



# Co-creating research

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# Land Acknowledgement

- We acknowledge this land on which we operate at the Knowledge Translation Program, where this work was done.
- For thousands of years, it has been the traditional land of the Huron-Wendat, the Anishinaabe, Chippewa, Haudenosaunee, and most recently the Mississaugas of the Credit River.
- We acknowledge that Toronto is covered by Treaty 13 with the Mississaugas of the Credit and The Dish with One Spoon treaty between the Anishinaabe, Mississaugas and Haudenosaunee
- As a white settler, I acknowledge my commitment to continuing to work with and listen to First Nations, Inuit and Métis communities in the spirit of reconciliation and partnership and to be an ally and learner on the path towards Reconciliation.



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# Competing interests

- No Pharma funding
- Receive CIHR funding for the SPOR Evidence Alliance



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**Thank you, Linda Wilhelm, Canadian Arthritis Patient Alliance**



# Objectives

By the end of the session, participants will:

- Have increased knowledge of co-creation of research
- Have increased knowledge of strategies for engaging older adults and caregivers in research
- Be able to identify challenges and opportunities for co-creating research with patients, caregivers and other stakeholders



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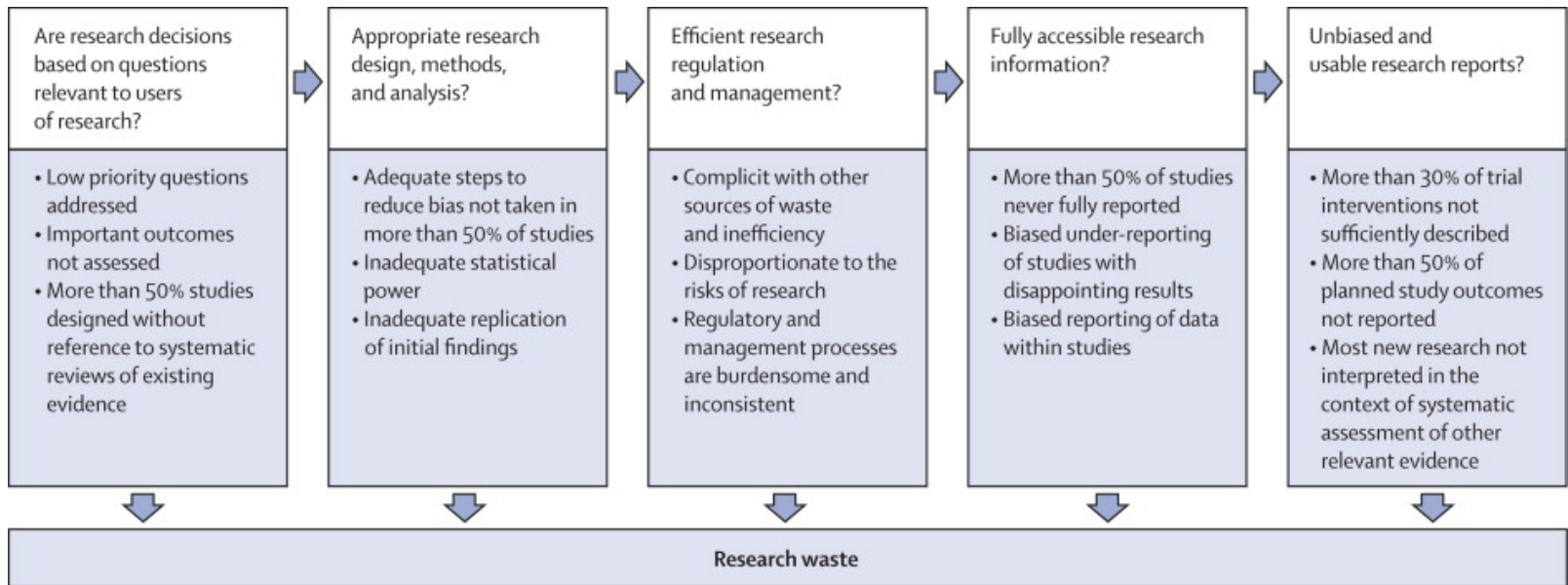


Figure. Avoidable waste or inefficiency in biomedical research

**85% of research funding is wasted - \$250B/year**

Lancet 2014;383;101-4



# Why is patient oriented research (POR) important?

- 50% of patients do not get treatments of proven effectiveness
- Up to 25% get care that is not needed or potentially harmful
- This care is expensive.
  - In 2021, Canada is expected to spend approximately \$308 billion on health care, or \$8019 per person.
- Patients and clinicians have a right to expect that important health decisions are made on the basis of solid evidence

CFHI (2011) Canada's Strategy for Patient-Oriented Research:

Improving health outcomes through evidence-informed care

August . Retrieved at: <http://www.cihr-irsc.gc.ca/e/44000.html>; SPOR Overview, retrieved at:

<http://www.cihr-irsc.gc.ca/e/47473.html>



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- ‘Engaging patients as partners in research builds trust in the research process from the perspective of the patient. It is empowering and promotes a culture of shared decision making’

- Linda Wilhelm, CAPA





# Strategy for Patient Oriented Research (SPOR)

- National 10-year strategy introduced in 2011 to improve healthcare systems and practices
  - Aimed at improving length of time for the uptake of research into health systems practice
  - Involves ensuring the right patient receives the right clinical intervention at the right time
  
- The SPOR strategy includes five core elements:
  1. Support units
  2. Networks
  3. Capacity development
  4. Patient engagement
  5. Clinical trials



Abelson, Julia. (2015) Patient Engagement and Canada's SPOR initiative: A resource Guide for Research Teams and Networks.

# What is POR?

- Research carried out **with/by patients** rather than research **to/for/about patients**
- Focuses on patient priorities and improves patient outcomes individually and in communities.

Andrews et al. (2015) More than just a ticking box ... how patient and public involvement in research design and funding application for a project to evaluate a cycling intervention for hip osteoarthritis. *Research Involvement & Engagement*; SPOR Capacity Development Framework, (2015); CIHR, <http://www.cihr-irsc.gc.ca/e/44000.html>



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# What is patient engagement in research?

INCREASING IMPACT ON THE DECISION 

	<b>INFORM</b>	<b>CONSULT</b>	<b>INVOLVE</b>	<b>COLLABORATE</b>	<b>EMPOWER</b>
<b>PUBLIC PARTICIPATION GOAL</b>	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.
<b>PROMISE TO THE PUBLIC</b>	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.



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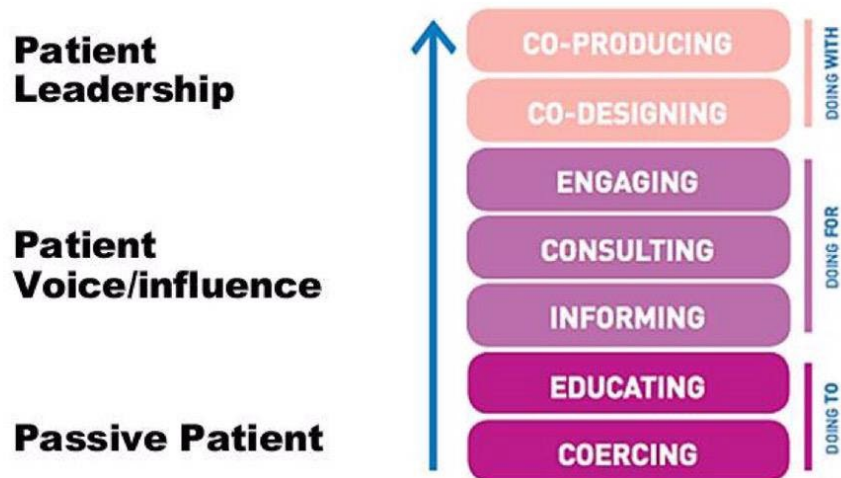
Adapted from the International  
Association of Public Participation  
(IAP2)



# What is patient engagement in research?

## Patients Views on Engagement:

### Where are we on the ladder?



Source: new economics foundation

1. Patients who seek to shape the practice of patient engagement by providing consulting to researchers and health institutions and organizations.
2. Patients with pre-existing professional-level research experience who volunteer their skills
3. Patients who volunteer to provide their perspectives and feedback

Johannesen (2018) Patient views on "ladders of engagement. Ontario SPOR Support Unit



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## There are lots of knowledge users in health research

Stakeholders	Description
Patients	Individuals with personal experience of a health issue and informal caregivers, including family and friends.
Policymakers and regulators	Individuals and organizations that create and monitor healthcare policies and regulations
Researchers	Individuals and their related organizations that generate research evidence
Research funders	Entities that provide monetary support for research efforts
Clinicians	Health care professionals that work as a primary care giver of a patient in a hospital, skilled nursing facility, clinic, or patient's home.
Health care managers	Individuals who oversee admissions, staffing and upkeep of medical centers, making sure that patients receive the necessary services.

# What does co-creation with knowledge users look like?

Collaborate to identify issues to be investigated

Help prioritize the health issues

Assist in framing the research questions

Be involved in designing the study and plan

Help collect data

Assist in interpreting findings

Collaborate to develop tools and publications

Disseminate and help implement knowledge



# Why is patient engagement in research important from an ethics perspective?

- ‘Meaningful patient engagement:
  - grounds research in a deep understanding of the health situations and the living or lived experiences of actual patients, including groups that are typically under-represented in research, to make research more relevant and usable by those patients;
  - promotes research methods that are culturally safe, respectful, and appropriate;
  - legitimizes research in the eyes of the community that the research is intended to benefit;
  - strengthens capacity of patients to shape research that matters to them;
  - builds relationships among patients and others involved in research that are mutually respectful;
  - creates an ethical space for respectful dialogue and discussion where each person can speak in their own voice.’
    - Ethics guidance for developing relationships with patients and researchers <https://cihr-irsc.gc.ca/e/51910.html>



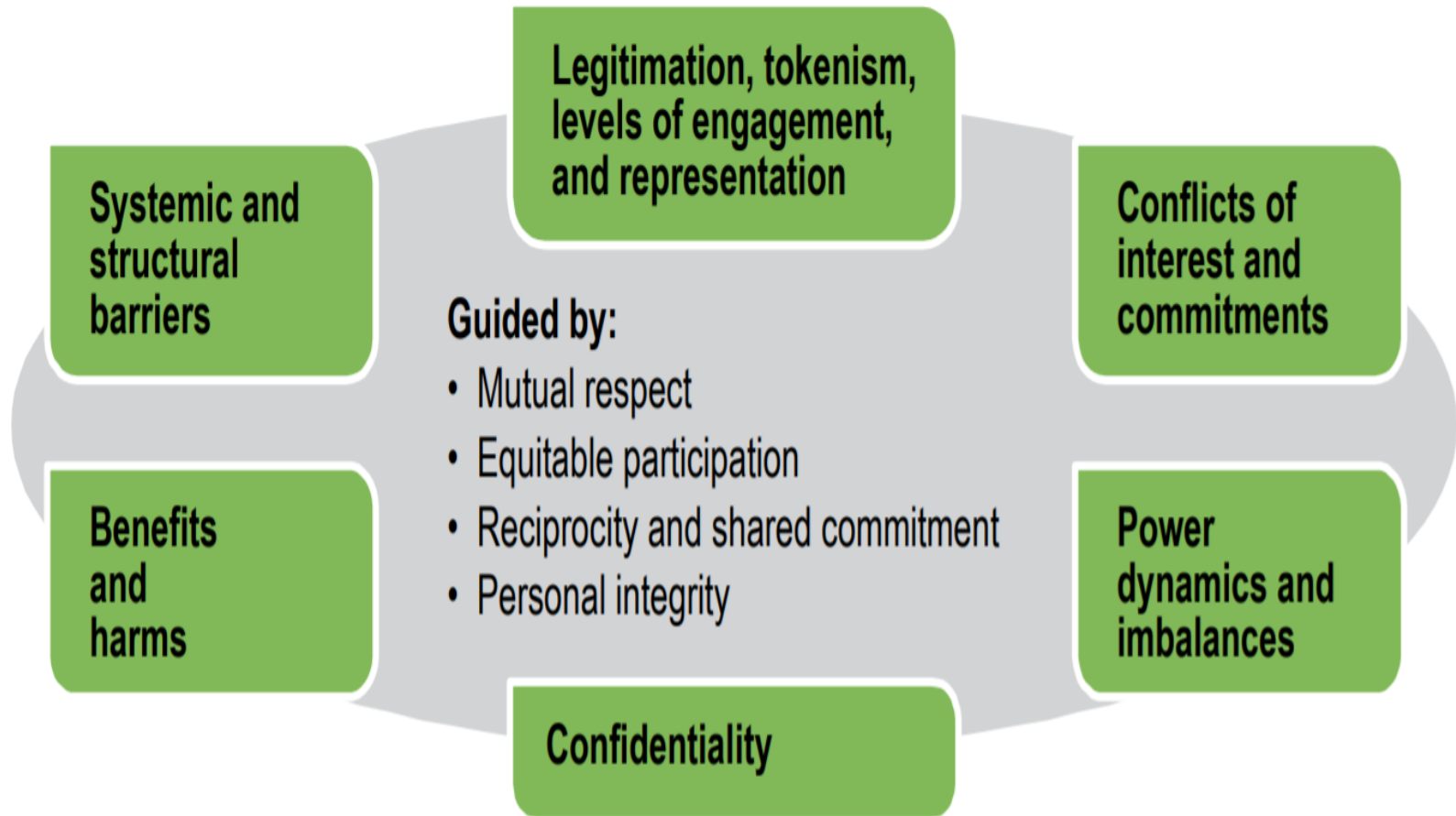


# Fostering trust

- ‘There are four core considerations to build research partnerships that foster trust:
  - mutual respect for different ways of knowing and interacting
  - equitable participation and rights
  - reciprocity and a shared commitment to producing relevant research results
  - personal integrity’
    - Ethics guidance for developing relationships with patients and researchers  
<https://cihr-irsc.gc.ca/e/51910.html>



**Figure 2. Reflecting on ethical concerns throughout the research process**



Key points and questions for reflection are provided under each of these concerns. Somewhat different questions are posed for patients than for researchers, institutions, and funders. However, everyone is encouraged to find answers in light of the four overarching considerations



**How can we engage older adults?**

# How can we create meaningful roles for patients and researchers?

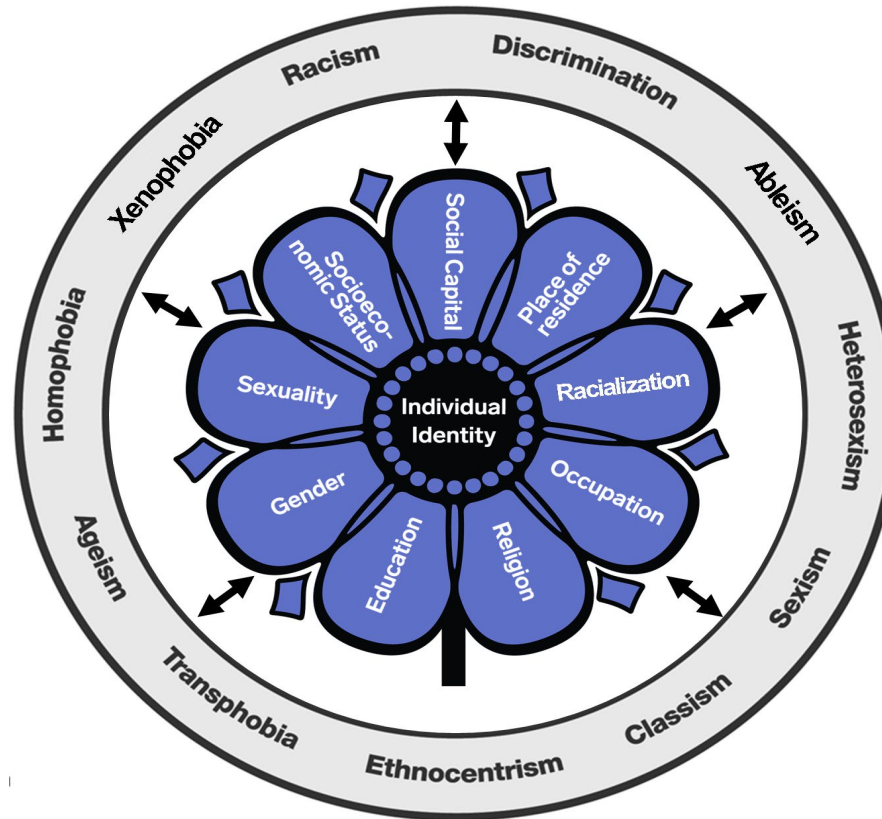
- Start early
- Build reciprocal relationships
  - Including validation of impact
- Provide training for patients and researchers – including training in EDI and intersectionality
- Clarify roles and responsibilities



Shippee et al. (2013) Patient and service user engagement in research: a systematic review and synthesized framework.

# Intersectionality

Crenshaw K. Stanford Law Review; 1991;43:1241-99.



### Intersectionality & Knowledge Translation Tools

Please see below for our featured tools:

- [Intersectionality Guide](#)
- [Intersectionality Guide one-pager](#)
- [Intersectionality & Knowledge Translation Reflection Workbook](#)
- [Intersectionality & Knowledge Translation Reflection Workbook one-pager](#)
- [Intersectionality & Knowledge Translation Guide to Common Approaches to Assessing Barriers and Facilitators to Knowledge Use](#)
- [Intersectionality & Knowledge Translation \(KT\) Selecting and Tailoring KT Interventions Workbook](#)

### SHARE BUTTONS



# Intersectionality & Knowledge Translation (KT)

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## Intersectionality Guide

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## PATIENT AND PUBLIC ENGAGEMENT PLANNING TEMPLATE

**Instructions:** Patient engagement is about meaningful engagement of patients/public in the research process (not just as subjects of research). This template has been designed to assist with the development of Patient Engagement plans for health research but can be used to plan other projects. Begin with box #1 and work through to box #10 to address the components of the engagement planning process. Select all that apply and discuss the template with your research team.



### 1 WHY<sup>1</sup>

Why do you want to involve patients?

- Gathering ideas for new research areas based on patients needs
- Ensuring research is focused on the public's interests and concerns and that money and resources are used efficiently
- Ensuring transparency and accountability
- Ensuring that the methods are acceptable and sensitive to the situations of potential research participants
- Making the language and content of information more appropriate and accessible
- Increasing participation in research
- Collecting data by, with and for patients
- Taking diverse perspectives into account when analysing data
- Taking diverse perspectives into account when making decisions
- Increasing the dissemination and uptake of research findings in practice or policy
- Meeting the requirements of funders
- .....

**Consider:** if there is a useful role for patients. Is the topic appropriate? Are there options to choose from or are decisions already made?

### 2 WHO<sup>1</sup>

Who do you need to involve?

- In-patients
- Out-patients
- Former patients
- Caregivers
- Family
- Public
- Patient support group
- Patient organisation
- Community group
- People who have experience with a specific condition, service or treatment
- .....

**Consider:** the broad and different views and experiences you will need. Engage people as "independent citizens" not as "experts" or representatives of specific stakeholder groups.

**Tip:** Involve more than one person. This allows you to involve different people at different stages of the research process, and allow people to choose how they want to be involved.

### 3 WHEN<sup>1</sup>

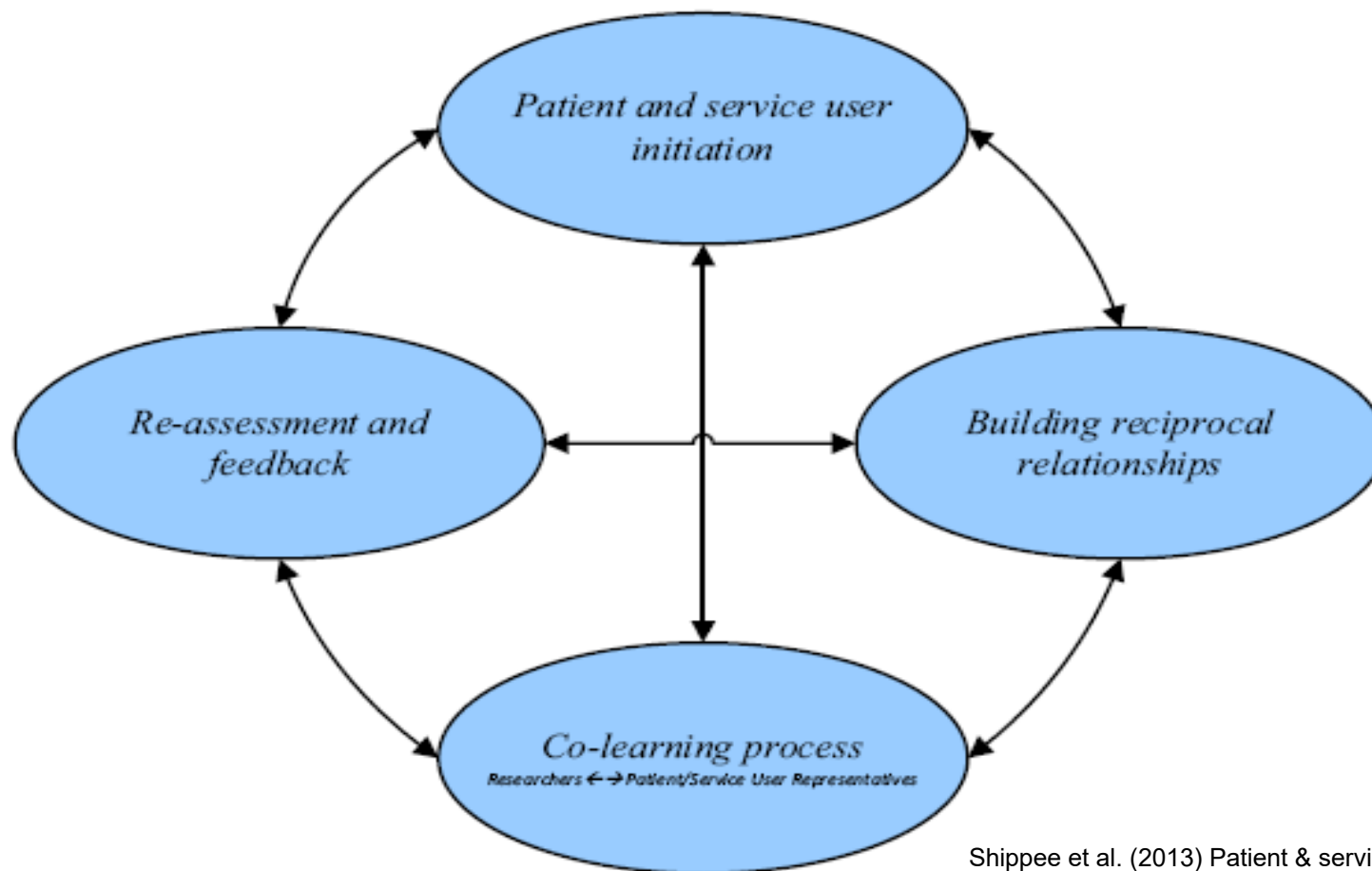
When and how can patients be involved?

Research process:

- Identifying priorities: patients' experiences of a condition can help generate new ideas or clarify questions that you may have about new studies.
- Grant writing and review process: patients can help support proposals and collaborate on grant applications.
- Design and managing: patients can inform the design of data collection tools, for example piloting a questionnaire. Patients can help develop communication materials that are clear to patients and the public.
- Data collection and analysis: patients can help to collect and analyse data
- Dissemination: patients can advise on who to share research findings with and the different ways to communicate with them.
- Implementation: patients can help develop and implement interventions.
- Evaluating: patients involvement should be evaluated from both the patients' and the researchers' point of view.

**Tip:** You can involve patients in different stages of the research cycle. It is most effective to involve patients as early as possible; however, it is never too late.

# Engagement process



Shippee et al. (2013) Patient & service user engagement in research. *Health Expectations*, 18: 1151-1166.



# How to create clear and meaningful roles

## Co-create a terms of reference document

- Background
- Vision
- Purpose
- Core values
- Confidentiality
- Membership
- Governance
- Meeting (frequency and method of decision-making)
- Compensation

### Partners in Research (PiR) Patient Representatives Terms of Reference 2017-2018

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#### Background

Many individuals involved in healthcare research and practice believe that it is important for patients and researchers to work together to improve healthcare system and practices. However, patients and researchers are unsure how best to engage patients and therefore need training on 'how to do' **patient-oriented research (POR)**. Simply put, POR refers to research (at all levels) that includes patients as active partners, focuses on patient-identified priorities, and improves patient outcomes.

#### Vision

To address this need, the Knowledge Translation Program in the Li Ka Shing Knowledge Institute at St. Michael's Hospital will design an online POR course, *Partners in Research (PiR)*. The goal of this project is to increase the knowledge and skills in POR and to increase the use of effective POR methods. This course will be targeted to patients, families, healthcare researchers, and graduate students.

#### Responsibilities and opportunities

- To contribute to the development of the online course
- To ensure relevance of project content from a patient's perspective are integrated
- To ensure that the project addresses outcomes that are important to patients

#### Members

There are two separate groups patient representatives may sit on, the PiR Steering Committee and the PiR Working Group.

#### The Steering Committee

##### Expectations

- Meet *quarterly* by webinar or teleconference to contribute to the strategic direction of the project.
- Provide oversight of the engagement process, evaluation and sustainability plans.

##### Patient Representation

- The Steering Committee will consist of 2 patient representatives.

#### The Working Group

##### Expectations



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# Assumptions about patient roles & preferences



## An example

- CAPA worked closely with The Canadian Rheumatology Association on vaccine decision making, as well as the shift to virtual care and developing best practice statements.
- Rheumatologists were convinced that the biggest concern patients had about vaccination was the risk of a disease flare.
- Patients were, for the most part, willing to risk a short disease flare for protection from the effects of getting COVID-19 and being able to feel more comfortable venturing out in public again.



# Considerations for older adults

- Ask about what accommodations are needed:
  - Hearing
  - Vision
  - Mobility
  - Transportation...
- Identify strategies for engaging priority populations
  - e.g. go to them; provide a phone, computer, data plan
- Identify supports for those with cognitive impairment
- Tailor supports to their needs at each point in the research process
  - e.g. glossary of terms, assign a 'buddy', POR coaches
- Provide compensation for the patient and their caregiver
- Develop a plan and supports for patient illness



**Some examples**

# Evaluating the comparative effectiveness of geriatrician-led models of care across healthcare settings

- Integrated models of care such as comprehensive geriatric assessments (CGA) can help prioritize and manage complex health needs of older adults.
- CGAs are often conducted by geriatricians and an interdisciplinary team, and models vary across healthcare settings.
- It is unclear which geriatrician-led models of care are most effective at improving outcomes.

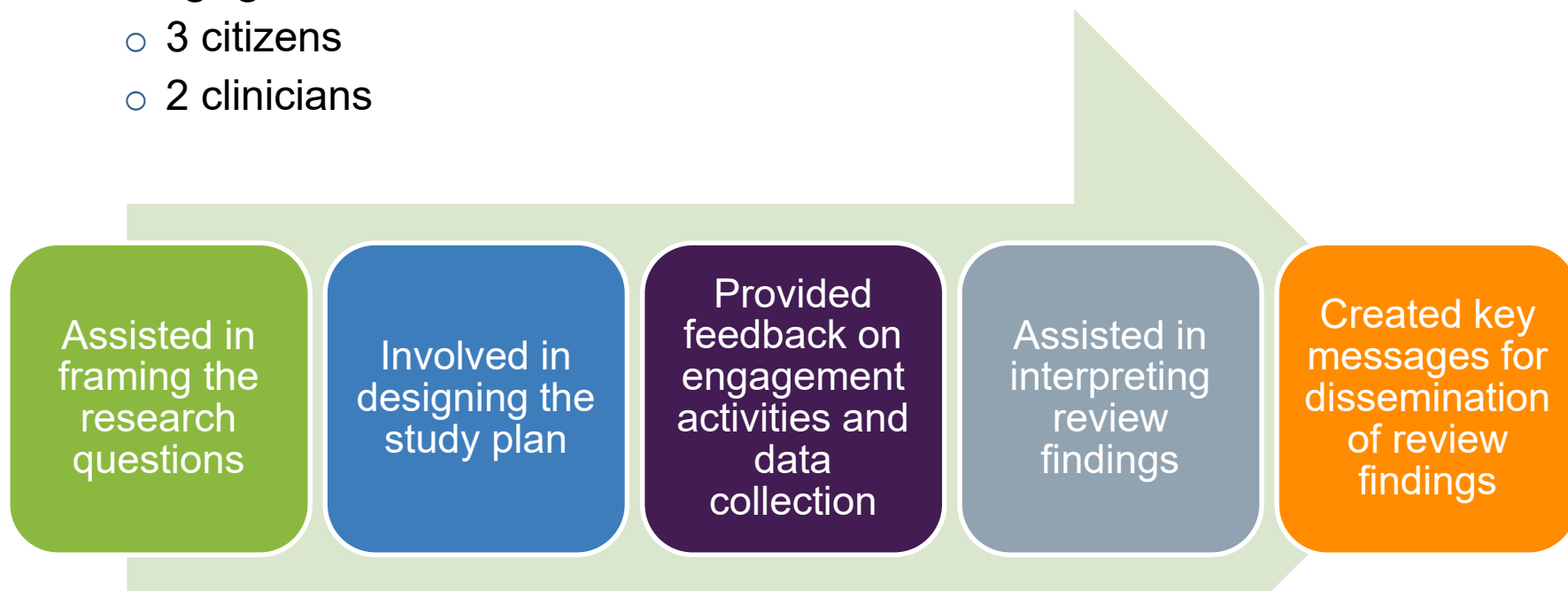
- Soobiah C et al. J Clin Epidemiol. 2019 Sep;113:58-63.



# Steering Committee

Established a steering committee to guide conduct of systematic review and engagement activities

- 3 citizens
- 2 clinicians



Adapted from: Patients in Research Presentation St. Michael's Hospital 2018



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# Knowledge User (KU) Engagement Strategy within the Systematic Review

1. Engage with KU to select outcomes & measures

2. Complete review & analysis

3. Engage with KU to create the key messages from review

4. Evaluate KU engagement





# Impact

- Establishing a steering committee allowed us to identify potential issues and challenges prior to conducting steps of the review
- Active KU engagement in the conduct of the review allowed us to tailor the review findings to outcomes and measures that were preferred
- Assessment of KU engagement allowed us to understand if the activities employed in the review were engaging
  - In-person meeting was rated higher for engagement than online activities



# Looking For Research-Based Evidence?

The SPOR Evidence Alliance can help gather information from research evidence in a systematic and transparent way to answer your health-related questions.

Ask a Question





## WELLNESS HUB

Support for Congregate Living Centres

[IPAC+](#) ▾ [CARE+](#) ▾ [Vaccine+](#) ▾ [Shelter Hub](#) [LTC Hub](#) [Research](#)

Resources and Support for Congregate Living Centres  
during COVID-19 and Beyond



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## Ethics and operational issues in co-creating research with patients and caregivers

# Challenges

- Avoiding tokenism
  - Video from PiR



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# Challenges

- REB considerations
  - Requirements for patient and caregiver partners to complete courses such as TCPS
- Compensation
  - Ensure it includes the courses above, caregiver time etc.
- Publications
  - Some journals push back on patients as authors
    - Requirements for 'affiliation with an organization'
    - Declarations of conflicts of interest
  - In contrast, some journals are asking for inclusion of a section on how patients were engaged in the research
- Thesis committees
  - Requirement for faculty appointment

# Challenges during COVID-19

- Rapid research calls
  - Evolving research questions
- Compensation
  - Additional need for child care, computers, data plans etc.
- Stress, burnout amongst residents, families/caregivers, clinicians in long-term care homes/retirement homes
  - Provide wellness resources/support, using trauma-informed care
  - ‘We have found that engaging with patients over the past 20 months or so is even more important than before the pandemic.’
    - Linda Wilhelm



# Summary

1. Co-producing research can decrease research waste
2. Strategies for engaging older adults in research need to be developed with them as partners and be grounded in principles of establishing trust
3. Don't do what I did and present on co-production without a patient partner





# Acknowledgements

- Linda Wilhelm
- Lorraine Bayliss
- Annette McKinnon
- Eliot PausJenssen
- All of our patient and caregiver partners



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# Resources

- <https://cihr-irsc.gc.ca/e/51910.html#10>
- <https://www.healthtalk.org/patient-and-public-involvement-research/overview>
- <http://arthritispatient.ca/>
- <https://research-teams.pcori.org/inclusion#Establishing%20and%20Maintaining%20Trust>

