Recovery Alberta

MENTAL HEALTH AND ADDICTION SERVICES

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Knowledge Bites Lunch ‘n’ Learn
May 29, 2025

Community Advisory Committee Engagement in "Re. CBT Dialysis"

(A realist evaluation: Why, for whom, in what circumstances does CBT work for people with depressive symptoms receiving dialysis?)

Kara Schick-Makaroff,
Professor and Associate Dean Graduate Studies

Lori Suet Hang Lo,
PhD student, U of A

Alexandra Albers,
NP student
Faculty of Nursing,
U of A

Community Advisory Committee Members:
Loretta Lee, Justin LeRoux, Kevin Kemp, Monika Bolin, Jeff Costley, Sabiha Zaman

May 2025

Recovery Alberta
MENTAL HEALTH AND ADDICTION SERVICES

COMMUNITY ADVISORY COMMITTEE ENGAGEMENT IN "RE. CBT DIALYSIS"

(A REALIST EVALUATION: WHY, FOR WHOM, IN WHAT CIRCUMSTANCES DOES CBT WORK FOR PEOPLE WITH DEPRESSIVE SYMPTOMS RECEIVING DIALYSIS?)

Community Advisory Committee Members:
Loretta Lee, Justin LeRoux, Kevin Kemp, Monika Bolin, Jeff Costley, Sabiha Zaman

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Lori Suet Hang Lo, PhD student
Alexandra Albers, NP student
Faculty of Nursing, U of A

UNIVERSITY OF ALBERTA

May 29 2025
Recovery Alberta
Knowledge Bites

Acknowledgements

The University of Alberta, its buildings, labs and research stations are primarily located on the territory of the Néhiyaw (Cree), Niitsitapi (Blackfoot), Métis, Nakoda (Stoney), Dene, Haudenosaunee (Iroquois) and Anishinaabe (Ojibway/Saulteaux), lands that are now known as part of
Treaties 6, 7 and 8 and homeland of the Métis.
The University of Alberta respects the sovereignty, lands, histories, languages, knowledge systems and cultures of all First Nations, Métis and Inuit nations.

https://albertashistoricplaces.com/2018/08/08/beading-the-way-adornment-and-the-quest-for-cultural-survival/

Conflict of interest

The collaborative research we present today was funded by these sources,
for which we are very thankful.

Learning objectives

Explore patient engagement strategies

Engage patients as partners in research

Illustrate community partnered research

Introductions

Community Advisory Committee Members

Context: Program of research

The goal of our program of research is to
enhance knowledge about use of quality-of-life assessment and
promote equitable person-centred care,
to improve services
for people living at home with chronic and life-limiting illnesses,
particularly kidney failure.

Context: Program of research

Our goal is to have
clinicians, administrators, and programs
look at the information that patients provide
and *act* on that information
with patients.

Context of lessons learned

- ePRO Kidney
  - CIHR, $587,000
- PRO use in Kidney Disease: Realist Synthesis
  - KFOC, $100,000
- Mental Health and Kidney Health
  - AHS SCN, $61,000
- Tailoring a Pathway for Mental Health Care for Albertans on Dialysis
  - KFOC, $100,000 → Moving to implementation in Can SOLVE CKD 2.0
- Novel methods for Equitable People-centred Health Measurement
  - NPA: Dr. R. Sawatzky, CIHR, $1.1M
- CBT Dialysis
  - Alberta Innovates, $1.1M

An unaddressed gap: Globally

https://www.nationsonline.org/oneworld/map/world_map.htm

An unaddressed gap: Alberta

<u>Demographics (N = 312)</u>

34.9% Female

Mean years: 62.5 (13.86 SD)

75.1% urban address

33% Albertans receiving dialysis reported moderate to severe depressive symptoms (PHQ-9 score ≥ 10)

Alberta Health Services
Medicine Strategic Clinical Network™

Schick-Makaroff, K., Berendonk, C., Overwater, J., Streith, L., Lee, L., Escoto, M., Cukor, D., Klarenbach, S., & Sawatzky, R. (2022). How are Albertans "adjusting to and coping with" dialysis? A cross-sectional survey. *Canadian Journal of Kidney Health and Disease, 9*,1-14. https://pubmed.ncbi.nlm.nih.gov/36046483/

What might help?

Natale P, Palmer SC, Ruospo M, Saglimbene VM, Rabindranath KS, Strippoli GFM. Psychosocial interventions for preventing and treating depression in dialysis patients. *Cochrane Database of Systematic Reviews*. 2019(12).

“Re: CBT-dialysis”

“A realist evaluation: Why, for whom, in what circumstances does CBT work for people with depressive symptoms receiving dialysis?”

The aim of this realist study is to evaluate and explain how, why, for whom, and in what circumstances therapist-guided and remotely delivered CBT works in order to provide equitable mental healthcare to individuals with depressive symptoms receiving dialysis.

UNIVERSITY OF ALBERTA

TRINITY WESTERN UNIVERSITY

UNIVERSITY OF LEEDS

THE UNIVERSITY OF BRITISH COLUMBIA

ALBERTA INNOVATES

Research questions

1. How is CBT intended to work?
2. What are the different types of depressive symptom trajectories, as well as related patient-reported outcomes, and capacities to engage with CBT including social determinants of health (SDOH), healthcare interventions, and health-related variables for people receiving dialysis?
3. How does CBT work to improve depressive symptoms for people receiving dialysis?
4. Why, for whom, and in what circumstances does CBT work for people receiving dialysis with depressive symptoms?

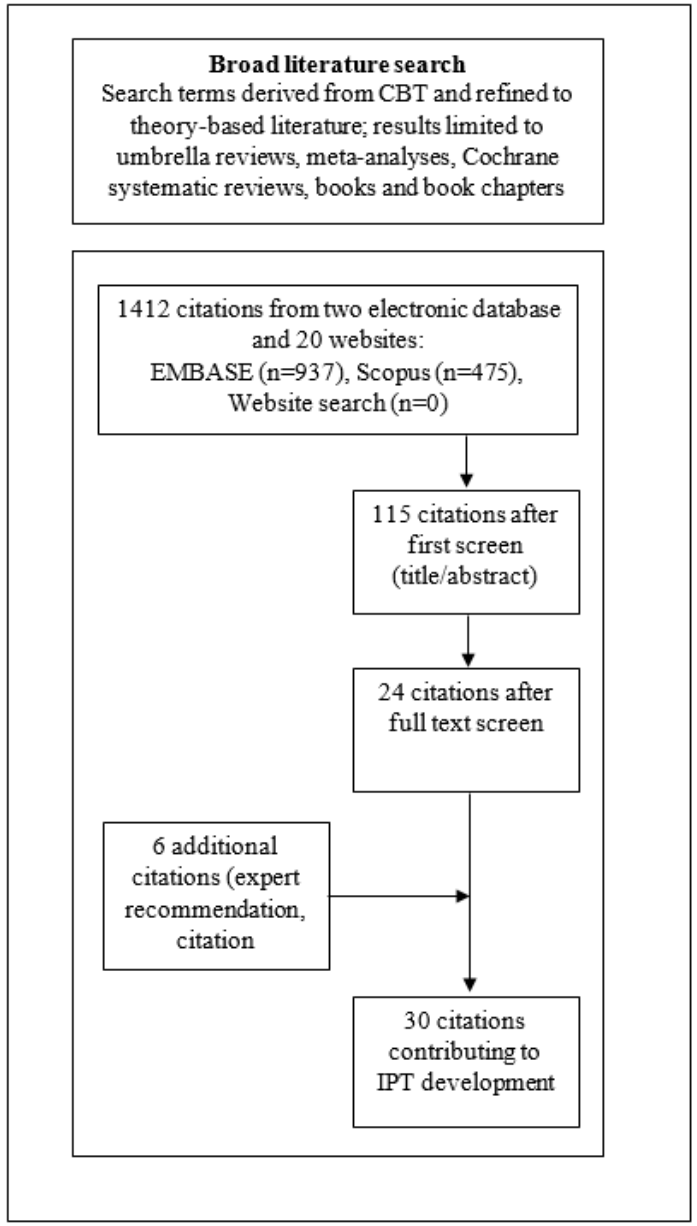
Schick-Makaroff, K., Sawatzky, R., Greenhalgh, J., Cukor, D., Wong, H., Klarenbach, S., Berendonk, C., Micklitz, K., Lo, S. H. L., & Kennedy, M. (2025 – in press). Protocol for “Re: CBT Dialysis” - A realist evaluation: Why, for whom, and in what circumstances does cognitive behavior therapy work for people with depressive symptoms receiving dialysis? *BMJ Open.*

DEVELOP Initial Programme Theory (IPT)

Realist synthesis step 1:

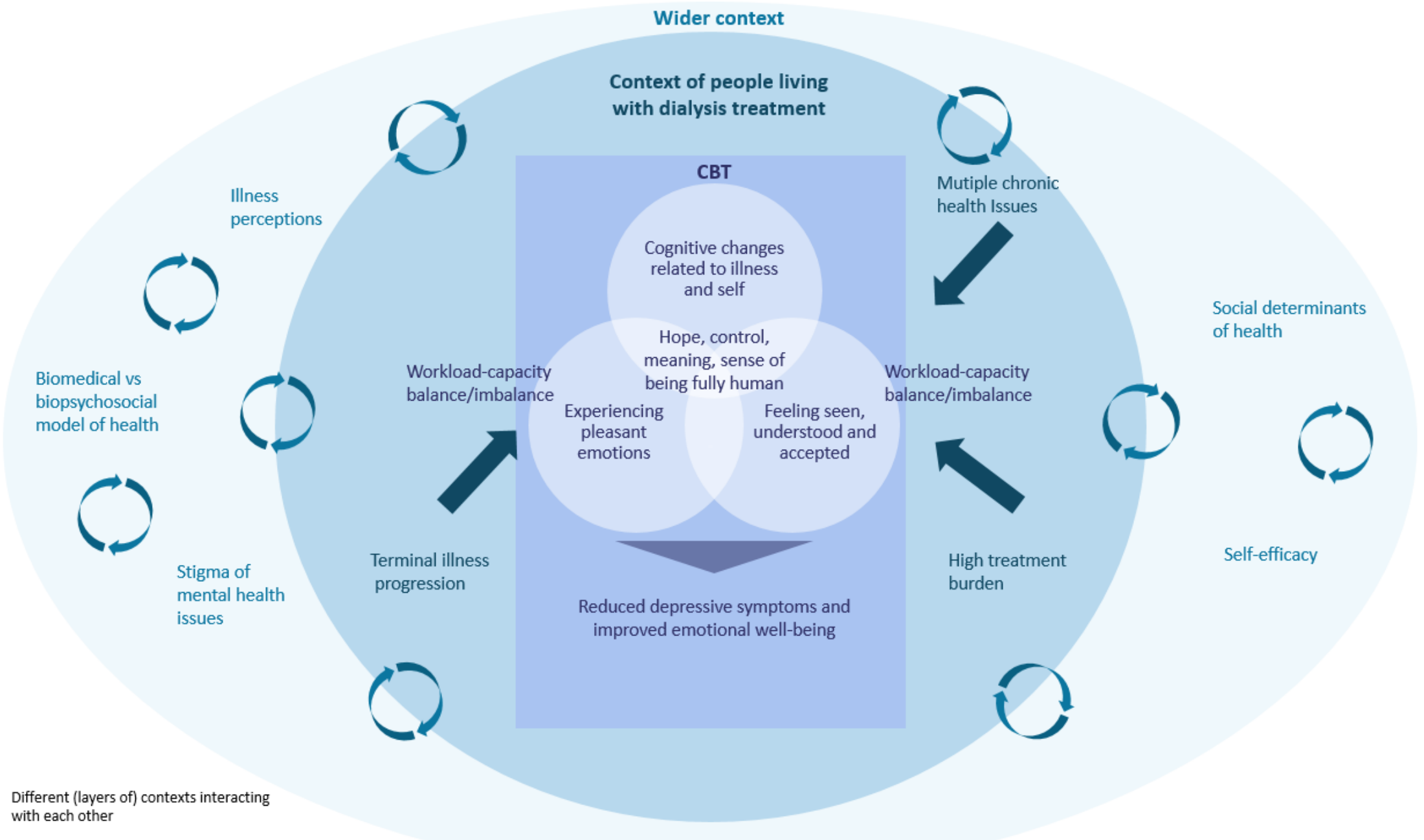
- Scoping search to locate existing theories on CBT
- Interview CBT therapists (n=7) to develop candidate theories of how people on dialysis may benefit from CBT

Flow Diagram



Micklitz, K., Greenhalgh, J., Lo, S. H. L., Sawatzky, R., & Schick-Makaroff, K. (2025 – under review). How are people undergoing dialysis expected to benefit from cognitive behavioral therapy? A realist analysis

Initial Programme Theory



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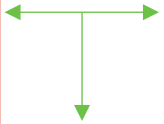

Quantitative cohort study:

- Tracking depressive symptoms trajectories (n=254)
- Secondary data analysis (longitudinal n=543 and survey n=312)
- Develop participant profiles to inform IPT

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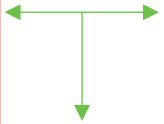

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TEST & REFINE Programme Theory: *Why, how, for whom, in what circumstances does CBT work?*

Realist evaluation:

- Deliver CBT to people on dialysis (n=100)
- Track symptom trajectories
- Interview participants (n=30) to explain outcomes and test/refine IPT
- Interview therapists (n=8) to test/refine IPT

DEVELOP Initial Programme Theory (IPT)

Realist synthesis step 1:
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Realist synthesis steps 2-5:
- Systematic search on CBT for depressive symptoms in dialysis
- Article selection (relevance, rigor)
- Analyzing data in NVivo
- Synthesizing the evidence to test/refine IPT
- Additional search for evidence if needed

Patient Engagement Grant (2024)

- Came together on July 12, 2024
- We organized various activities and group discussions to discuss:
  - preliminary data analysis
  - recruitment strategies
  - CBT intervention

Learning objectives

Explore patient engagement strategies

Engage patients as partners in research

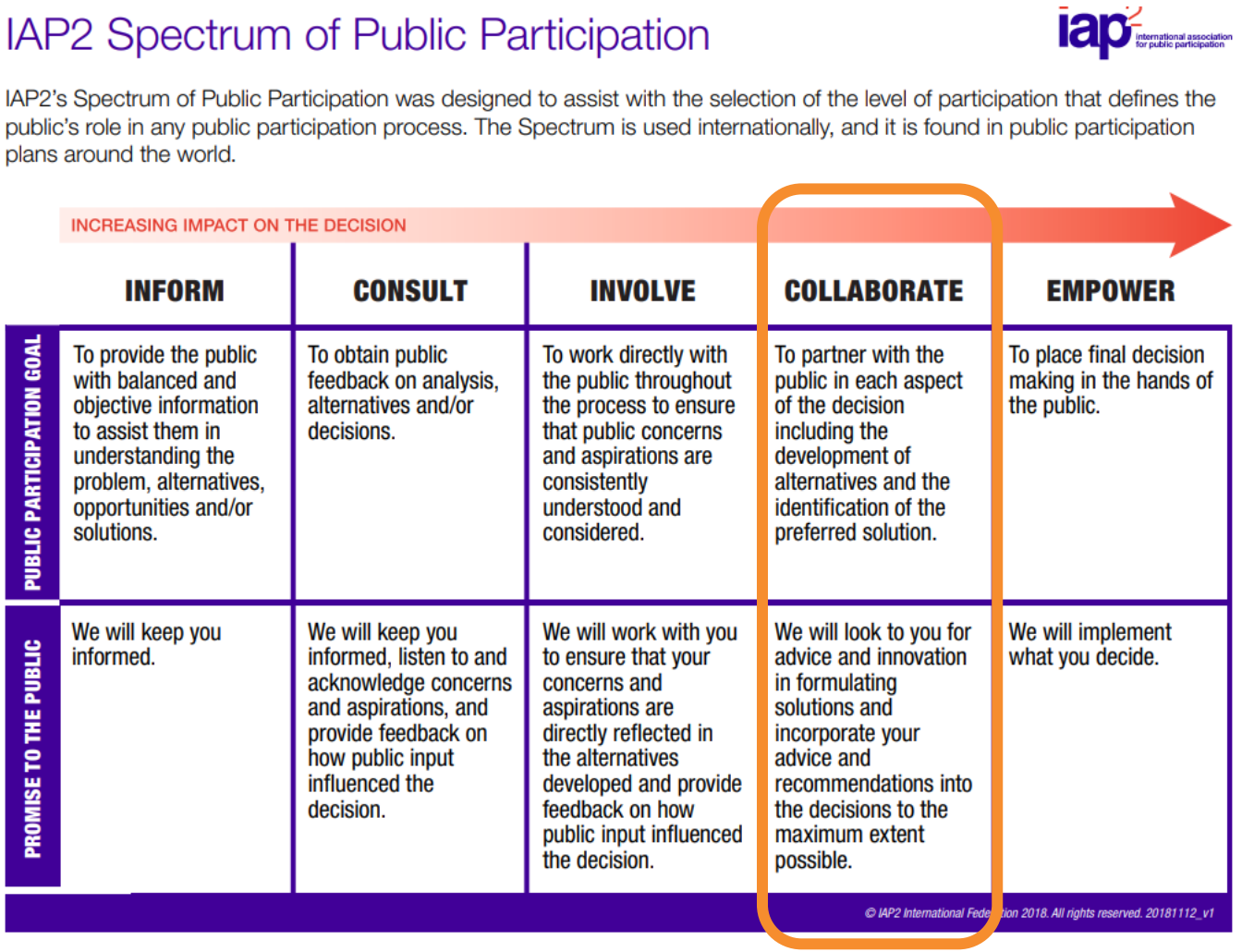
Illustrate community partnered research

How do you contribute to our Community Advisory Committee?

Community Advisory Committee Members

Patient engagement strategies

- My first Patient Advisory was during my PhD (2007-2011):
  - https://onlineacademiccommunity.uvic.ca/illnessnarratives/
    - Created booklets, videos, curated art exhibit, co-presented at conferences
  - Informed by IAP^2: International Association for Public Participation
    - Founded in 1990
  - IAP^2 Spectrum: “Collaborate”



IAP2 Spectrum of Public Participation

iap international association for public participation

IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

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.

Patient engagement strategies

#1 Strategy: Patient / Committee Advisory Committee

- Informed by:
  - IAP^2 Spectrum of Public Participation
  - CIHR, Strategy for Patient-Oriented Research: Patient engagement framework
  - AB SPOR Support Unit, Patient Engagement Platform
  - Integrated knowledge translation

- Co-create terms of reference (annually review and revise)

Santana M, Ahmed S, Fairie P, *et al.* Co-developing patient and family engagement indicators for health system improvement with healthcare system stakeholders: a consensus study. *BMJ Open 2023; 13:e067609*
https://bmjopen.bmj.com/content/13/2/e067609

Christmas 2022 – Community Advisory Committee zoom call

Patient engagement strategies

Community Advisory Committee:

- Have 1 or 2 Co-Chairs
  - Co-develop agendas (circulated in advance) and co-lead Advisory meetings (1 / mo.)
  - Circulate meeting notes / documents
  - Ice-breaker to start each meeting
  - Record zoom messages to team members who are ill etc.
  - Meetings are 1 hour
  - Held at 7pm because it is the best time for Patient Partners
  - We change the evenings (every 4 mo.) based on what is best for Patient Partners (I.E. Spanish lessons :)
  - Less updates; more questions
  - Invite those who have not spoken if they want to share / add (if they so choose)

Christmas 2022 – Community Advisory Committee zoom call

Patient engagement strategies

Community Advisory Committee:

- Training with AB SPOR
  - Co-developed initial terms of reference
  - Do we use the term “patient”?
- Involve from proposal inception onward
- Transparency about honorarium
  - Write into grant budget
- Co-present at research team meetings, conferences etc.
- Trainees required to attend / present
- Create trusting relationships

Maurer et al. (2022). Examining how study teams manage different viewpoints and priorities in patient-centred outcomes research: Results of an embedded multiple case study. *Health Expectations, 26,* 1606-1617. doi: 10.1111/hex.13765

Learning objectives

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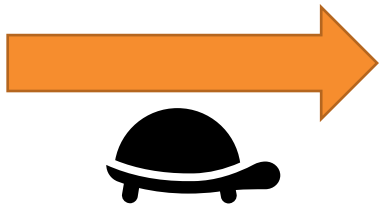
How have you seen our research shift because of input by the Community Advisory Committee?

Community Advisory Committee Members

Patients as partners in research

Examples of community members' engagement in our partnered work

- Pilot-test: interview guides, online surveys, modified Delphi survey
- Review all patient-facing documents
  - Surveys
  - Consent forms
  - Whiteboards
  - Recruitment:
    - Invitation letters
    - Facebook posts
    - Posters
- Syntheses: Feedback on
  - Search strategies
  - An "Initial Programme Theory"
  - Full draft of a "Programme Theory"
- Review lay abstracts
- Co-author publications
- Co-develop person-centred care principles guiding research



This work all moves very slowly….

What about patient-oriented research that is in Pillar 1?

"Patients' experiential knowledge, when translated into explicit demands, ideas, or judgements, can contribute to the relevance and quality of biomedical research." (Caron-Flinterman et al., 2005, p. 2575)

New model of translational research (Callard et al., 2012): Involve service users and other groups in an 'interlocking loop' (p. 398)

A systematic review found 7 studies that included patients at the broader level of biomedical research: Steering / advisory committees, shared decision making across the research life cycle (Ludwig et al., 2020)

1 BIOMEDICAL RESEARCH
Understanding how the body works to better prevent, diagnose, and treat disease.

2 CLINICAL RESEARCH
Exploring how to improve patient care and overall quality of life.

3 HEALTH SERVICES RESEARCH
Finding ways to strengthen the effectiveness and efficiency of our health care system.

4 SOCIAL, CULTURAL, ENVIRONMENTAL AND POPULATION HEALTH RESEARCH
Understanding how social, cultural and environmental factors affect our health.

Canada

https://cihr-irsc.gc.ca/e/53223.html

Callard, F., Rose, D. and Wykes, T. (2012), Close to the bench as well as at the bedside: Involving service users in all phases of translational research. Health Expect, 15: 389-400. https://doi.org/10.1111/j.1369-7625.2011.00681.x

Caron-Flinterman JF, Broerse JE, Bunders JF. (2005). The experiential knowledge of patients: a new resource for biomedical research? *Soc Sci Med, 60*(11):2575-84. https://doi.org/10.1016/j.socscimed.2004.11.023

Ludwig, C., Graham, I.D., Gifford, W. *et al.* (2020). Partnering with frail or seriously ill patients in research: a systematic review. *Res* Involv Engagem 6, 52. https://doi.org/10.1186/s40900-020-00225-2

‘Interlocking loop of translational research”

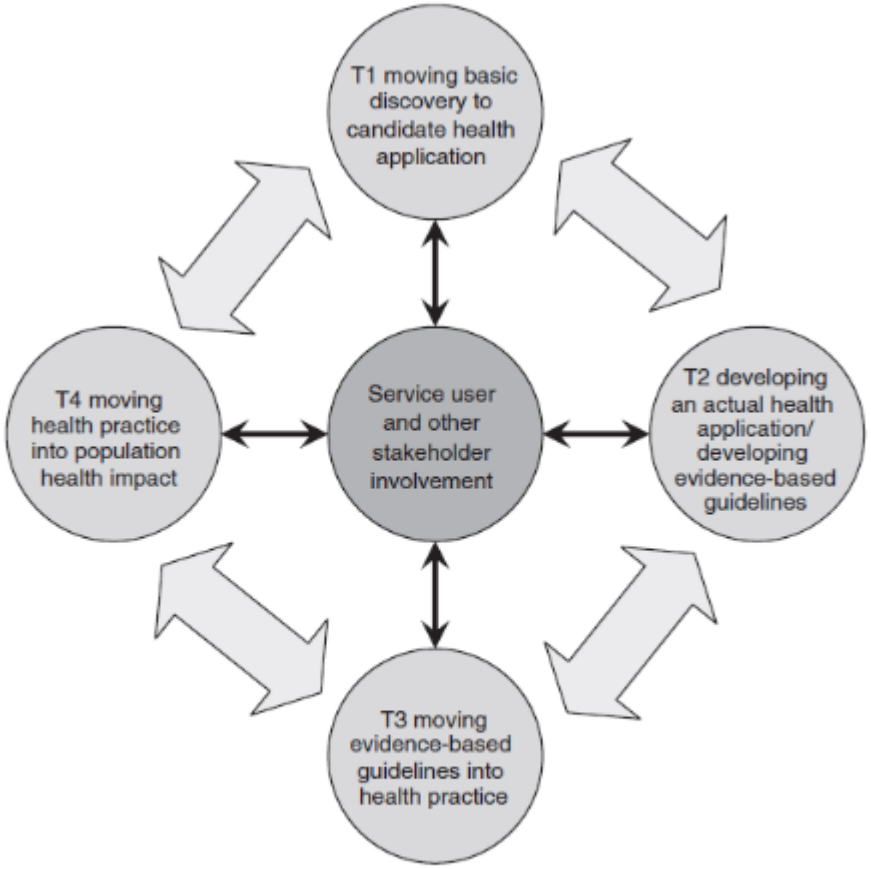


Figure 1 Continued. (c) Reconceptualized model of translational research that embeds service user and stakeholder involvement in all phases.

Callard, F., Rose, D. and Wykes, T. (2012), Close to the bench as well as at the bedside: Involving service users in all phases of translational research. *Health Expect, 15*: 389-400. https://doi.org/10.1111/j.1369-7625.2011.00681.x

Learning objectives

Explore patient engagement strategies

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How have you benefited from, or been impacted by, being a member of our Community Advisory Committee?

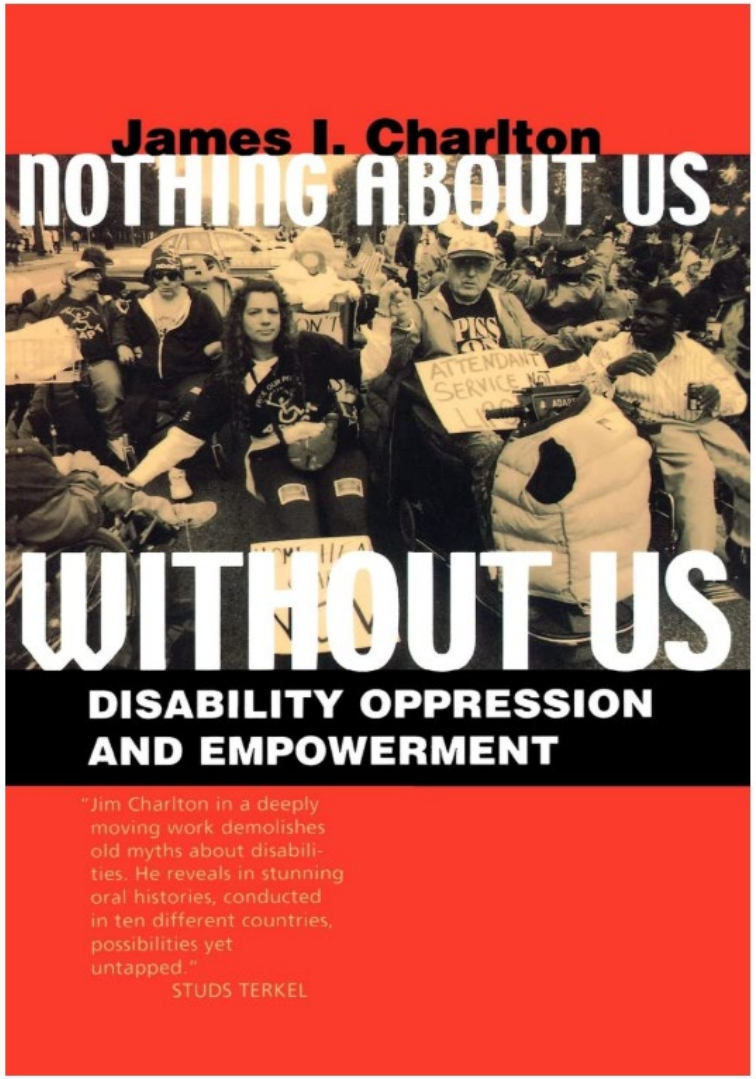
Community Advisory Committee Members

Lessons learned

1. Ensure initiatives align with the priorities of those most impacted: people receiving care
2. Strength comes from developing trusting relationships
3. Innovation arises from diversity of perspective

https://pxhere.com/en/photo/1358013

Implications for practice



THANK YOU & QUESTIONS

Kara Schick-Makaroff
kara.schickmakaroff@ualberta.ca

Lori Suet Hang Lo
suethang@ualberta.ca

Alexandra Albers
birchall@ualberta.ca

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