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Participatory Approaches in Health Research: From Co-production to Citizen Science.

Ms. Qiuxia Li & Éle Quinn
Discipline of Occupational Therapy, School of Health Sciences

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What is participatory research?

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Participatory Research

"a collaborative approach to research that involves the people whose lives are affected by the issues being researched. They are included equitably as partners throughout the research process. The aim is to improve people's lives and bring about social change."

King College London

"Systematic enquiry, with the collaboration of those affected by the issue being studies, for the purpose of education and taking action or effecting change."

Definition used by CDC and Institute of Medicine, USA, following The Royal Society of Canada Study of Participatory Research in Health Promotion Green et al., 1995

"Participatory Research is a research-to-action approach that emphasizes direct engagement of local priorities and perspectives."

Cornwall & Jewkes, 1995

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Participatory Research

"a **collaborative approach** to research that involves the **people whose lives are affected by the issues** being researched. They are included **equitably** as partners throughout the research process. The aim is to improve people's lives and bring about social change."

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"Participatory Research is **a research-to-action approach** … that prioritizes co-constructing research through **partnerships between researchers and stakeholders, community members, or others** with insider knowledge and lived expertise"

From Vaughn & Jacquez 2020

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Principles of Participatory Research

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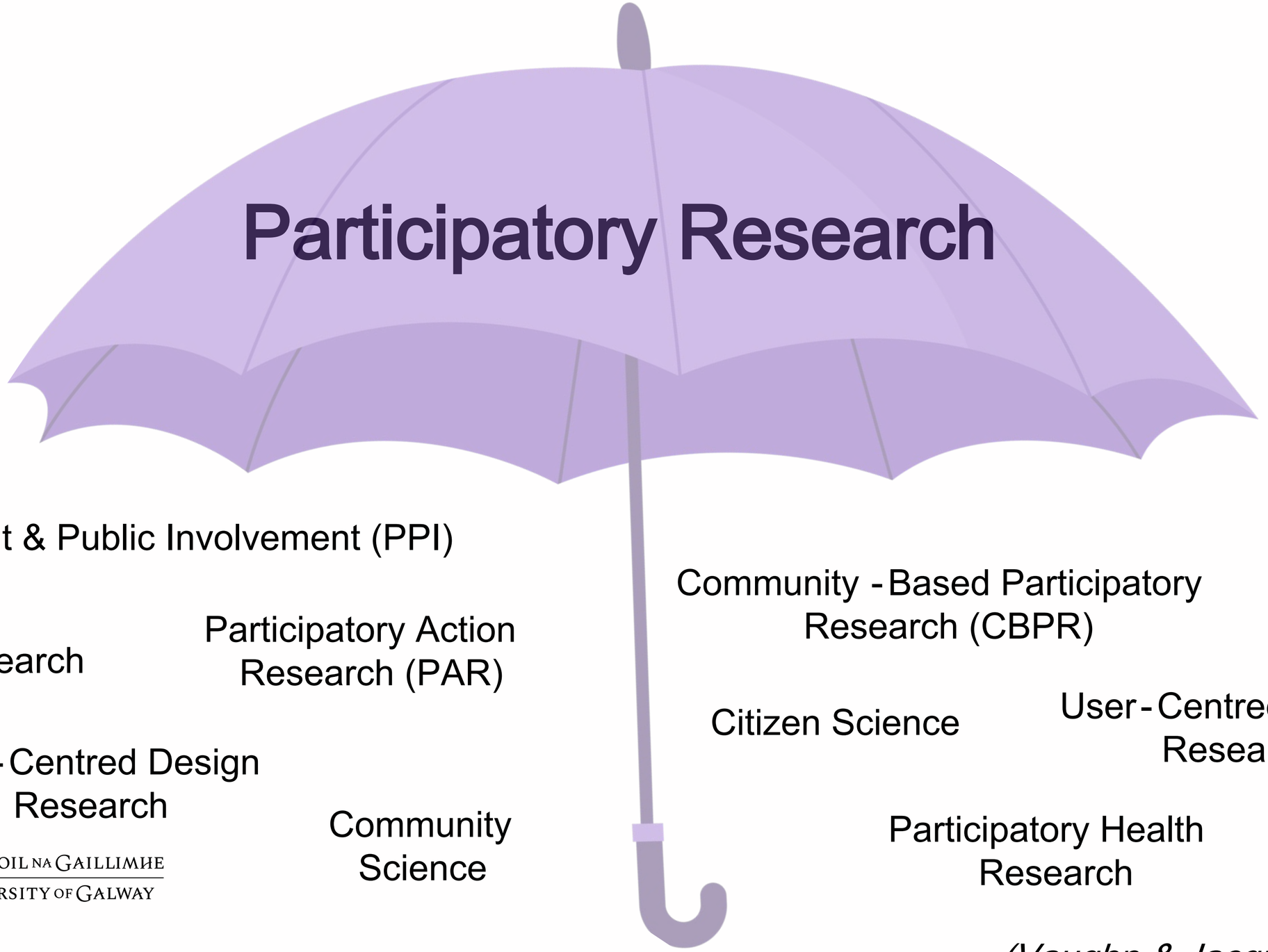
- Involves those whose lives are affected by the issues being researched
- They are included equitably as partners throughout the research process.
- Participatory research is an approach to research not a methodology
- Not a one-size-fits all approach
- All partners are experts
- Power among partners should be acknowledged and sensitively addressed
- It is a capacity building exercise for everyone

Participatory Research



Patient & Public Involvement (PPI)

Engaged Research

Participatory Action Research (PAR)

User-Centred Design Research

Community Science

Community-Based Participatory Research (CBPR)

Citizen Science

User-Centred Design Research

Participatory Health Research

(Vaughn & Jacquez., 2020)

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Interest-holders

A new term to replace stakeholders within the context of health research & policy *(Akl et al., 2024)*

- MuSE Interest-holder Groups: the 10'P's
  - Patients, patient organisations , caregivers
  - Public
  - Providers
  - Payers/Purchasers of health services
  - Policymakers
  - Program managers
  - Product makers
  - Payers of research
  - Principal investigators
  - Peer review editors

https:// methods.cochrane.org /equity/projects/multi -stakeholder -engagement -muse/stakeholder -engagement -guideline -development/muse

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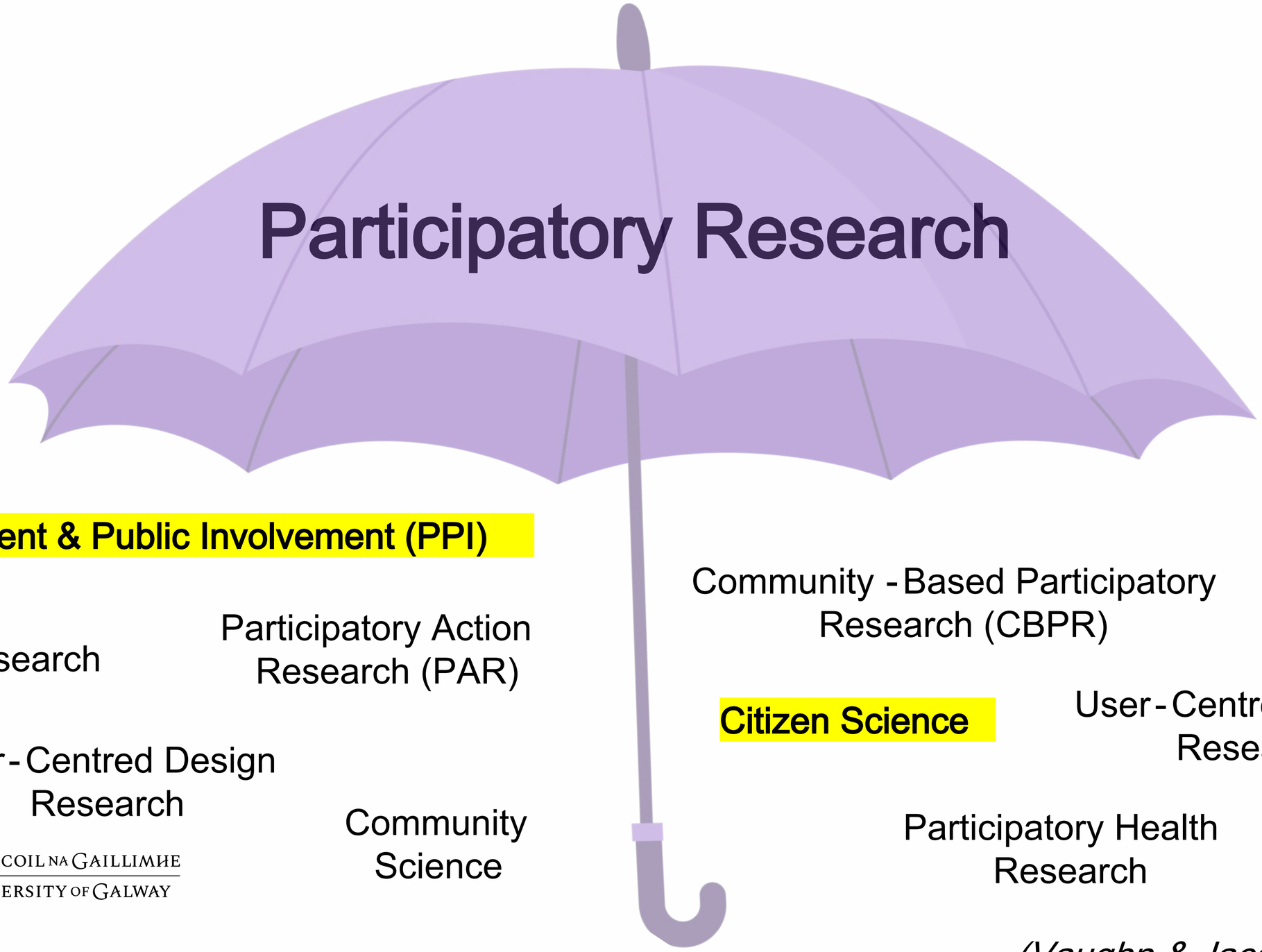
Participatory Research



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Participatory Health Research

(Vaughn & Jacquez., 2020)

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Patient & Public Involvement

Research carried out **WITH** and **BY** members of the public. Rather than to, about or for them.

(From INVOLVE UK - https:// www.involve.org.uk /)

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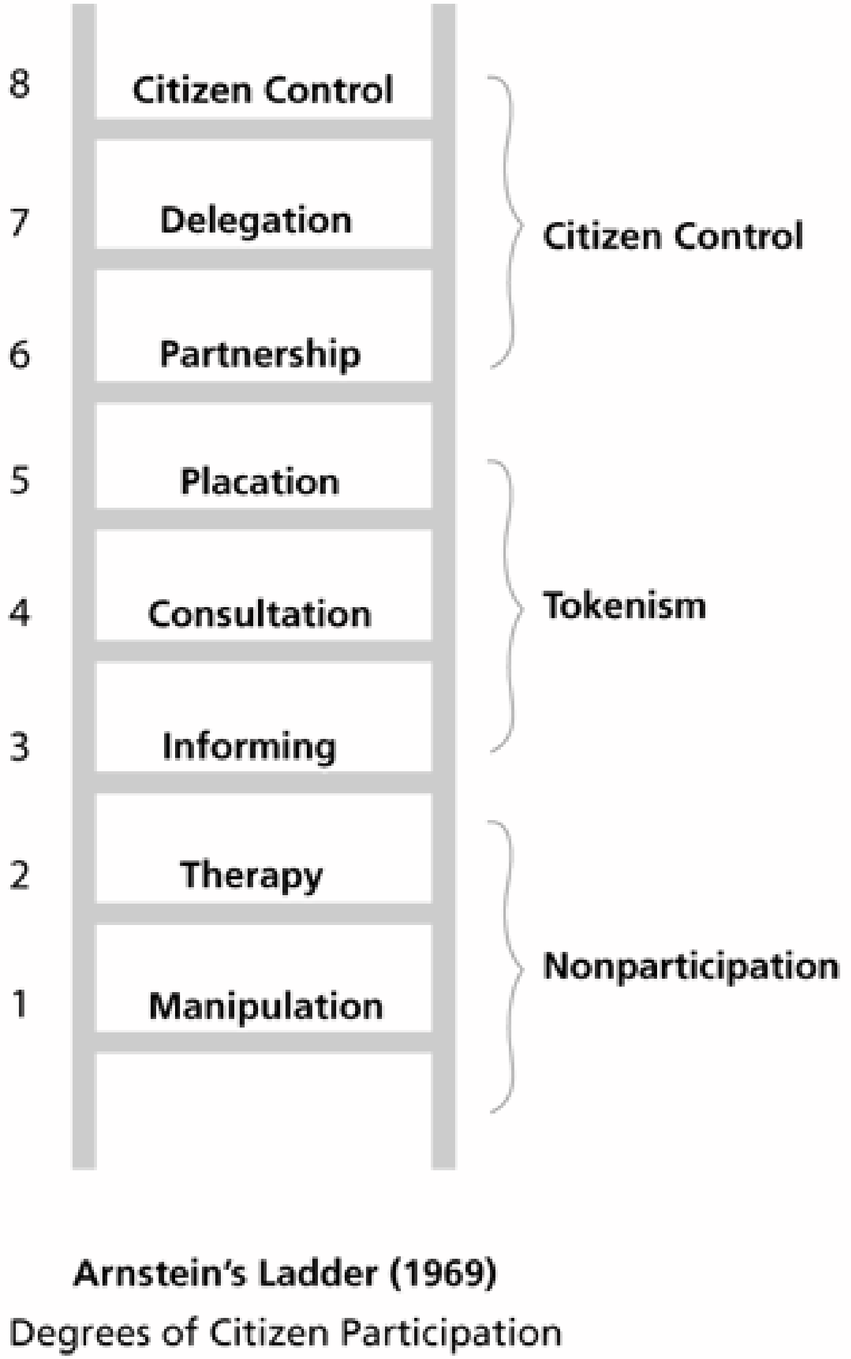
Conceptual models of involvement

Arnsteins Model of Citizen Participation

(Arnstein, 1969)



Arnstein's Ladder (1969)

Degrees of Citizen Participation

Conceptual models of involvement

Irish Health Research Forum (2013)

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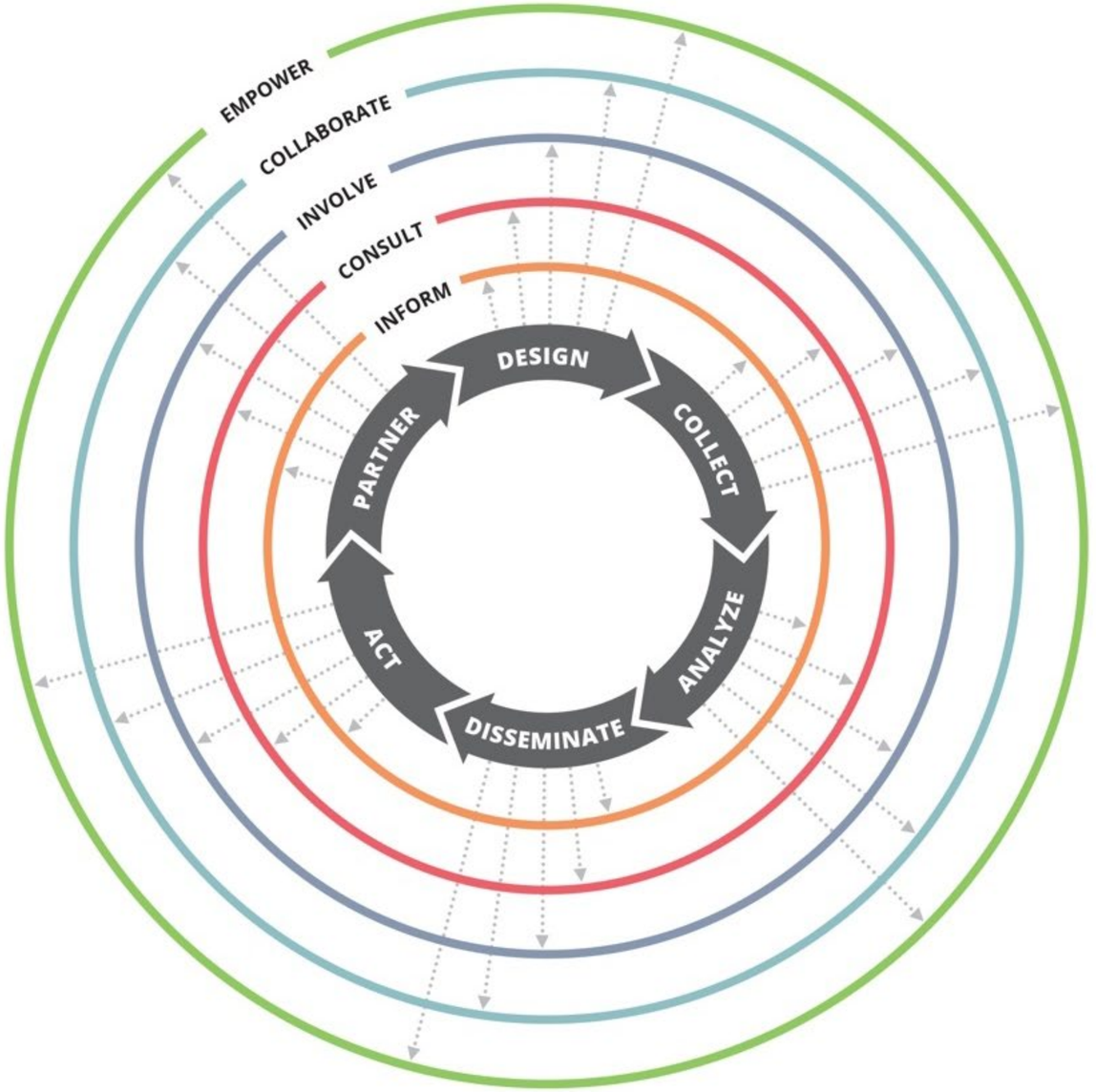
Participation Choice Points in the Research Process

At each step in the research process, there is a choice about the degree of participation. The choice guides the selection of research methods and tools.



INFORM

Information is provided to community

CONSULT

Input is obtained from community

INVOLVE

Researchers work directly with community

COLLABORATE

Community is partner in research process

EMPOWER

Community leads research decisionmaking

Levels of participation based on:
Spectrum of Public Participation
© International Association for Public Participation www.iap2.org

(Vaugn & Jacquez 2020)

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Citizen Science

Enables members of the public ('citizen scientists') to actively contribute to the scientific research process. Citizen scientists may be involved in a range of research activities, including developing research questions, designing project methodologies, data collection and analysis, and discussing, interpreting and disseminating research results

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(Rowbotham et al., 2023)

Citizen Science

1. Actively involves citizens in scientific process.
2. Have a genuine science outcome.
3. Mutually beneficial to professional scientists and citizen scientists.
4. Citizen scientists can participate in multiple stages of the process.
5. Citizen scientists receive feedback from the project.
6. Has limitations like any other science but is democratic in nature.
7. Project data and meta -data are made publicly available.
8. Citizen scientists are acknowledged.
9. Evaluated for their scientific output, data quality, participant experience and wider impact.
10. Legal and ethical issues are considered.

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(European Citizen Science Association, 2015)

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Lessons learned from Qiuxia

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Project: Developing an online intervention for caregivers of people with dementia

- Internet-based
- Psychosocial support
- Non-pharmacological

- Informal caregivers (partners, family members, friends)

PhD researcher: Qiuxia Li
Supervisors: Dr. Sinéad Hynes & Prof. Kieran Walsh
PPI panel: 5 members (caregivers, person with dementia)

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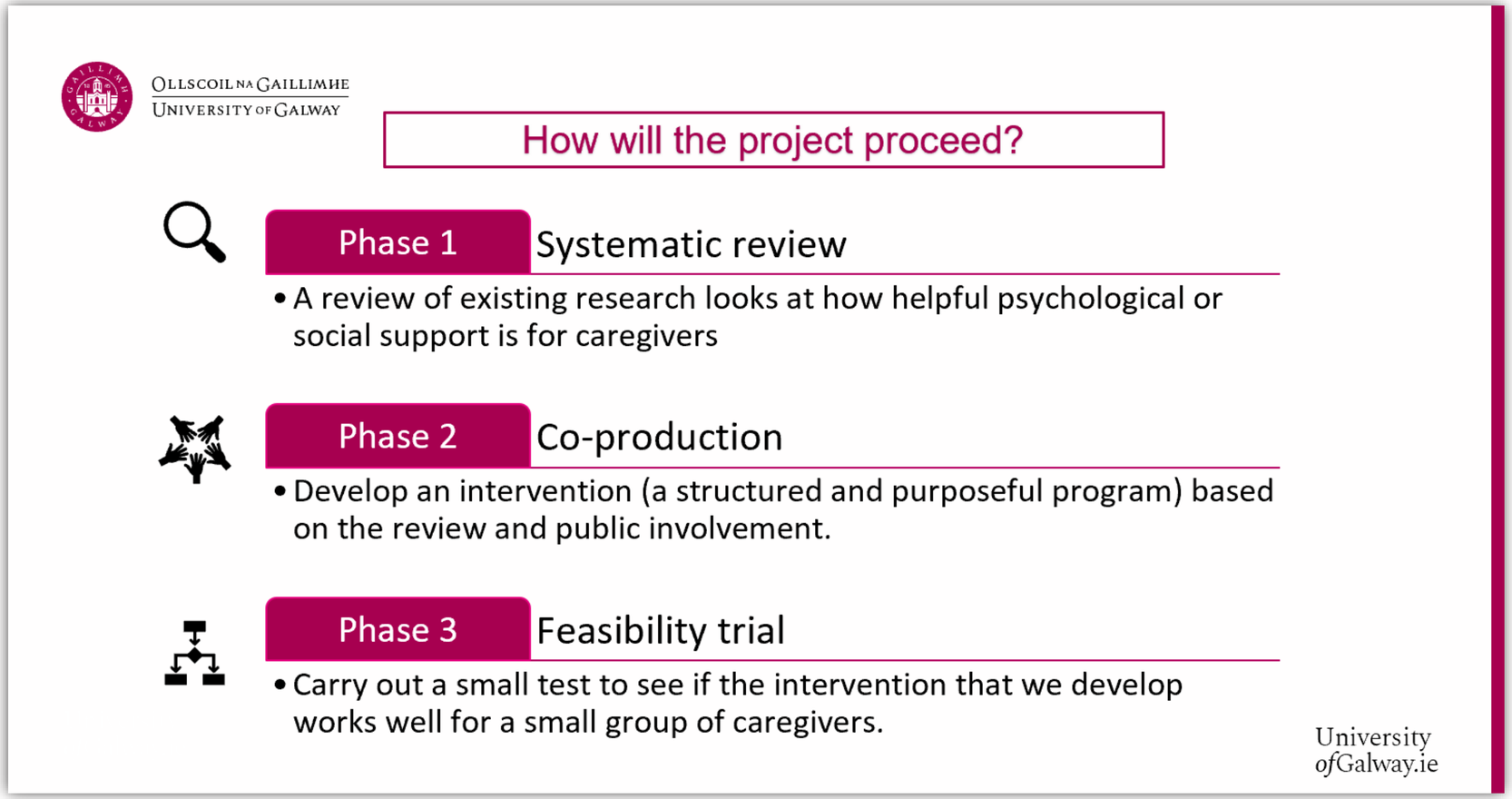
A slide I used in the first PPI meeting to give an overview of my PhD project:



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PPI in Research Stages

Online Intervention for Caregivers of People with Dementia

1. What is out there?

Systematic review

PPI: Shaping interpretation & identifying gaps

- PhD started from September, 2022
- The first PPI meeting: August, 2023

4.1. Patient and public involvement: perspectives on findings

To further ground the findings of this review in real-world experiences, insights from the public panel were incorporated to deepen our interpretation. Drawing on their experiences as dementia caregivers and individuals living with dementia, the panel highlighted several key gaps of online psychosocial interventions that need to be addressed. In terms of intervention design, they noted the duration of interventions might explain the observed results, with most interventions in the included studies lasting no longer than 3 months. Contributors felt online interventions might require a longer duration for effective engagement, and, while short-term interventions can facilitate relationship-building among participants, achieving the intended impact within such a brief duration might prove challenging (Rozental et al., 2015).

In terms of the nature of intervention delivery, contributors highlighted the significant isolation experienced by caregivers (Azevedo et al., 2021), suggesting that group-based interventions could be more effective in addressing their needs. Such a setting addresses the challenges of isolation and self-doubt by providing a platform for caregivers to exchange ideas and share experiences (Daynes-Kearney & Gallagher, 2023). The emphasis lies not in offering advice, recognizing the uniqueness of each situation, but rather in fostering a supportive environment where caregivers can share personal experiences, hopes, and strengths (Daynes-Kearney & Gallagher, 2025).

Regarding the intervention components, while providing educational information about dementia and caregiving skills is essential, contributors emphasized the critical need for caregivers to receive techniques and approaches to identify valuable resources and support, which is not sufficiently emphasized in the studies included in the review. This suggestion has also been noted in the international literature (Soong et al., 2020). Additionally, caregivers exhibit an increased need for self-care support throughout all stages of caregiving, especially as the care recipient's condition progresses and requires more intensive care (Lin et al., 2023), which was less emphasized in the included studies. Addressing these gaps by incorporating practical resource identification and ongoing self-care strategies into interventions could enhance their relevance and effectiveness for caregivers.

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PPI in Research Stages

Online Intervention

2. What do carers think?

Qualitative study

PPI: Developing materials & supporting data collection and analysis

Understanding caregivers' experiences and perspectives on online support: a qualitative study

Qiuxia Li[a], Brenda Buckley[b,c], Ray Lucey[c*], Helena Quaid[b,c], Maura Barry[c], Yuxiang Zhu[c], Kieran Walsh[d] and Sinéad M. Hynes[a,e]

[a]Discipline of Occupational Therapy, School of Health Sciences, College of Medicine, Nursing and Health Sciences, University of Galway, Ireland; [b]The Dementia Research Advisory Team, The Alzheimer Society of Ireland, Dublin, Ireland; [c]Patient and Public Involvement contributor, Ireland; [d]Irish Centre for Social Gerontology, Institute for Lifecourse and Society, University of Galway, Ireland; [e]Galway Neuroscience Centre, University of Galway, Ireland

ABSTRACT

Objectives: Family caregivers of people with dementia face emotional, physical, and social challenges. Online psychosocial interventions may offer valuable support when they are responsive to these challenges. However, little is known about how caregivers navigate online support in practice. This study explores caregivers' experiences and perspectives of online psychosocial support, identifies facilitators and barriers to online engagement, and highlights key features of meaningful online intervention.

Method: This study used a qualitative explorative design, informed by Patient and Public Involvement and a reflexive approach. Twenty-eight caregivers were recruited. 15 semi-structured interviews and 3 focus groups were completed to gather caregivers' experiences. Data were analysed using inductive thematic analysis.

Results: Three themes were identified: entering and navigating the online world; balancing the advantages and constraints; and expecting meaningful online support. While caregivers valued the accessibility and flexibility of online resources, barriers arose from online systems' complexity and usability challenges, and were often intensified by the emotional strain and time pressures of caregiving. Perceived benefits and barriers were shaped by the interplay of platform usability, caregiver characteristics, and current care demands.

Conclusion: Online interventions should address the tension between the convenience and usability of digital delivery and caregivers' need for emotional presence and meaningful connection. Well-designed online interventions hold considerable potential to enhance accessibility and promote greater equity in caregiving support.

ARTICLE HISTORY
Received 19 December 2025
Accepted 14 April 2026

KEYWORDS
Dementia; psychosocial intervention; online intervention; interview; focus group; qualitative study

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PPI in Research Stages

Online Intervention for Caregivers of People with Dementia

3. What should it look like?

Intervention planning

PPI: Informing design & prioritizing intervention components

Intervention Planning

- Helped define session topics and structure
- Created the group agreement "CARER"
- Discussion around the role of the facilitators

"Facilitators should not know the answer of the questions."— PPI panel

8-WEEK ONLINE PROGRAM

Contents

Week 1: Introduction and Building Relationships
Week 2: Understanding the Dementia Pathway and Caregiving Journey
Week 3: Coping with Daily Challenges
Week 4: Building and Using Social Support
Week 5: Self-Care and Balancing Caregiving Roles
Week 6: Managing Emotions and Stress
Week 7: Family Dynamics and Collaborative Caregiving
Week 8: Reflection and Planning Ahead

- Carers join 8 weekly online Zoom sessions, co-led by a **healthcare professional** and a **carer (peer supporter)**.

PPI in Research Stages

Online Intervention for Caregivers of People with Dementia

4. Is it feasible in practice?

Pilot & refinement

PPI: Guiding pilot evaluation and refinement

Group A: 7 carers
Led by an Occupational Therapist and a peer supporter

Group B: 8 carers
Led by a Speech and Language Therapist and a peer supporter

Feasibility test

- Reviewed and refined the post-intervention interview guide
- Suggested collecting reflections from the facilitators
- We finally named our intervention as "Carer Circles"
- Interpret the findings.

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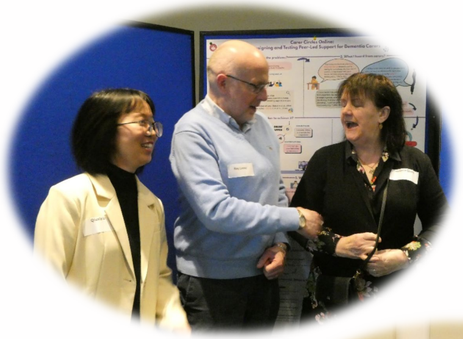
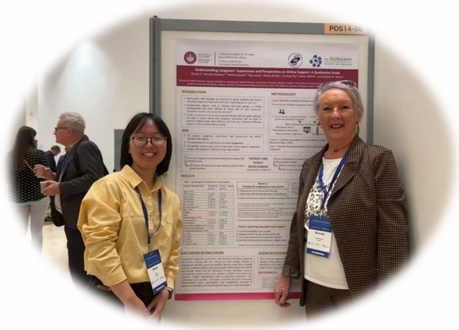
Some Reflections

Principles that really resonate with me:

- ✓ *Flexible Involvement*
- ✓ *Open Communication*
- ✓ *Trust and Respect*





Get in touch: Q.li6@ universityofgalway.ie (Qiuxia Li)

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Lessons learned from

THE PEOPLE'S REVIEW

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The People's Review is a systematic review **co-created** online with members of the public

Systematic Review

Carefully combine the results from multiple studies investigating the same thing

Systematic Review

Systematic reviews are the cornerstone of evidence-based healthcare

Systematic Review

They are not well understood or co-produced with the public

To support the public to understand **what** reviews are and **why** they matter

To support the public to be able to **think critically** about health claims and **use reviews** to support decisions

To develop and test a **novel online approach** to involving the public in a review


What participatory approaches?

Patient & Public Involvement

ACTIVE Framework

(Pollock et al., 2019)

At what stage in the review process did involvement occur?

What was the level of involvement (at each stage)?

Leading

Controlling

Influencing

Contributing

Receiving

Citizen Science

(ECSA, 2015)

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Layers of
involvement

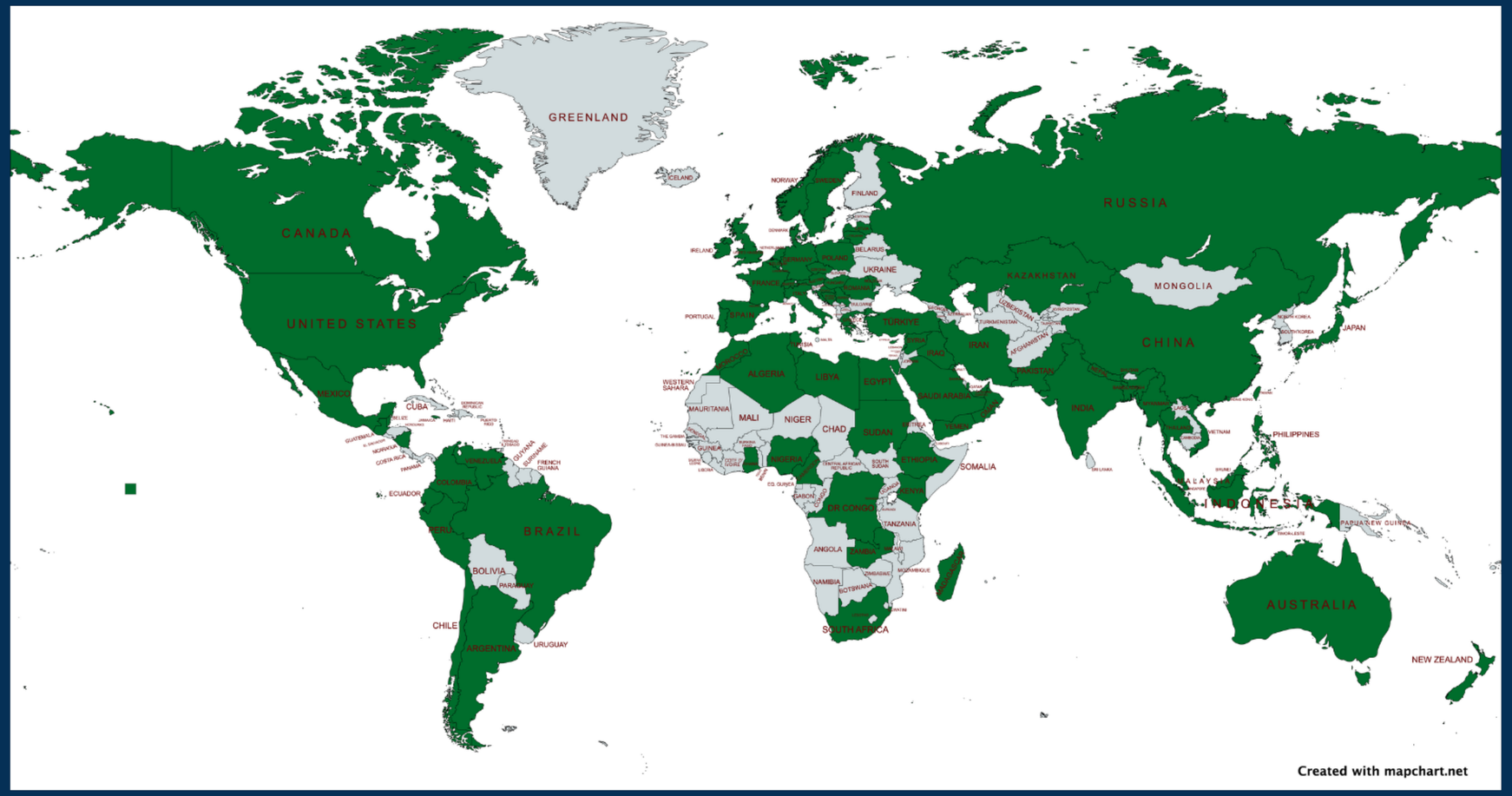
STEERING GROUP

Patient & Public Involvement (PPI)

‘The People’

Citizen Science

600+ people from 85+ countries



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How it works


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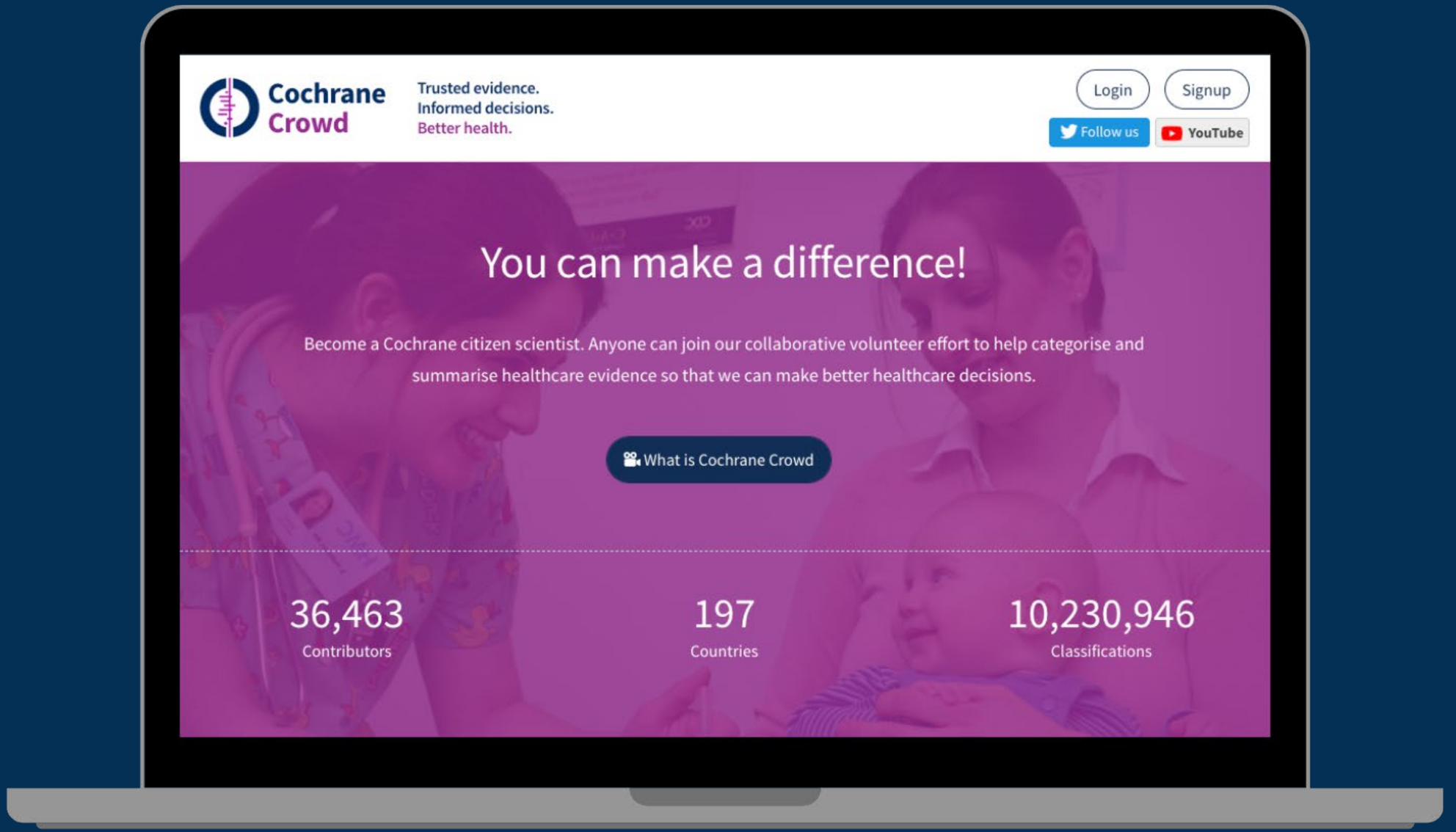
How The People's Review will work.
Everything takes place online.
1: Suggest a Question
All good reviews start with a good question. We would like you to suggest questions we might use for The People's Review.
Coming soon



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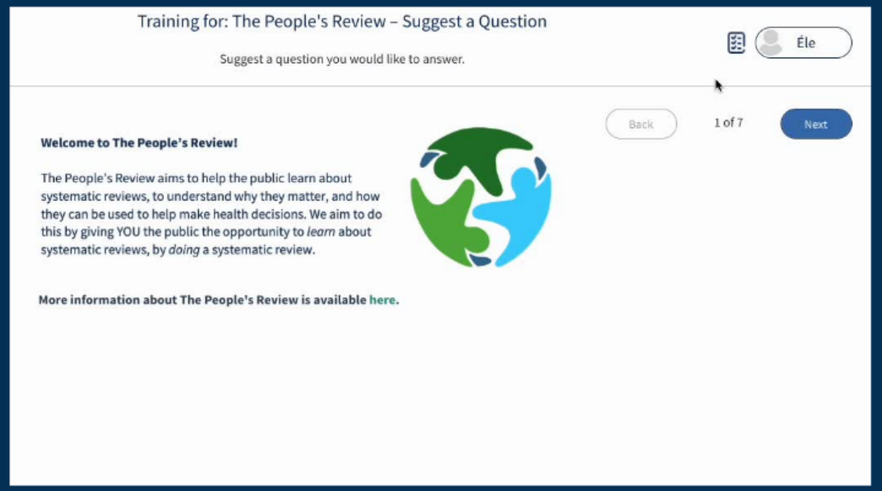
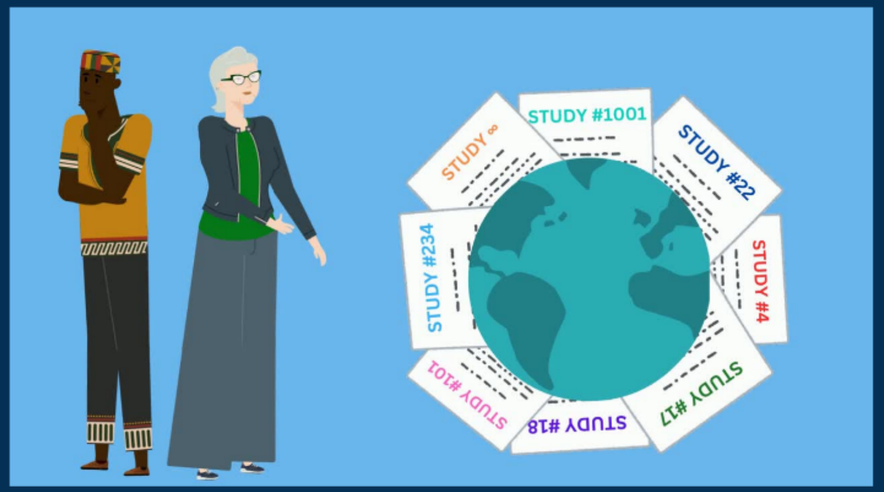
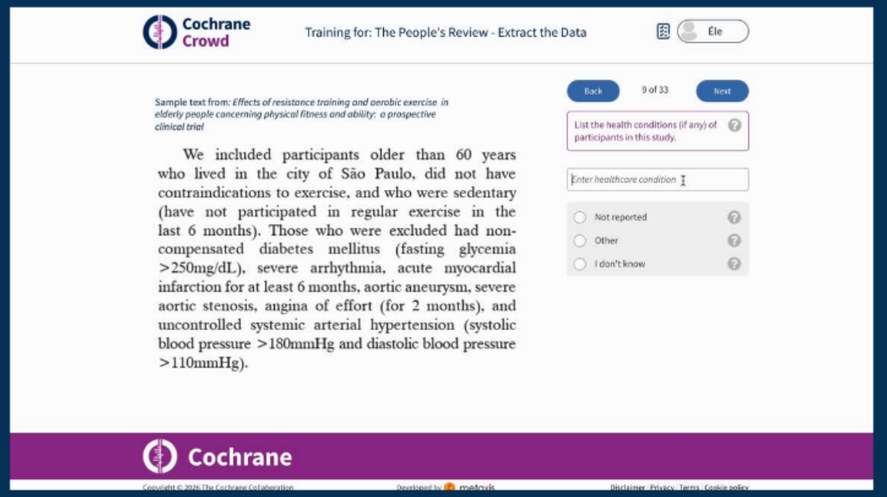
Bespoke Training







Learning-by-doing

The People's Review - Extract the Data

Pull out important information from the studies

Éle

Journal of Geriatric Oncology 13 (2022) 152–160

Contents lists available at ScienceDirect

Journal of Geriatric Oncology

A randomized-controlled trial comparing supervised aerobic training to resistance training followed by unsupervised exercise on physical functioning in older breast cancer survivors

Kerri M. Winters-Stone [a,b,*], Britta Torgrimson-Ojerio [d], Nathan F. Dieckmann [a,e], Sydnee Stoyles [a], Zahi Mitri [b], Shiuh-Wen Luoh [b,c]

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ABSTRACT

Introduction: This study compared the relative efficacy of aerobic training to resistance training on physical functioning in older breast cancer survivors and determined whether benefits could be maintained by transitioning to unsupervised home-based training.
Materials and methods: Early-stage, post-treatment, older (≥65 years) breast cancer survivors ($n = 114$; mean age 72 years) were randomized to 12 months of supervised aerobic ($n = 37$), resistance ($n = 39$) or stretching (active control; $n = 38$) training followed by 6 months of unsupervised home-based training. Outcomes included aerobic capacity by 6-min walk distance (6MWD; m), maximal upper and lower body strength (1-repetition maximum; kg); physical function by short physical performance battery (SPPB), SF-36 and Late Life Function and Disability Instruments.
Results: Over 12-months of supervised exercise, all groups improved in muscle strength and SPPB scores, but resistance trained women also improved 6MWD. Improvements in upper and lower body strength in the resistance group were significantly greater than those in the stretching control (+2.5 kg vs. +1.8 kg; $p = 0.05$) and aerobic

Back | Next

In what countries did the study take place?

Enter country

- Not reported
- Other
- I don't know

Supporting text

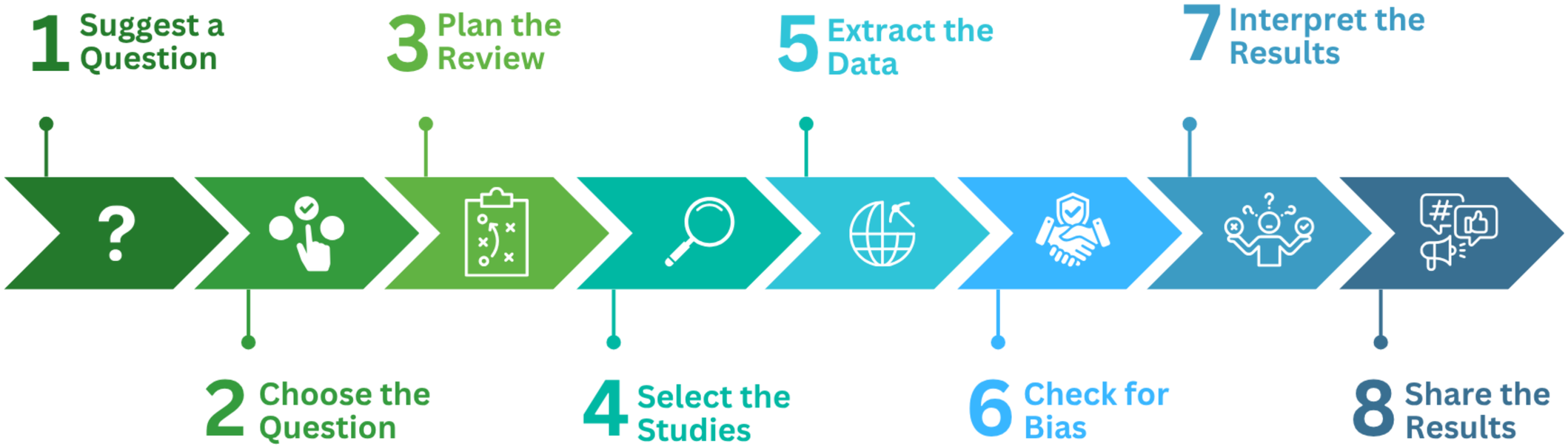
Show hints

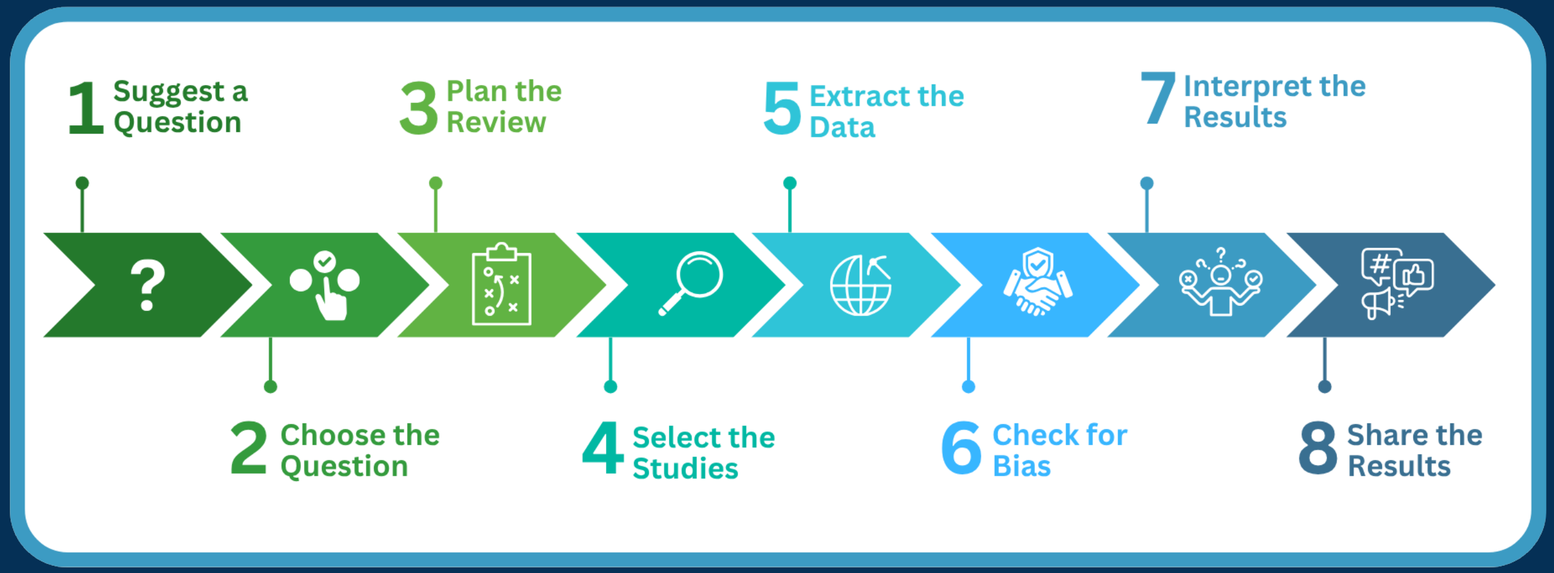
Notes

Quick reference guide

Previous study | Skip study | Next study

Stages of The People's Review





What did the People do?

1. Suggested 195 questions
2. Choose the question
3. Planned the review and co-authored the protocol
4. Screened 5798 abstracts
5. Extracted data from the 44 included studies
6. Checked for flaws in the studies
7. Made sense of the results
8. *Coming soon* : decide how the results should be shared and co-author the review

Does resistance training make a difference to quality of life or heart health for older adults compared to aerobic exercise?

Reflections from The People's Review

- Flexibility, accessibility & engagement!!
- Be honest and open
- Accessibility vs. accuracy
- Ask for help – you are not expected to be the expert in everything!
- There is no 'right' way but there is a 'wrong way'
- This work takes time
- Keep it simple
- Where/how you will involve people is not always obvious, it will emerge

More information:

www.thepeoplesreview.ie

The People's Review

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@thepeoplesrev

Quinn *et al. Research Involvement and Engagement* (2025) 11:28
https://doi.org/10.1186/s40900-025-00682-7

Research Involvement and Engagement

PLOS One

PROTOCOL Open Access

The People's Review protocol: planning an innovative study powered by the public

Éle Quinn[1*], Shoba Dawson[2], Jeremy Holt[3], Shahed Hossain[4], Patricia Logullo[5], Ann O'Brien[6], Maureen Smith[7], Derek Stewart[8], Shaun Treweek[9], Charlene Young[10], Chris Noone[11], David Moher[12] and Sinéad M. Hynes[13]

STUDY PROTOCOL

Does resistance training make a difference to the quality of life or heart health for older adults compared to aerobic exercise? A systematic review protocol from The People's Review

Éle Quinn[1,2,3*], Laura Bosner[4], Patricia Logullo[5], Kevin Murray[6], KM. Saif-Ur-Rahman[2,3], Charlene Young[7], Derek Stewart[7,8], Maureen Smith[7], Jeremy Holt[7], Shaun Treweek[9], Chris Noone[10], David Moher[11], Sinéad M. Hynes[1], The People[¶]

EVIDENCE SYNTHESIS IRELAND

Cochrane Ireland

HRB An Bord Taighde Sláinte Health Research Board

HSC Public Health Agency Research and Development

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Cochrane Crowd

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Practical case study

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Project:

Understanding Personal Factors Influencing Cardiac Rehabilitation Engagement and Developing Consensus-Based Recommendations: A Multi-Phase Study

Background:

Cardiovascular disease remains a leading cause of morbidity and mortality worldwide. Cardiac rehabilitation (CR) is a comprehensive secondary prevention programme that has been shown to improve physical functioning, psychological wellbeing, and cardiovascular outcomes. Despite its well-established benefits, participation in CR remains suboptimal. Many eligible patients decline referral, delay enrolment, attend only a limited number of sessions, or discontinue participation before programme completion.

Existing research has identified a range of factors associated with CR participation, including demographic characteristics, clinical status, health literacy, social support, psychological wellbeing, and healthcare system factors. However, less is known about how these factors interact and influence patients' decisions to attend, engage with, and sustain participation in CR over time.

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Aim: to understand how personal factors influence engagement with CR and to develop consensus based recommendations to support participation and sustained engagement.

Design:

- Phase 1: Scoping Review – To identify personal factors influencing CR engagement and map intervention strategies targeting these factors.
- Phase 2: Qualitative Interview Study – To explore how personal factors influence patients' decisions to attend, engage with, and sustain participation in CR. (Interview with patients and healthcare professionals
- Phase 3: Consensus development – To prioritise key personal factors and develop practical recommendations for improving engagement with cardiac rehabilitation, using Nominal Group Technique (NGT). (Participants are patients and healthcare professionals)

Questions:

1. Who should be involved in this project?
2. Why involve these people?
3. When should they be involved? (What stages of the research process?)
4. What are the people involved actually going to do?
5. How are the researcher going to support the involvement?

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Thank *you*

Questions?