



CHI Patient and Public Engagement in Health Research Lunchtime Learning Series

PATIENT ENGAGEMENT 101



ACKNOWLEDGEMENTS

Treaty 1 Land – home of the Anishinaabeg, Cree, Oji Cree, Dakota and Dene peoples and homeland of the Metis Nation

Agenda

- What is Patient-Oriented Research?
- What is Patient Engagement?
- Guiding Principles
- What Patient Engagement is Not
- Core Beliefs
- Why We Should Engage
- Levels of Engagement
- Funding announcement



Disclosures

- I am employed by the George and Fay Yee Centre for Healthcare Innovation as the Patient/Public Engagement Lead.





**GET
COMFORTABLE
* * * *
BEING
UNCOMFORTABLE**



SPOR Definition of Patient-Oriented Research

- Engages patients as partners;
- Focuses on patient-identified priorities;
- Improves patient outcomes;
- Is conducted by multidisciplinary teams in partnership with relevant stakeholders; AND
- Aims to apply the knowledge generated to improve healthcare systems and practices.



What is Patient Engagement in Health Research?



“the *meaningful* and *active* involvement of patients in the:

- **Governance** of research;
- **Priority-Setting** of research;
- **Conducting** of research; and
- **Knowledge Translation** of research”



— CIHR, SPOR definition

PATIENT ENGAGEMENT (PE)

INVOLVE defines public involvement in research as:

research that is carried out “with” or “by” members of the public rather than “to,” “about” or “for” them.



PATIENT ENGAGEMENT (PE)

People, informal caregivers and communities with lived experience of a health issue(s) having a say in decision-making about the research process.



Guiding Principles

- Inclusiveness
- Support
- Mutual respect and partnership
- Co-building
- Co-learning
- Reciprocal relationships
- Transparency, honesty and trust



Patient Engagement is NOT:

- People being recruited to a clinical trial or other research study to take part in the research;
- People completing a questionnaire or participating in a focus group as part of a research study;
- Science festivals open to the public with debates and discussion on research;



Patient Engagement is NOT:

- Open day at a research centre where members of the public are invited to find out about research;
- Raising awareness of research through media such as television programs, newspapers and social media; and
- Dissemination of research findings to participants, colleagues or members of the public

Core Belief



The involvement of patients in health research will lead to:

- Improved health outcomes and an enhanced health care system;
- Increase the quality, appropriateness, acceptability, transparency, and relevance of research
- Ensure that health research addresses issues of importance to people with lived experience of a health condition.

Excludes the Involvement of Certain Individuals



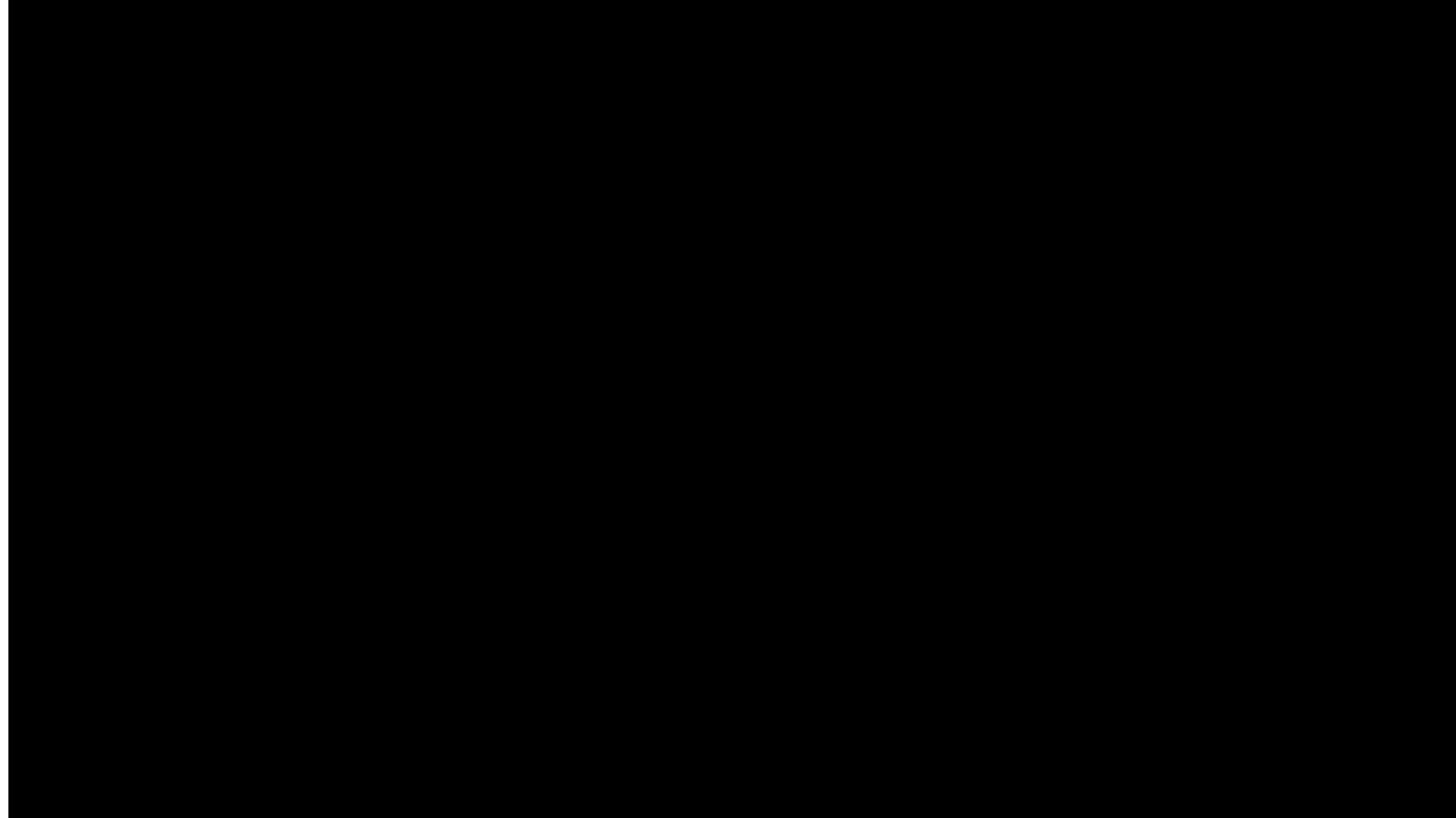
Who may not identify as “patients” because:

- Unable to access the healthcare system because of geography and/or systemic barriers
- Living with mental health or substance use issues where taking up the label of “patient” is associated with stigma
- Refuse to engage or prematurely exit because of unresponsive or disrespectful care
- Living with a dis/Ability and feel have been continually medicalized



WHY SHOULD I ENGAGE?

Importance of PE in Health Research



Why should I engage?



To help identify **research priorities** that matter most to people living with the health condition being researched

Why should I engage?



To help shape and clarify **research questions** so they reflect the needs and concerns of patients and informal caregivers

Why should I engage?



To help ensure the **methods** proposed for the study are appropriate, acceptable and sensitive to the very real context in which patients and informal caregivers live, work and play

Why should I engage?

To help ensure research uses **outcomes** that have true meaning to the lives of patients, informal caregivers and communities



Why should I engage?



To help ensure that the **language and content** of the information provided to participants in studies is appropriate and accessible (e.g. questionnaires and patient/participant leaflets)

Why should I engage?



To help **increase participation** in a research study by: making sure the research is appropriate and acceptable to potential participants; improving the information provided so people can make informed choices; and helping to include voices that are traditionally less heard in research

Why should I engage?



To help co-develop ways to share your research findings with other patients, caregivers, families and communities.

Why should I engage?



To identify a wider set of research topics or **new areas of research**

Why should I engage?



To interpret **research findings** from the perspective of people with lived experience and informing recommendations that will help improve the lives of patients and caregivers

Why should I engage?

To help ensure research reflects the concerns, interests and values of the public and that **money and resources are used efficiently**



LEVELS OF ENGAGEMENT

Levels of patient and public involvement



1. Consultation – obtain **feedback or input** from patients about different decisions in the research process
2. Involvement – **working directly** with patients and/or members of the public throughout the research process – especially at the planning stage
3. Collaboration – **actively partnering** with patients and/or members of the public in every aspect of the research process (shared decision-making)
4. Patient & public-directed – this is when patients and/or members of the public actively **control, direct and manage** the research process.

Consultation Level

- Considered the lowest level of engagement
- Obtain feedback and input on research decisions
- Researchers still maintain decision-making power
- Examples of participatory approaches: Advisory Groups, focus groups, interviews, public and town hall meetings, comment forms and surveys, etc.



Collaborate Level

- Actively partnering together
- Shared decision-making
- Examples of participatory approaches: Patient/Public Partners sitting on research team having equal say in research decisions; PhotoVoice; World Cafés; Digital Storytelling; Two-Eyed Seeing; Participatory decision-making and design



Patient/Public-Directed

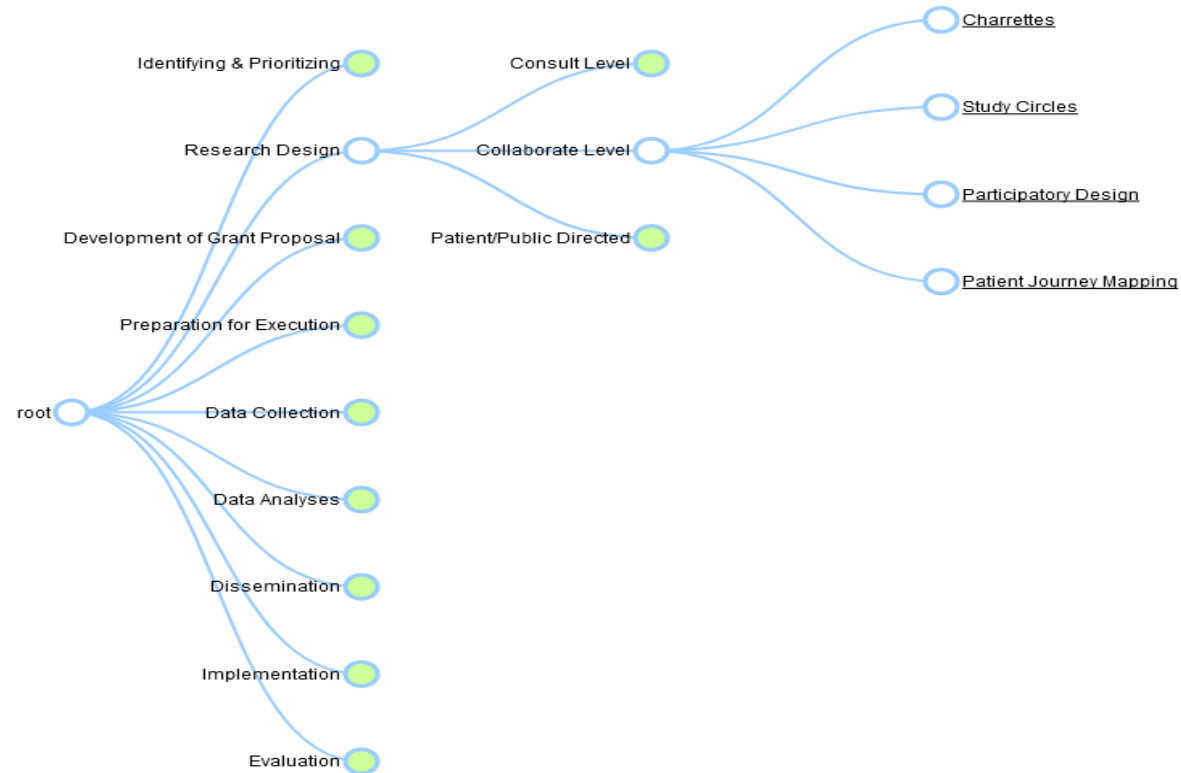
- Patients/public/community actively **control, direct and manage the research project**
- All decision-making with regard to the research process is made by patients/public/communities
- Researchers role might be to provide support, advice, training, or carry out research under the patient/public/community's direction
- Approaches include: participatory decision-making and design



CHI Online PE Mapping Tool



THE INTERACTIVE MAP TOOL



Assessing Expectations and Willingness to Engage



Internal

- To what extent does the research team **believe** that engagement will improve the outcome of the research?
- What is the **potential** for patients to influence decision-making within the research process?
- What is the likelihood the research will **fully consider** patient input?
- What **resources** are likely to be available to support PE?

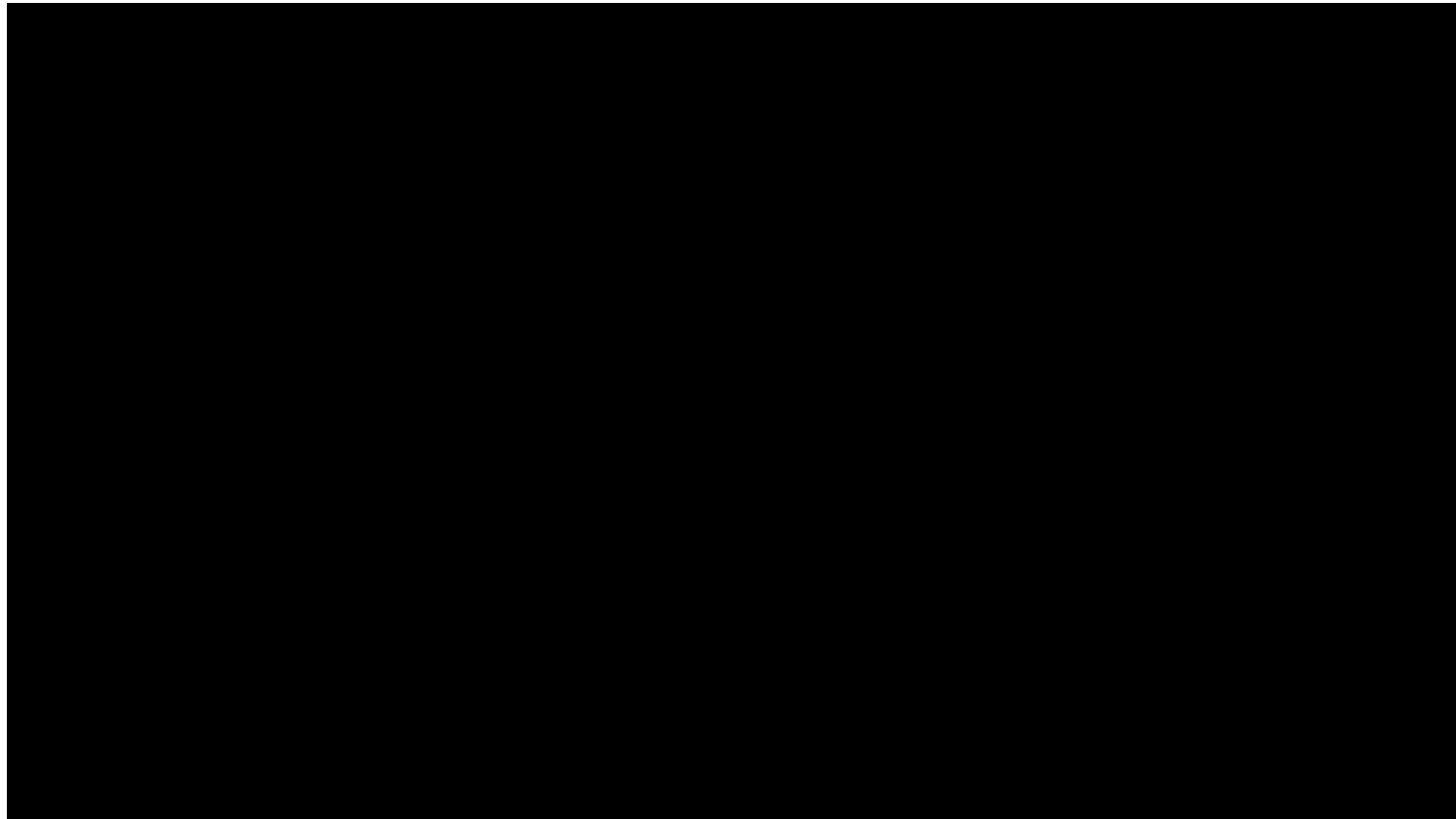
Assessing Expectations and Willingness to Engage



External

- Previous **history** of engagement
- What **inequities** exist in relation to the health issue being researched? Who is affected differently? Who has different access to services?
- What are the **values and expectations**?
- What **level** do people expect to be engaged?
- How would people **prefer** to be engaged?

Aspirations for Patient and Public Engagement



Funding Award Announcement



**SEEKING GRANT
SUBMISSIONS**


GEORGE & FAY YEE
Centre for Healthcare Innovation

PATIENT & PUBLIC ENGAGEMENT

Funding Award for Patient & Public Engagement in
the Research Design and Grant Development Phase

Application Deadline

Oct 12, 2018
5 pm CST

For more info visit

CHimb.ca



chimb.ca

Questions?





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Knowledge Translation platform

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