



Inclusion of people with lived experience in knowledge mobilization

Nothing About Us Without Us

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Introductions



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Overview of session



1

Introduction to working with people with lived experience

2

Principles and values for working with people with lived experience in research and knowledge mobilization

3

Workshop to put into practice for your research



1. Introduction to working with people with lived experience





What is lived experience?

- People who have firsthand experiential knowledge that can inform research, education, practice and/or policy
 - Live with a health condition (e.g., low back pain)
 - Caregivers, family members
 - Use health and social services
- Heterogenous terminology used internationally

Patient
engagement

Patient
partner

Patient and
public
involvement

Consumer
and
community
involvement

Person with
lived
experience

Patient
advocate

End user
engagement

Service user
engagement

Stakeholder
engagement

Co-design /
Co-create /
Co-produce

Patient
partnered
research

Participatory
research

Role of lived experience in research



Passive

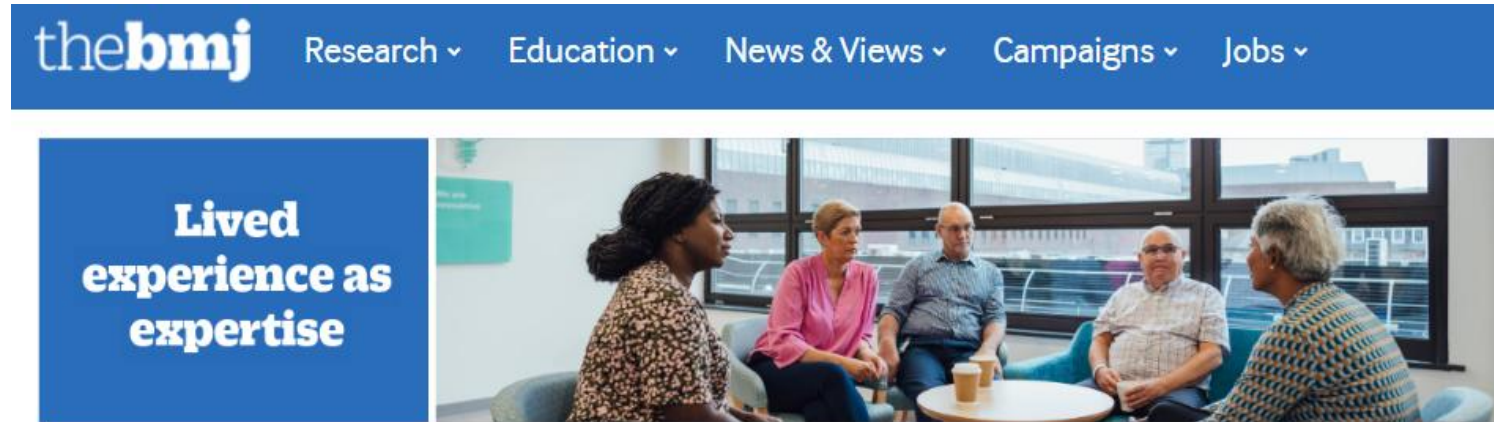
- Study participant
- Study data point

Active

- Partner / Co-Investigator
- Researcher



Lived experience as expertise



This Collection highlights the power of recognising lived experience as expertise, which can transform healthcare, and it considers opportunities and challenges in implementing meaningful engagement, with a health equity and intersectional lens. All lead authors are experts by experience.

“Lived experience is increasingly recognized by clinicians, policy makers, researchers and the public as essential expertise to ensure that healthcare is relevant, responsive, effective, resilient, equitable, and fully inclusive.”

<https://www.bmj.com/collections/lived-experience>



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REVIEW ARTICLE

Open Access

‘Is it worth doing?’ Measuring the impact of patient and public involvement in research



Kristina Staley

Table 3 Reported impacts of involvement on research

Categories of impact identified through literature reviews

1. Impact on the research agenda—the topic, research question and funding decisions
2. Impact on research design and delivery—influencing the research design, tools and choice of method, recruitment, data collection and analysis, writing-up and dissemination.
3. Impact on research ethics—the consent process and developing ethically acceptable research
4. Impact on the people involved
5. Impact on the researchers
6. Impact on participants
7. Impact on the wider community
8. Impact on community organisations
9. Impact on implementation and change



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Lived experience as expertise in KM



“The public needs to be embedded in the implementation of any research and encouraged to help mobilise the knowledge. If the public understands the research findings, they can offer practical and realistic advice on how it can be used to benefit themselves and everyone else in the real world. Surely this is why research is carried out in the first place.”



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National Institute for Health and Care Research, How to involve the public in knowledge mobilization:
<https://evidence.nihr.ac.uk/collection/how-to-involve-the-public-in-knowledge-mobilisation/>

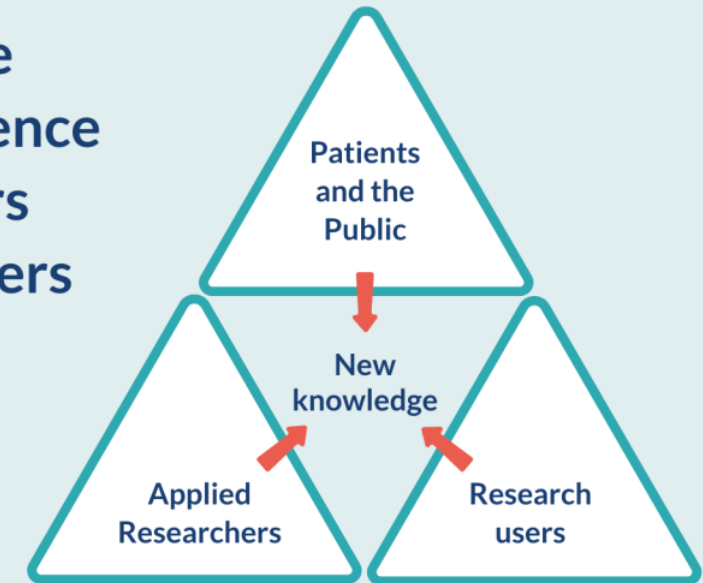
Lived experience as expertise in KM



Knowledge mobilization

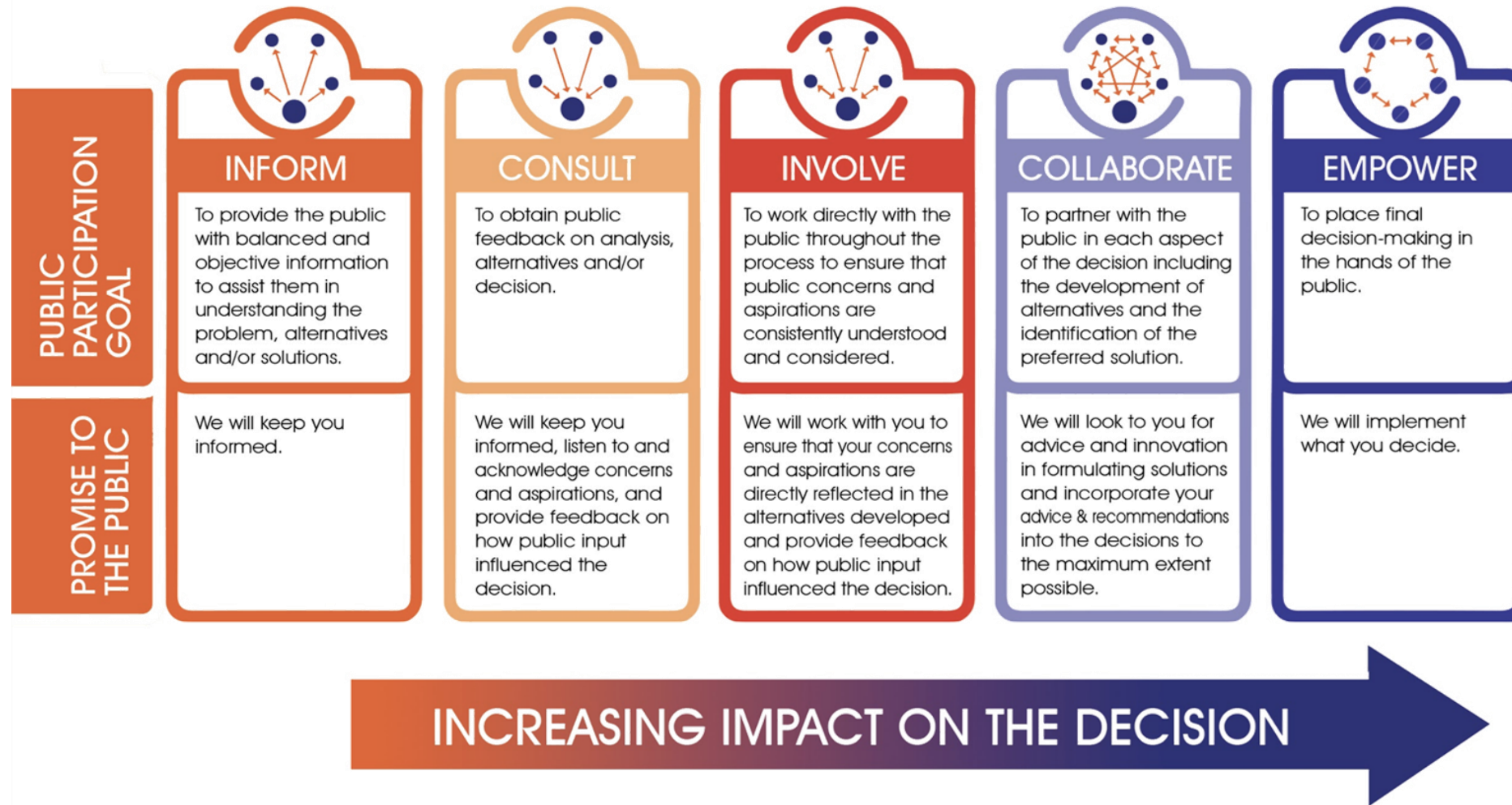
- Process that paves the way to impact via **active collaboration with key partners throughout research**, including working with the people and organisations who will use or benefit from research
- Integrated **knowledge from multiple perspectives** creates new insights and understanding about research plans and findings for **real-world impact**
- PWLE help to **align research with the needs of research users** and to **co-produce and mobilise knowledge**

Patients and the public can influence both researchers and research users

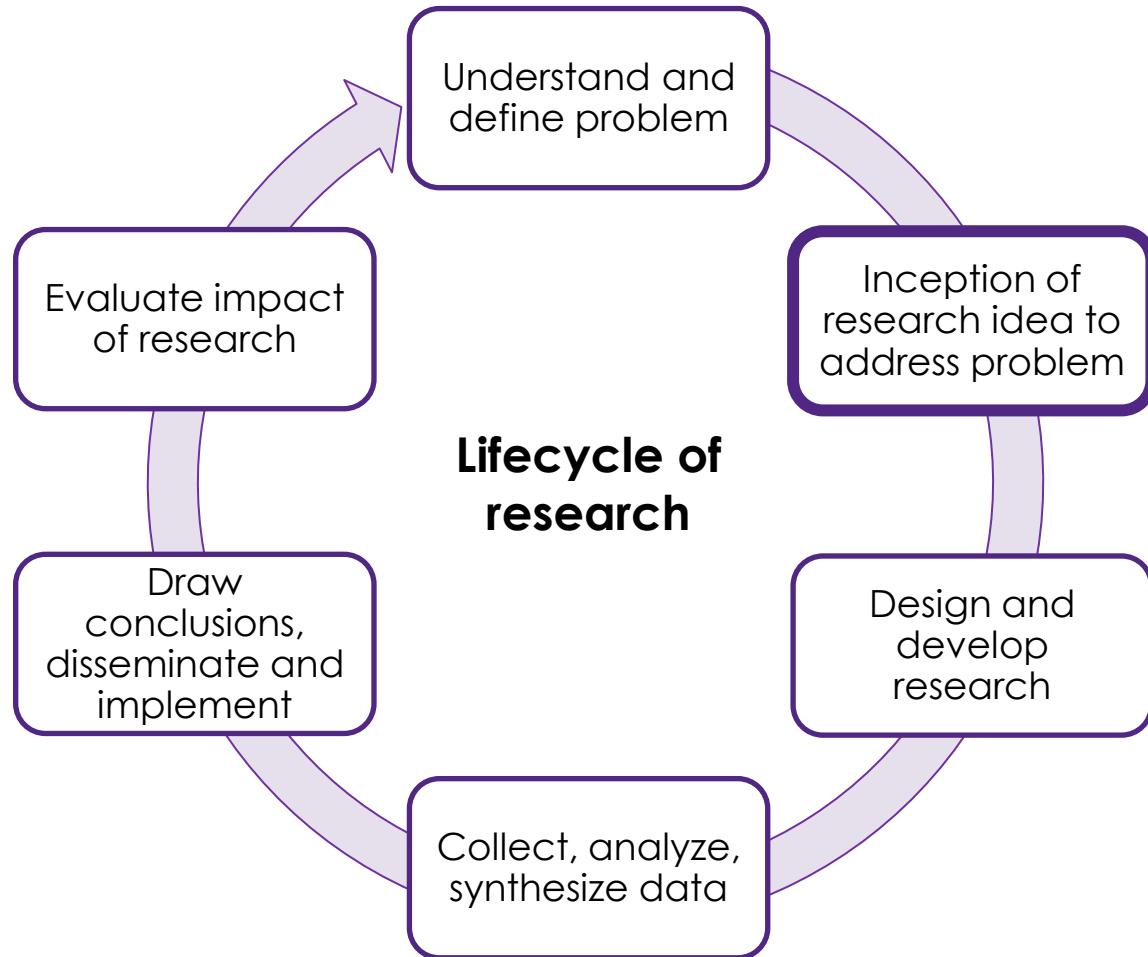




Working with PWLE in KM



Working with PWLE in KM



Shark Tank research project idea pitch

3-minutes to pitch research project idea

Quantitative feedback

Patient partners rated:

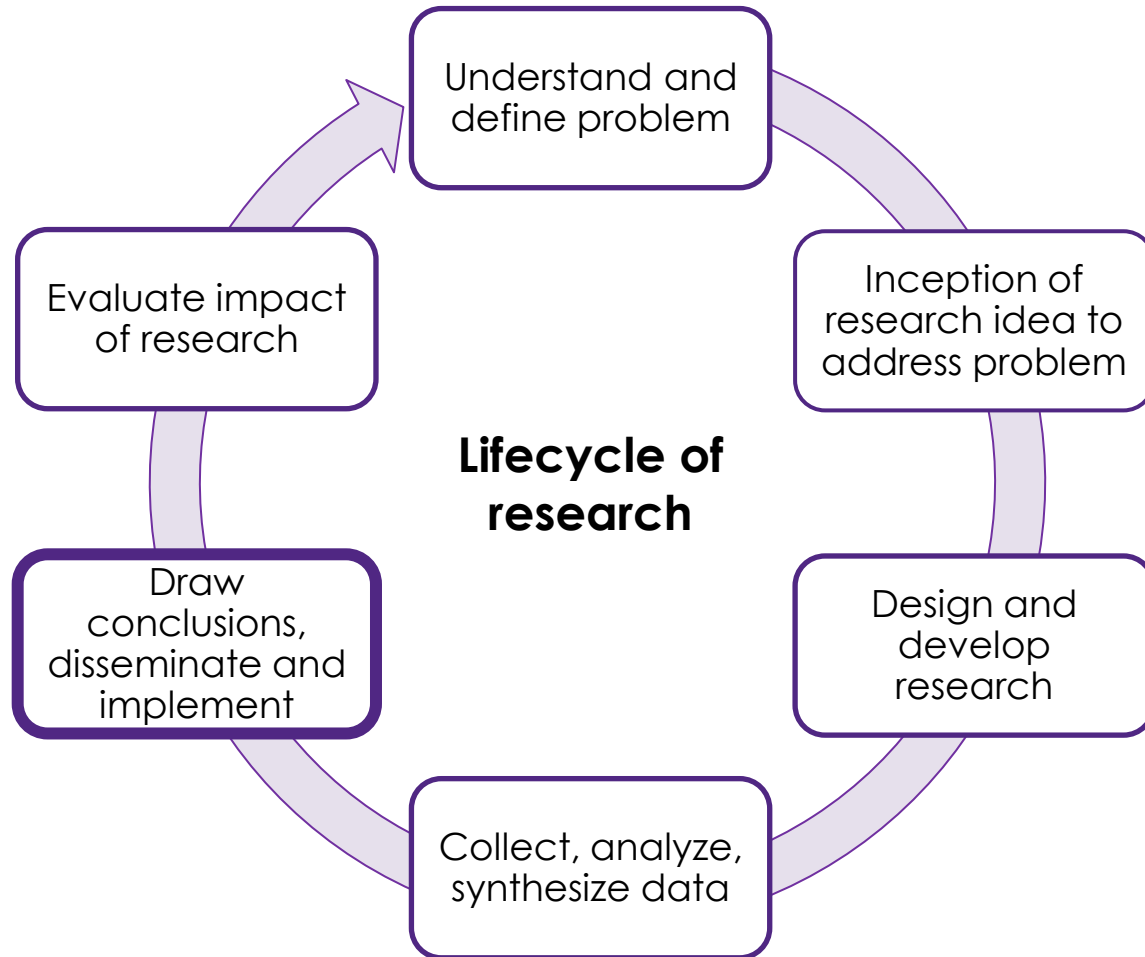
- Importance of project
- Impact of project
- Clarity of presentation

Qualitative feedback

Breakout discussion:

- What did you like about the project?
- What advice do you have to improve the project?

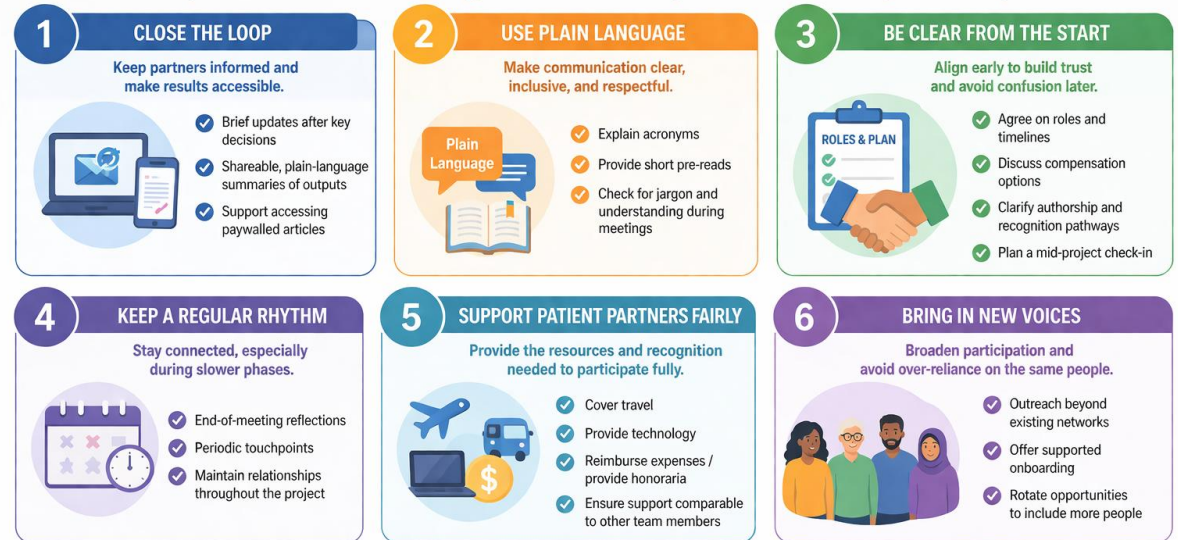
Working with PWLE in KM



Study results as sharable infographic

Practical recommendations from our study

Simple actions for meaningful, sustainable patient-academic partnerships

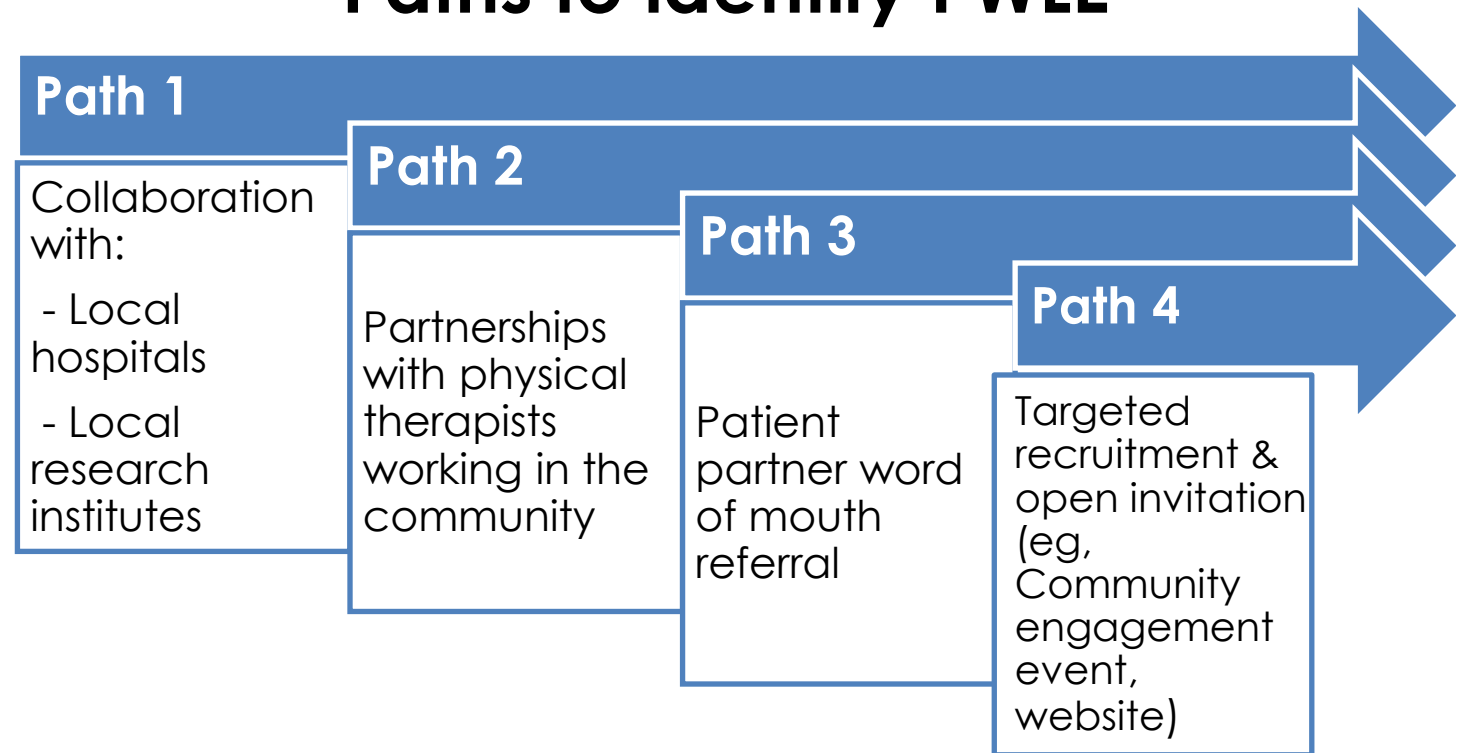




Identifying PWLE to work with

- Consider who will benefit from or use your research
- Use multiple paths
- Go into the community
- Focus first on developing a trusting relationship

Paths to identify PWLE





2. Principles and values for working with people with lived experience in research and knowledge mobilization



Build a trusting relationship as a precursor to a partnership



- Respect lived experience as expertise
- Consider how PWLE will benefit from work with researchers
- Working with PWLE should be grounded in trust, reciprocity and ongoing discussion, which takes time to understand PWLE goals, preferences, motivations, etc
- *Time to build relationships is a challenge in academia* – solution is to plan early and schedule meetings in advance to stay on track



Share power and decision-making

- Strategies to reduce hierarchy between researchers and PWLE
 - Plan for iterative co-design in timelines – takes more time than you think
 - Creating time for those involved to share their ideas, questions, time to reshape the paradigm of co-design
 - Transparency about how decisions are made



Create safe, accessible and welcoming spaces



- consider accessibility
- trauma-informed communication
- cultural safety
- plain language
- flexible participation options
- varied communication approaches





Be clear about purpose, roles and expectations

- Roles, responsibilities, timelines, time commitment
- How patient input will be used?
- What support is available to help with the learning curve?

Avoid tokenism - Everyone's voice matters

- Create meaningful opportunities to influence decisions and outputs
- Communicate back what changed based on PWLE involvement or feedback

Recognize and compensate contributions



- Range of ways this can be achieved, needs to start with open conversation
- compensation to reflect time, expertise, prep, contributions
- Up front parking paid at a minimum



Summary

Lived experience is
expertise

Consider what lived
experience you need
and how people with
that experience can
meaningfully engage
in your research

Plan early for
engagement and
knowledge
mobilization

Target knowledge
mobilization products
to the needs of your
research users



3. Workshop to put into practice for your research



Workshop

Learning Objectives:

By the end of this workshop, participants will be able to:

1. Identify opportunities to partner with people with lived experience throughout the KMb process
2. Apply practical strategies to strengthen lived experience engagement in their own KMb activities



Which PWLE are important to work with as partners in your research?



People with lived experience are those who:

- Live with MSK conditions
- Care for someone with an MSK condition
- Use healthcare systems and services

What unique expertise do people with lived experience bring that you may not have?



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Where will you identify PWLE to work with in your research?



Multiple options are useful; could include:

- Established advisory groups
- Community centres
- Exercise classes
- Healthcare clinics
- Hospitals
- Senior Centres
- Social Media groups
- Sports teams
- Schools

How will you build a trusting and mutually beneficial relationship with PWLE as part of your research?



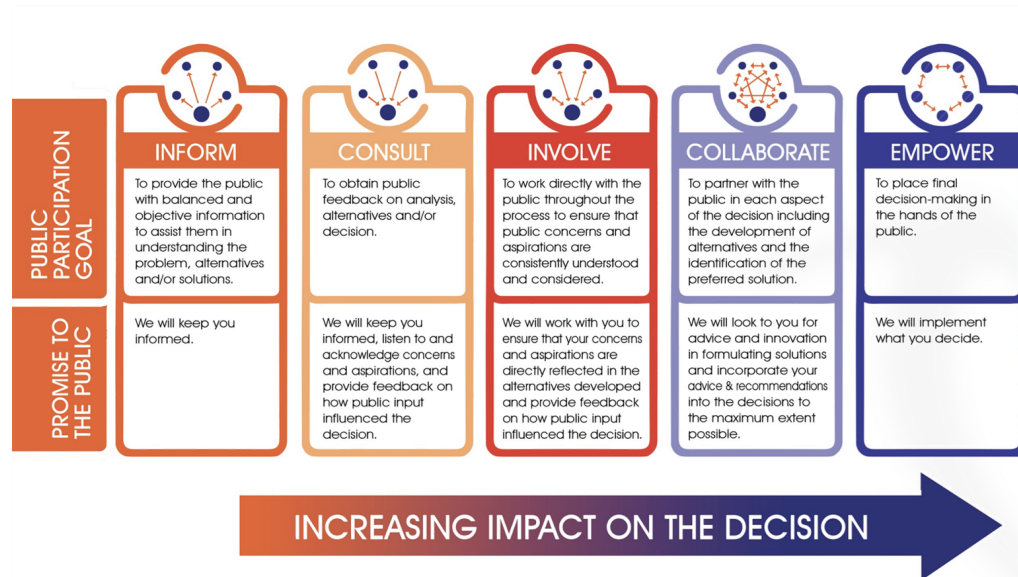
Consider:

- How will everyone get to know each other?
- How will you communicate (e.g., frequency, mode?)
- How will you approach compensation for contributions of PWLE?
- **How will you create a welcoming environment for PWLE?**

How will you plan to partner with PWLE as part of your research?



- Consider the methods of engagement will you employ



Meaningful engagement includes:

- Early involvement
- Shared decision-making
- Respect for experiential expertise
- Accessibility
- Appropriate compensation
- Ongoing relationships

How will you work with PWLE to mobilize your research findings in a usable way?

People with lived experience help:

- Identify relevant messages
- Use language that resonates with target audiences
- Choose effective dissemination channels
- Improve trust and uptake of research findings
- Facilitate uptake of research findings

Three Key Takeaways

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- 1 People with lived experience are experts in how research fits into real life
 - 2 Meaningful KMb engagement starts early and continues throughout research
 - 3 Co-created knowledge products are often more relevant, accessible and impactful



**CANADIAN MUSCULOSKELETAL
REHAB RESEARCH NETWORK**

Thank you!



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