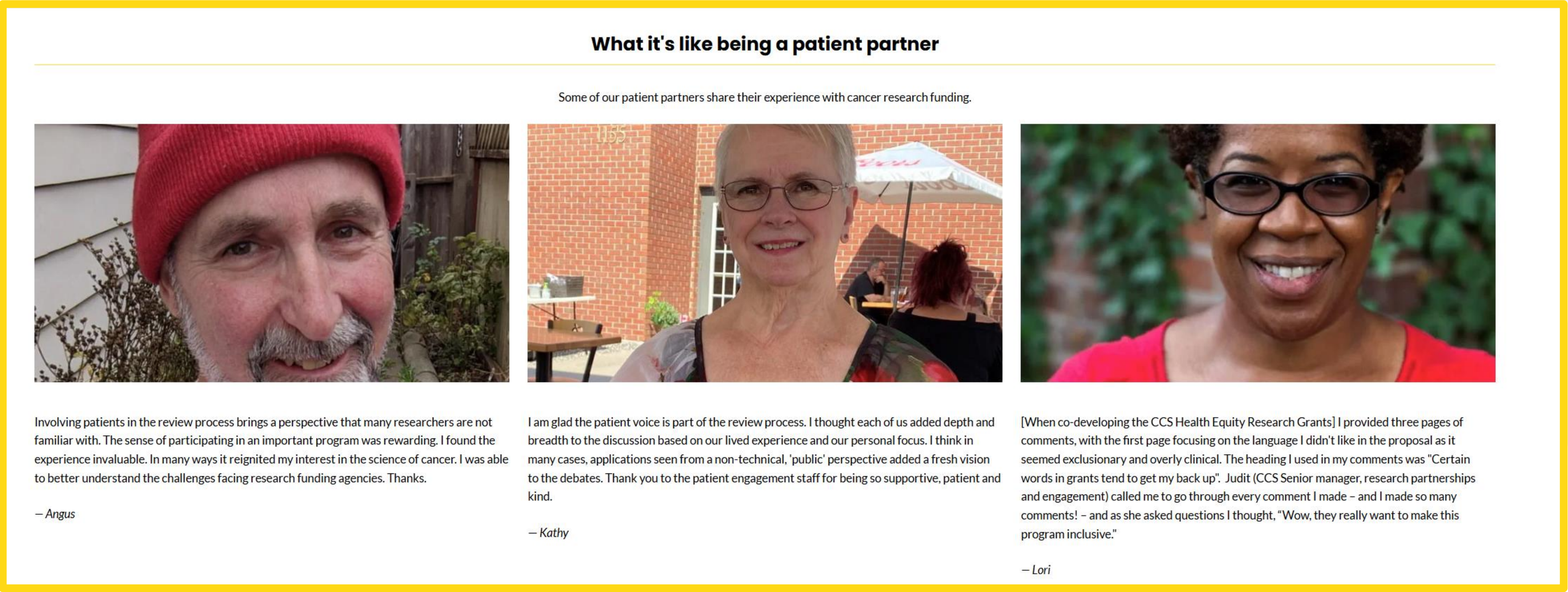
What we look for in a PWLE and how we fit people to their strengths



What it's like being a patient partner

Some of our patient partners share their experience with cancer research funding.

Involving patients in the review process 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. In many ways it reignited my interest in the science of cancer. I was able to better understand the challenges facing research funding agencies. Thanks.

— Angus

I am glad the patient voice is part of the review process. I thought each of us added depth and breadth to the discussion based on our lived experience and our personal focus. I think in many cases, applications seen from a non-technical, 'public' perspective added a fresh vision to the debates. Thank you to the patient engagement staff for being so supportive, patient and kind.

— Kathy

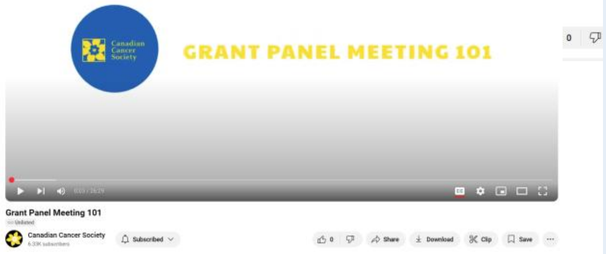
[When co-developing the CCS Health Equity Research Grants] I provided three pages of comments, with the first page focusing on the language I didn't like in the proposal as it seemed exclusionary and overly clinical. The heading I used in my comments was "Certain words in grants tend to get my back up". Judit (CCS Senior manager, research partnerships and engagement) called me to go through every comment I made – and I made so many comments! – and as she asked questions I thought, "Wow, they really want to make this program inclusive."

— Lori

Training in PE in Research at CCS

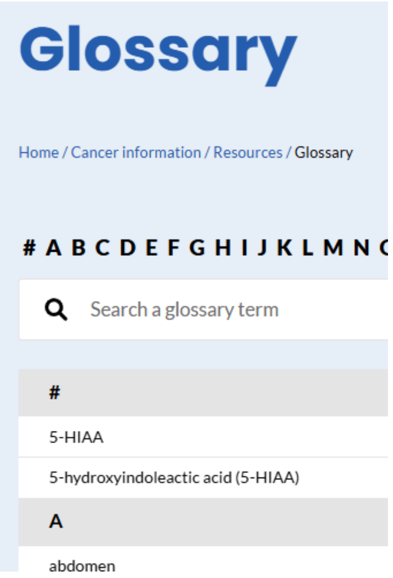
VIDEO TOPICS

1. Panel Member Selection
2. Panel Members & Roles
3. Panel Meeting Schedule
4. Panel Meeting Discussion
5. PSC Importance



Grant Panel Meeting 101

Canadian Cancer Society



Glossary

Home / Cancer information / Resources / Glossary

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

Search a glossary term

#

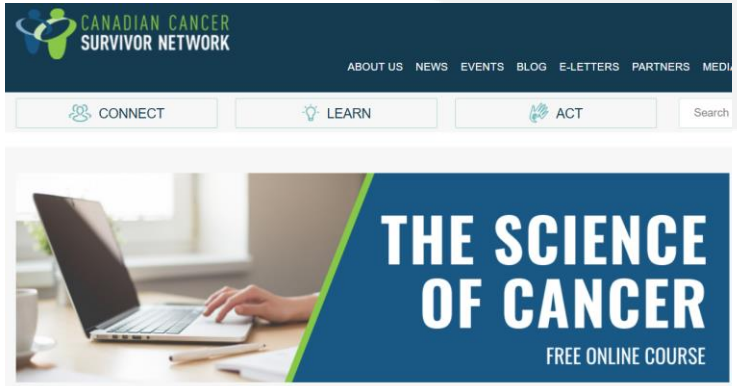
5-HIAA

5-hydroxyindoleactic acid (5-HIAA)

A

abdomen

Bias in Peer Review



THE SCIENCE OF CANCER

FREE ONLINE COURSE

PANEL MEETING OVERVIEW

PANEL MEMBERS

- PC Panel Chair
- SR Scientific Reviewer
- PSC Patient, Survivor & Caregiver Reviewer
- SO Scientific Officer
- CCS Canadian Cancer Society Staff
- ER End-User/Decision Maker Reviewer
- OB Observer

*Note: Observers do not actively participate in the panel

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 triaged, meaning only reviewer reports are sent to these applicants and the proposal is not discussed further.
PC CCS

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 triaged and these are added to the meeting discussion.
PC SR PSC SO CCS ER

STEP ③
Time to review research proposals! 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.
PC SR PSC ER

STEP ④
The Scientific Officer and reviewers assigned to the proposal are announced, and reviewers give their initial score. Reviewers use a standardized rating 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 merit.
SR PSC SO ER

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

STEP ⑥
Reviewers then each provide their assessment. For instance, the PSC Reviewer may provide their review of the proposal followed by the Scientific Reviewers and in some cases End-User/Decision-Maker Reviewers.
SR PSC ER

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.
SR PSC ER

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

STEP ⑨
The Chair asks reviewers assigned to the proposal to provide a final score. A reviewer may increase, decrease, 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.
PC SR PSC ER

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 next proposal for review. Steps 3 – 10 are then repeated!
PC

Training resources are self-paced and a compensated activity

Canadian
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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

practices, including
opportunities
Facilitator: Marion Crowe, CFNHM, CAFM,
Health Managers Association
Panelists: David McLaren, CFNHM, CIL, Vice-President, FNHMA Board of
Kebaowek First Nation, QC
Judy Sugar, CFNHM, Health Director, Piapot First Nation Health Services, SK

10:00 - 10:30 am
Health Break... Last chance to visit exhibitors and artisans! [Grands Foyers/Imperial 5,7,9]
Sponsored by:

CONCURRENT WORKSHOPS

10:30 am - 12:00 pm
WORKSHOP I
Sponsored by:
Wellness from a Holistic Community Lens Using Land-Based Practices and Mino-Tehewin Kihkinohamakewinan (Good Heart Teachings) [Stephen]
As a community leader in ensuring healthcare access, the Sioux Lookout First Nations Health Authorit
(SLFNHA) established the Anishinaabewaadiziwin (Way of Life) department to support the holistic
Kiiwetinoong community members. The department shows that integratin
supports healing and wellness for community membe
members with Elders,

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

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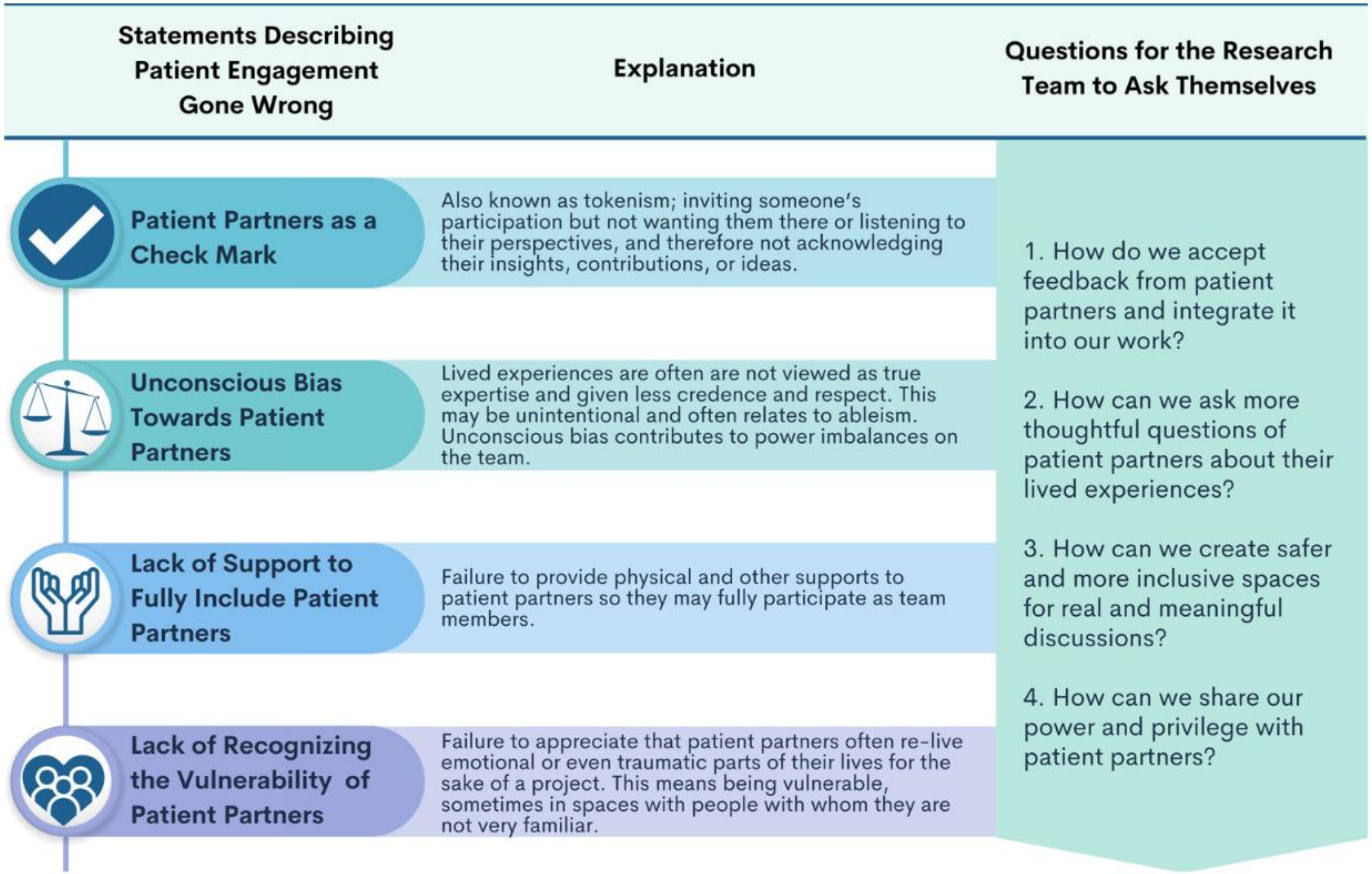
Challenges in Patient Engagement



Statements Describing Patient Engagement Gone Wrong	Explanation	Questions for the Research Team to Ask Themselves
Patient Partners as a Check Mark	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.	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?
Unconscious Bias Towards Patient Partners	Lived experiences are often are 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.	
Lack of Support to Fully Include Patient Partners	Failure to provide physical and other supports to patient partners so they may fully participate as team members.	
Lack of Recognizing the Vulnerability of Patient Partners	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.	

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

Richards et al. Research Involvement and Engagement (2023) 9:41
https://doi.org/10.1186/s40900-023-00454-1

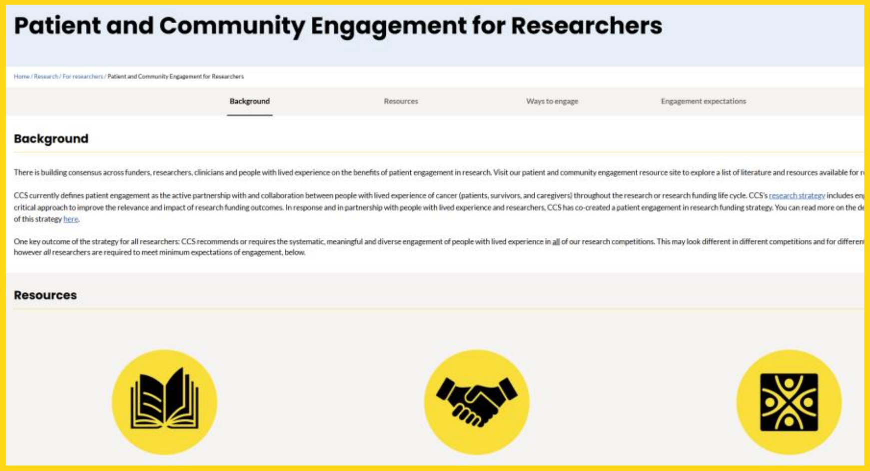
What Patient Engagement Is and Is Not:

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

Canadian Cancer Society

How to Connect with a Charity Funding Partner on Patient Engagement

1



Patient and Community Engagement for Researchers

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

Background | Resources | Ways to engage | Engagement expectations

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 r

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 en critical 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 de of this strategy here.

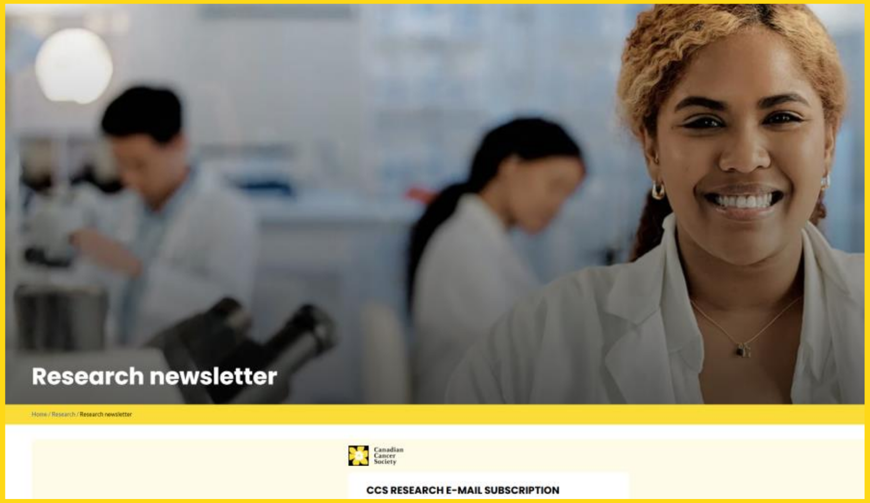
One key outcome of the strategy for all researchers: CCS recommends or requires the systematic, meaningful and diverse engagement of people with lived experience in all of our research competitions. This may look different in different competitions and for differen however all researchers are required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

Resources

3

Our Website: www.cancer.ca

2



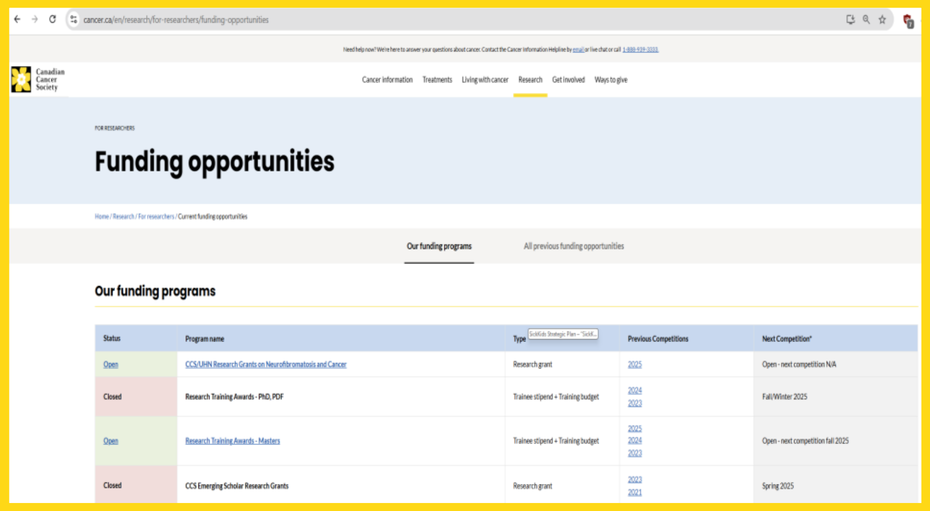
Research newsletter

Home / Research / Research newsletter

Canadian Cancer Society

CCS RESEARCH E-MAIL SUBSCRIPTION

4



Need help now? We're here to answer your questions about cancer. Contact the Cancer Information Helpline by email or live chat or call 1-888-939-3333.

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/UHN Research Grants on Neurofibromatosis and Cancer	Research grant	2025	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

Resources

- 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

Partnering– In Each and Every Moment

Dr Julia Orkin

Associate Professor, University of Toronto

Associate CMO, Clinical Operations, System Integration & Patient/Family Experience

Medical Director. Complex Care

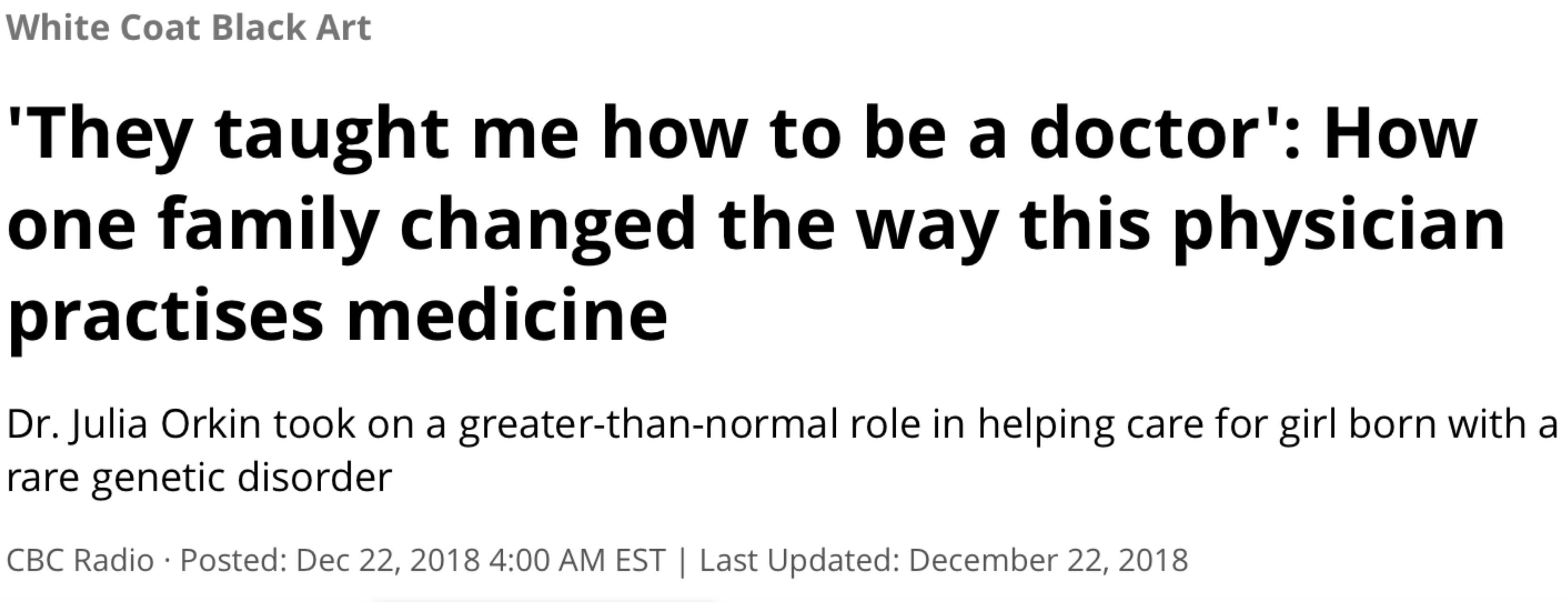
SickKids®
2025

Objectives

- Explore the role of family/patient engagement in clinical research
- A tale of two projects: describe the experience of patient/family partnership across two research projects
- Share opportunities for integration with family/patient partners in all we do

Sloane

Sloane



White Coat Black Art

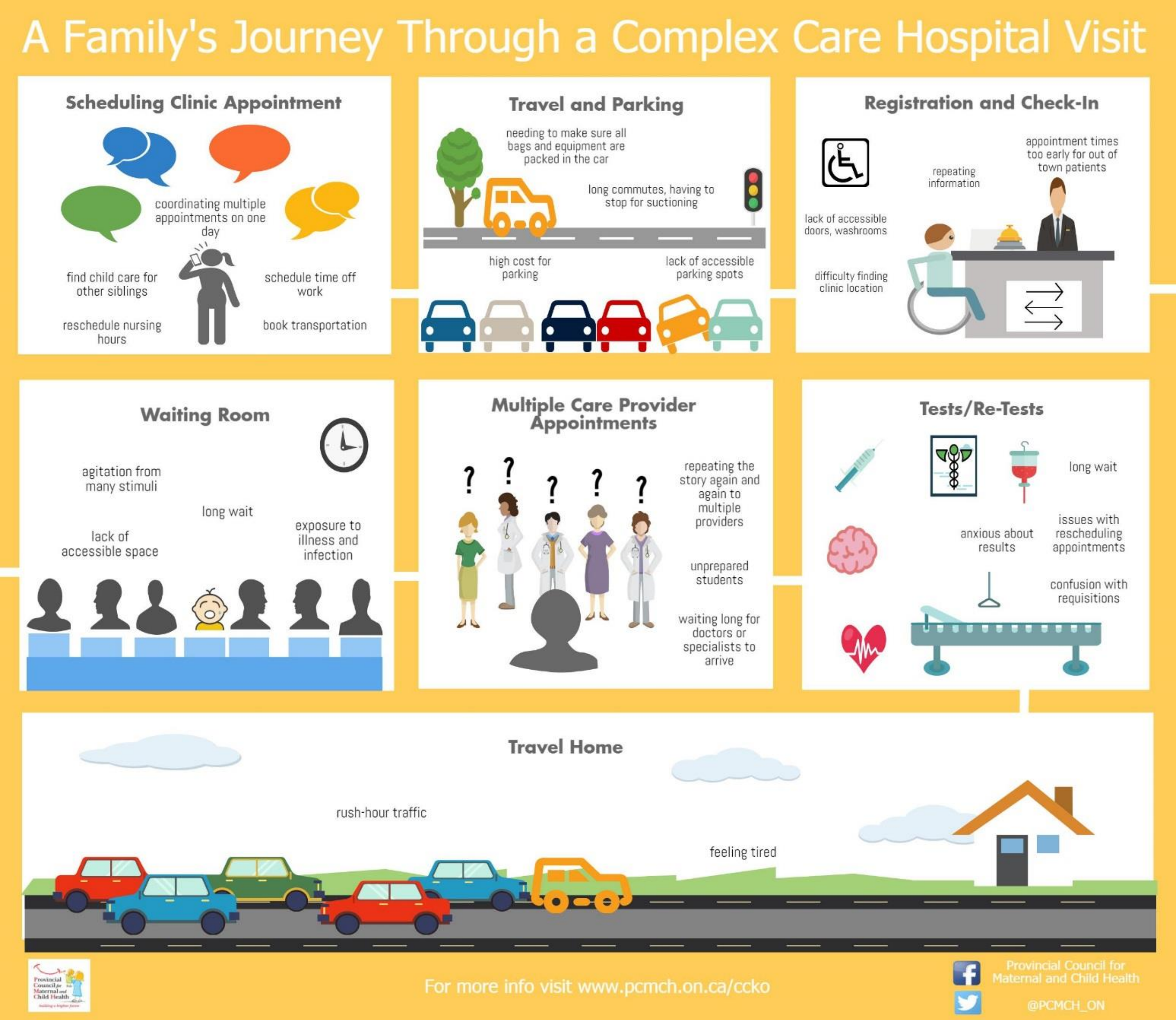
'They taught me how to be a doctor': How one family changed the way this physician practises medicine

Dr. Julia Orkin took on a greater-than-normal role in helping care for girl born with a rare genetic disorder

CBC Radio · Posted: Dec 22, 2018 4:00 AM EST | Last Updated: December 22, 2018

Lesson 1: The magic of listening AND changing

STORY 1
“ See you on Tuesday”



A Family's Journey Through a Complex Care Hospital Visit

Scheduling Clinic Appointment

coordinating multiple appointments on one day

find child care for other siblings

schedule time off work

reschedule nursing hours

book transportation

Travel and Parking

needing to make sure all bags and equipment are packed in the car

long commutes, having to stop for suctioning

high cost for parking

lack of accessible parking spots

Registration and Check-In

repeating information

appointment times too early for out of town patients

lack of accessible doors, washrooms

difficulty finding clinic location

Waiting Room

agitation from many stimuli

long wait

lack of accessible space

exposure to illness and infection

Multiple Care Provider Appointments

repeating the story again and again to multiple providers

unprepared students

waiting long for doctors or specialists to arrive

Tests/Re-Tests

long wait

anxious about results

issues with rescheduling appointments

confusion with requisitions

Travel Home

rush-hour traffic

feeling tired

For more info visit www.pcmch.on.ca/ccko

Provincial Council for Maternal and Child Health

@PCMCH_ON

› Healthc Policy. 2021 Aug;17(1):104-122. doi: 10.12927/hcpol.2021.26574.

Process Evaluation of a Hub-and-Spoke Model to Deliver Coordinated Care for Children with Medical Complexity across Ontario: Facilitators, Barriers and Lessons Learned

Jia Lu Lilian Lin [1], Samantha Quartarone [2], Nasra Aidarus [3], Carol Y Chan [4], Jackie Hubbert [5], Julia Orkin [6], Nora Fayed [7], Nathalie Major [8], Joanna Soscia [9], Audrey Lim [10], Simon D French [11], Myla E Moretti [12], Eyal Cohen [13]

Original Investigation

March 20, 2023

Effectiveness of Structured Care Coordination for Children With Medical Complexity

The Complex Care for Kids Ontario (CCKO) Randomized Clinical Trial

Eyal Cohen, MD, MSc[1,2,3,4,5,6]; Samantha Quartarone, MSc[1]; Julia Orkin, MD, MSc[1,3,4]; et al

» Author Affiliations | Article Information

JAMA Pediatr. 2023;177(5):461-471. doi:10.1001/jamapediatrics.2023.0115

Lesson 2: Start early and often

Story 2- “Peer Support is the answer”

Coached Coordinated Enhanced Neonatal Follow Up

Principle Investigators

Dr. Julia Orkin (SickKids)

Dr. Eyal Cohen (SickKids)

Dr. Nathalie Major (CHEO)

Dr. Paige Church (Sunnybrook)

Nurse Navigators

Pictured: Eleanor Warren (CHEO/The Ottawa Hospital) Annette Van Bergen (Mount Sinai Hospital) Amie Nowak (BCCW) Rosanna Manarin (Sunnybrook) Andre-Anne Matte (McGill) Kim Colapinto (SickKids) Not pictured: Melissa Zweiers, Lea Carle Herbert

Patient-Partner Lead

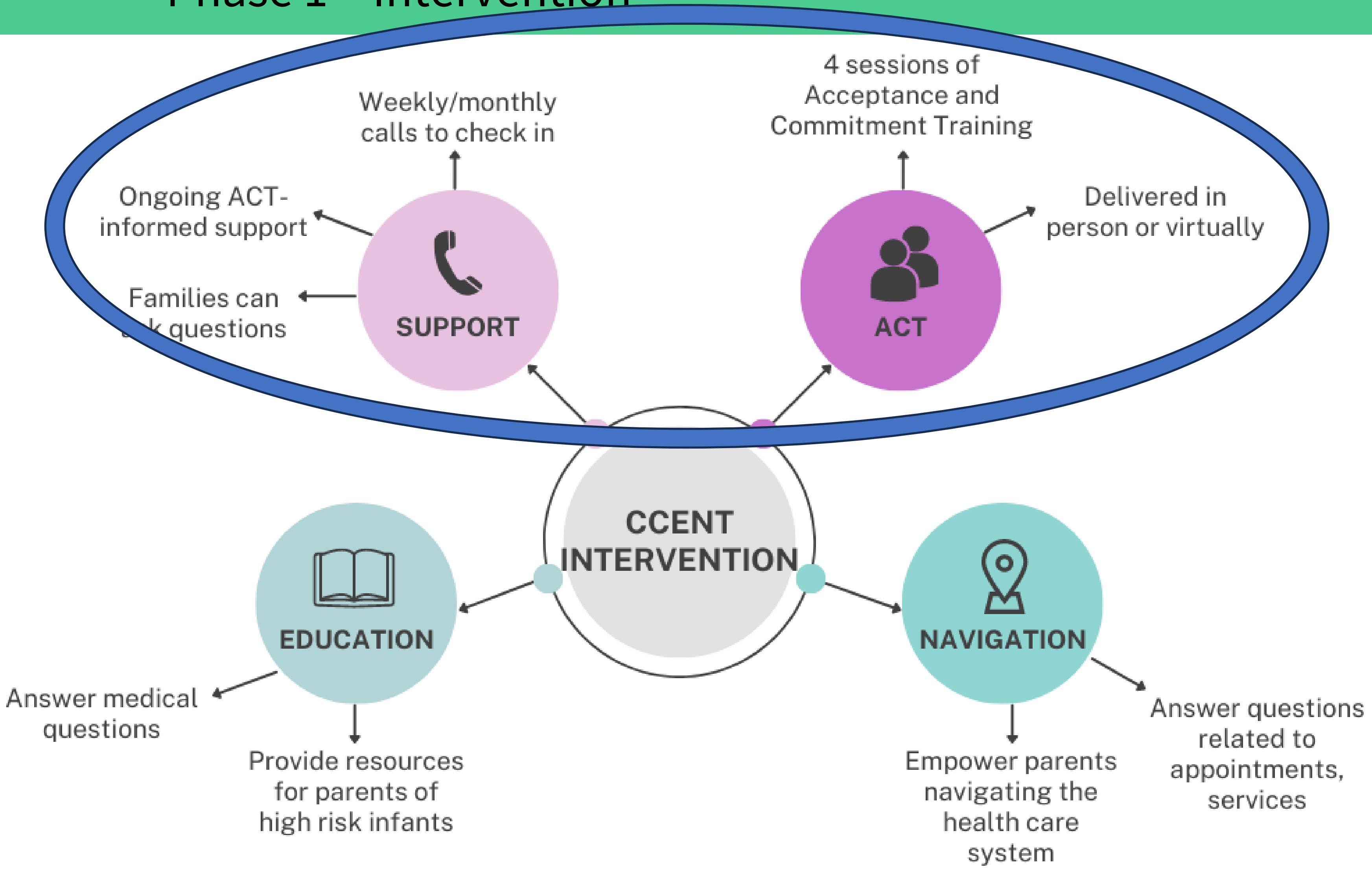
Kate Robson (Sunnybrook)

Phase 1 – Intervention

Delivered by Nurse Navigators (NN)

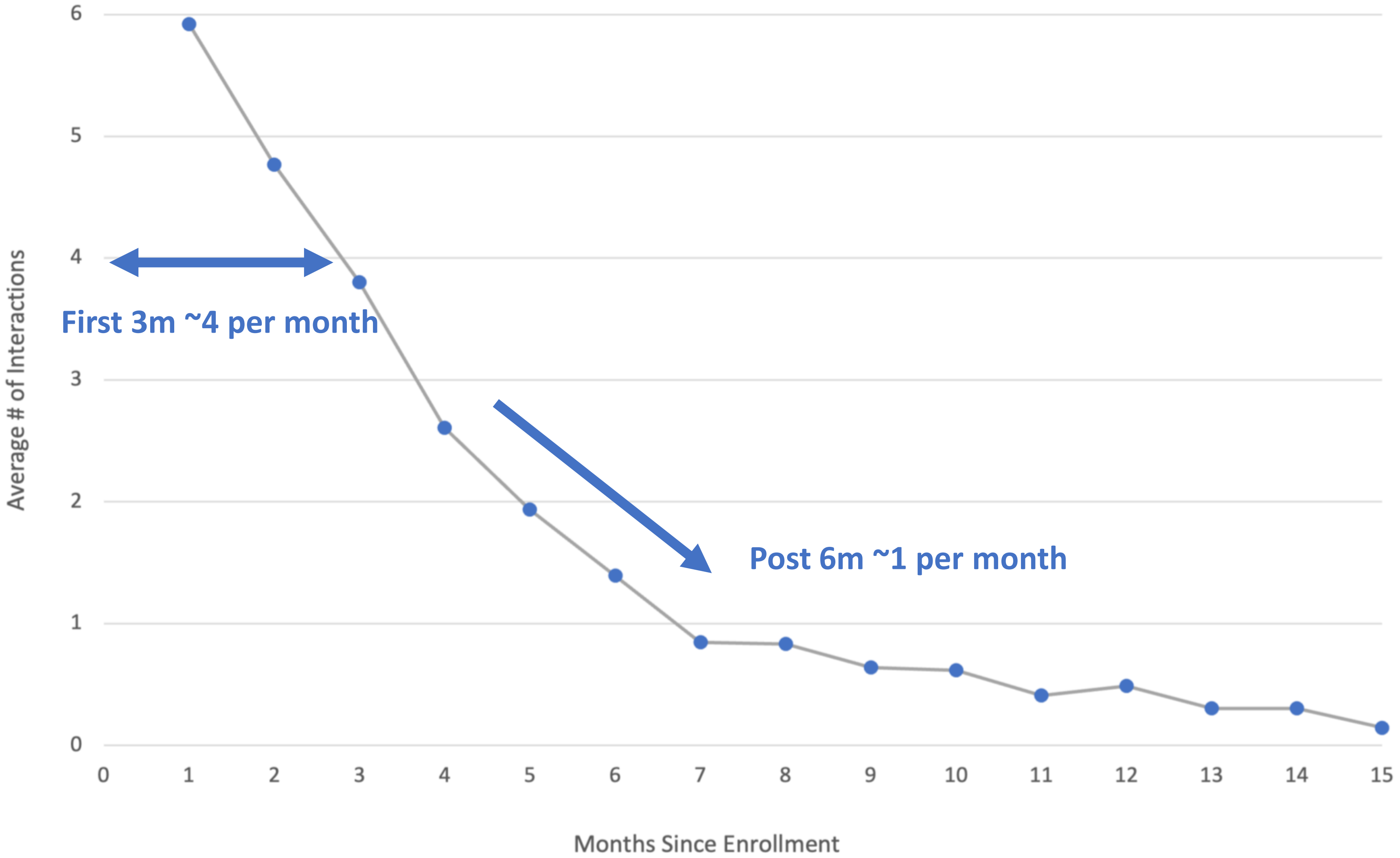
4

Pillars of the CCENT model



Phase 1 – Results

NN Interactions
Over Time

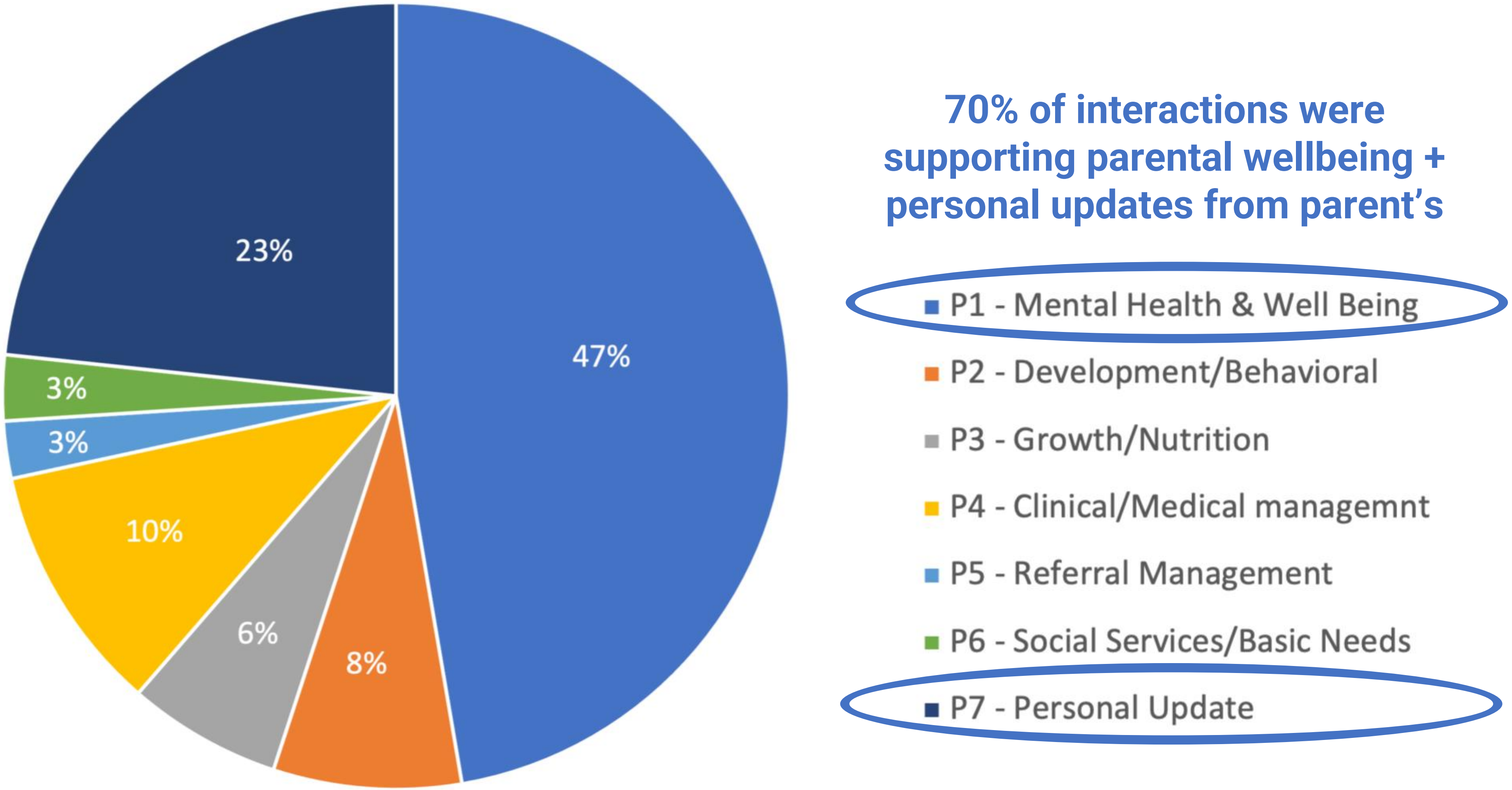


First 3m ~4 per month

Post 6m ~1 per month

Phase 1 – Results – Fidelity Outcomes

NN Interactions



70% of interactions were supporting parental wellbeing + personal updates from parent's

Phase 1 – Results – Quantitative

Primary Outcome: Compare parental stress between intervention and control groups at 12 months

- ***Measure:*** Parental Stress Index Fourth Edition Short Form

Null Result – no significant differences in PSI 12 months or any other time points

Baseline
6-weeks
4-months
12-months
18-months

Implementation Science Phase 2 - Process

Identify core components of the CCENT intervention

Identify barriers and facilitators to implementation

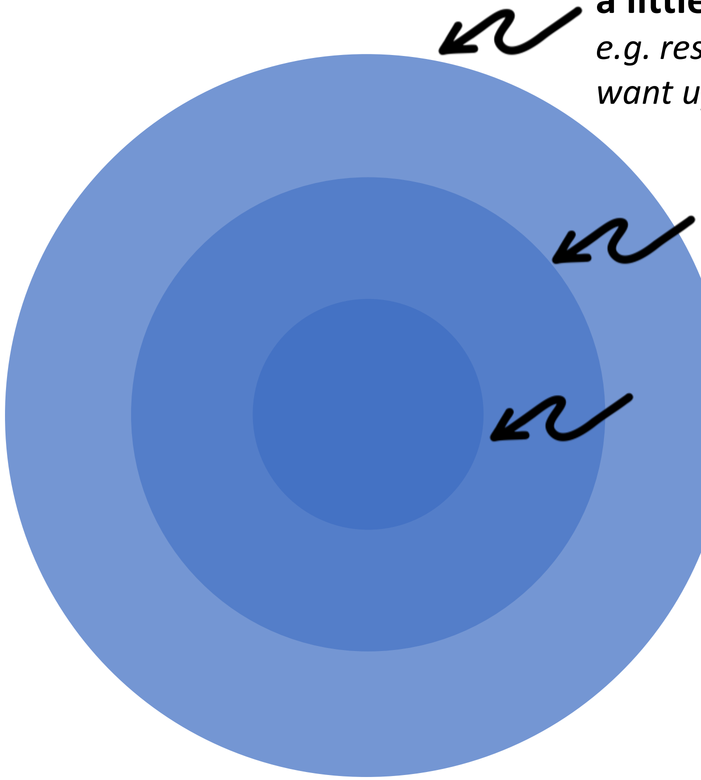
Map identified barriers and facilitators to implementation strategies

Co-design optimized intervention with key stakeholders (i.e., parent partners, implementation science experts)

Implement optimized navigator role

A two-pronged vision for the future of engagement at SickKids

An **enterprise-wide community** of patients and families who want to support the design of care, research and learning.



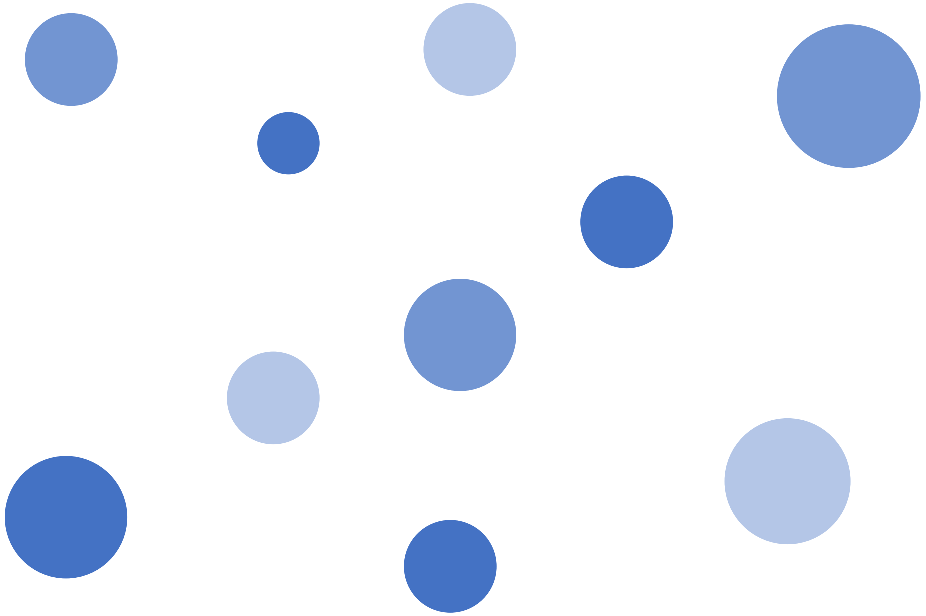
a little engaged
e.g. respond to surveys, want updates

more engaged
e.g. involved in a few local projects

very engaged
e.g. sit at BQSC, involved in large projects, etc.

A broader + more diverse community to recruit from
Will include patients & families from PFACs
We can keep them connected to each other + SickKids

A suite of services, tools and processes to **make engagement easy** for staff, **consistent** enterprise-wide and **value creating**



Provide consultations, tools and templates
Evaluate engagement to drive ongoing improvement
Easier onboarding + fair compensation policies

Thank you for listening.