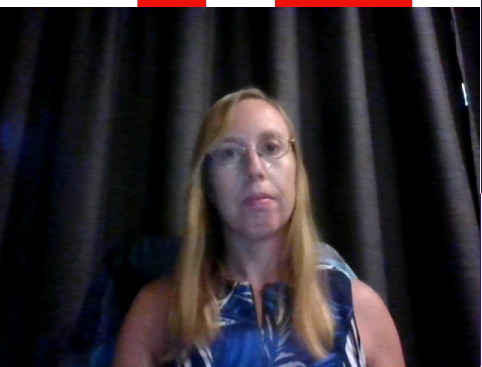# Insights from an ethical toolkit for "Sharing Power with Communities in Priority-Setting for Health Research Projects"

Dr Bridget Pratt

Senior Lecturer in Healthcare Ethics, Queensland Bioethics Centre

November 1, 2022

Bridget.Pratt@acu.edu.au

What is the toolkit?

- A reflective project planning aid for use before priority-setting is undertaken for a health research project.

- Helps researcher and community partners design a priority-setting process where power is shared more evenly.

Sharing Power with Communities in Priority-Setting for Health Research Projects: A Toolkit

How was it developed?

- Development of the toolkit occurred over a 3-year period of *conceptual* and *empirical* ethics research.
  - 51 in-depth interviews and 1 focus group were performed as well as 2 case studies.

Sharing Power with Communities in Priority-Setting for Health Research Projects: A Toolkit
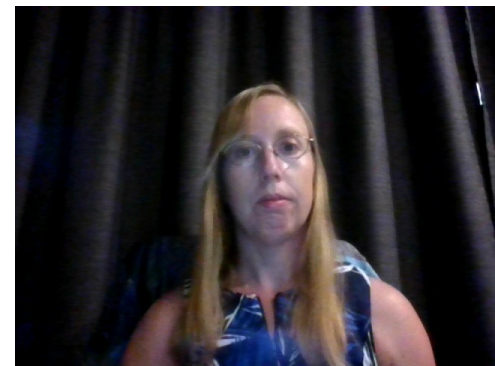
What is in the toolkit?

- The toolkit is a set of four worksheets and a companion document
    - Worksheet 1: Selecting Partners
    - Worksheet 2: Deciding to Partner
    - Worksheet 3: Deciding to Engage with the Wider Community
    - Worksheet 4: Designing the Priority-setting Process

- It is freely available at: https://www.researchforhealthjustice.com/r4hj-framework

Sharing Power with Communities in Priority-Setting for Health Research Projects: A Toolkit
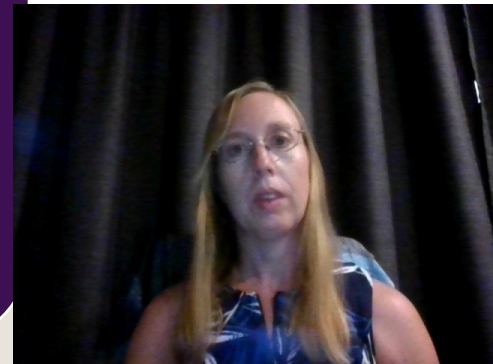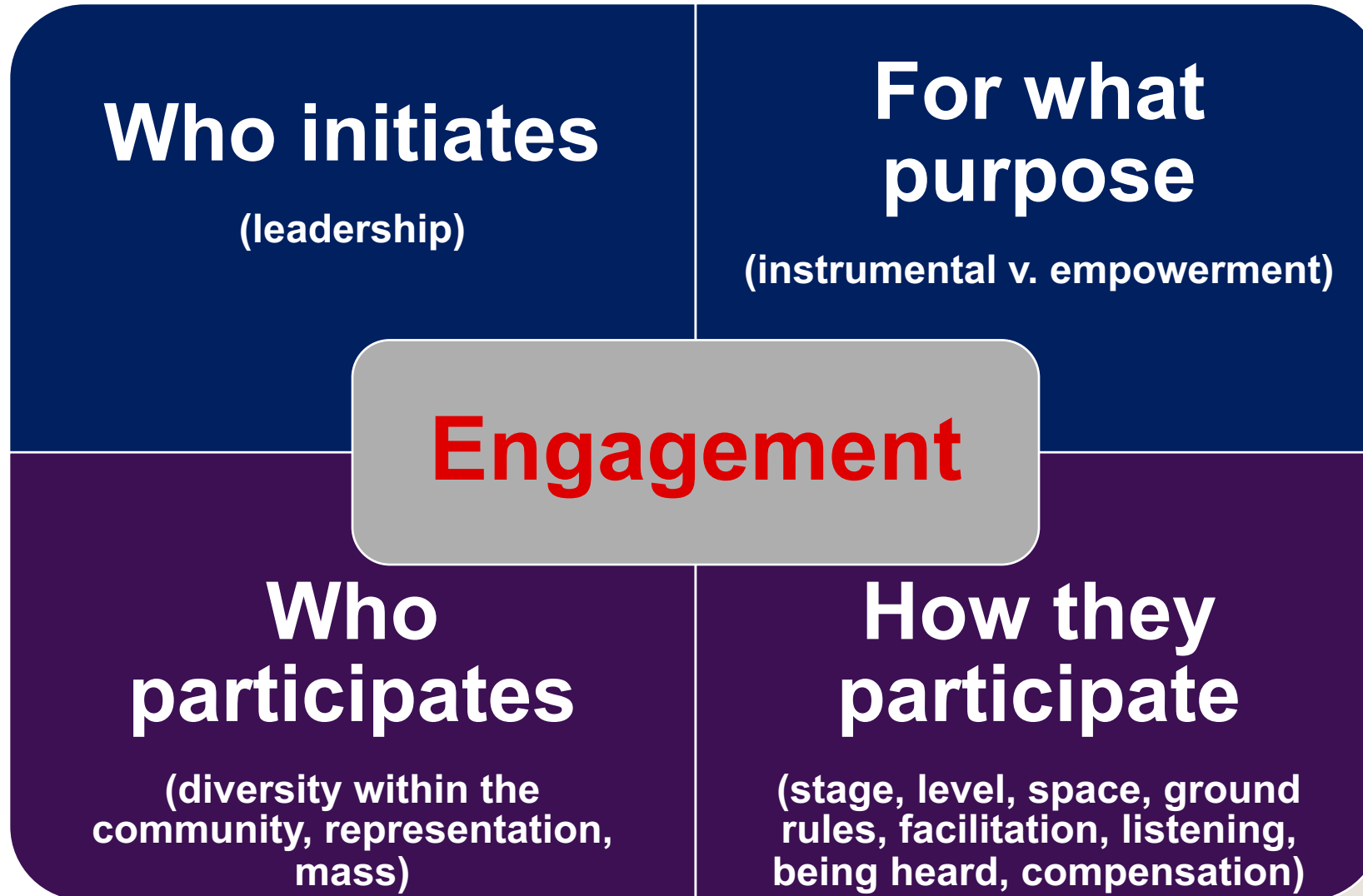
Worksheet 4: Designing the Priority-setting Process

Reflecting on and collectively answering Worksheet 4 questions will promote the design of priority-setting processes where power is more evenly shared with communities, particularly those considered disadvantaged and marginalised.
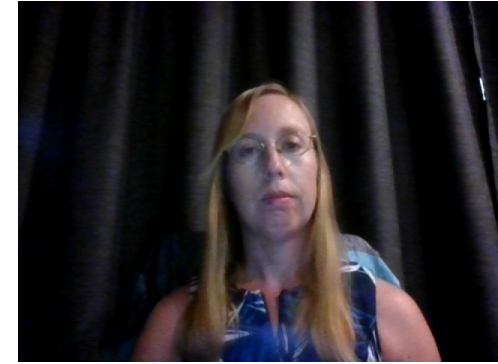
Deconstructing engagement

Who initiates

(leadership)

For what purpose

(instrumental v. empowerment)

Engagement

Who participates

(diversity within the community, representation, mass)

How they participate

(stage, level, space, ground rules, facilitation, listening, being heard, compensation)

Sites of power

- **Leadership**
- Empowerment
- **Diversity within community**
- Representation
- **Mass**
- Stage of participation

- Space
- Ground Rules
- Level of participation
- Facilitation
- Listening
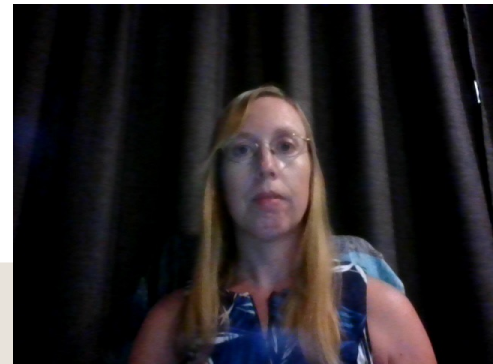- Being heard
- Compensation

Each site has associated ethical considerations (and worksheet questions)!

Leadership

- **Ethical consideration/Worksheet question:** Who will lead the health research project?
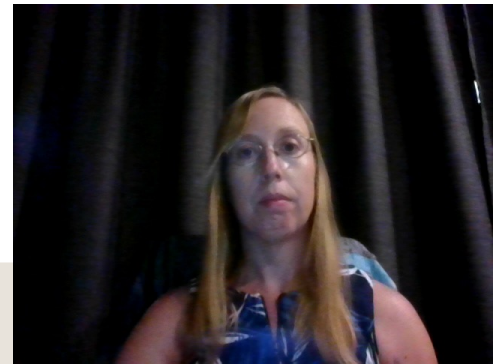
"I think we oftentimes say, those who set the table often control the table."
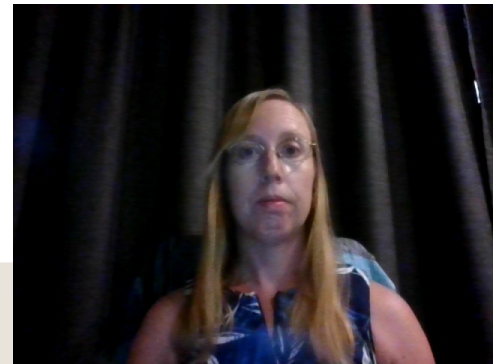
(Development researcher, UK)

Leadership

- **Meaningful engagement practice:** To avoid reinforcing unequal power dynamics, it is important that locally-based researchers and community partners are amongst those leading health research, including any engagement done with the wider community as part of it.
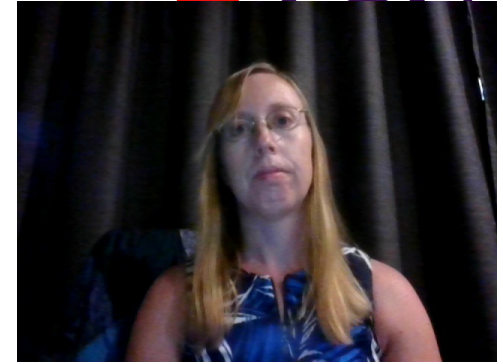
Diversity and mass

- **Ethical considerations/Worksheet questions:** Are a range of community members being engaged?

- Will the number of community partner staff and community members participating in decision-making be greater or equal to academic partner staff
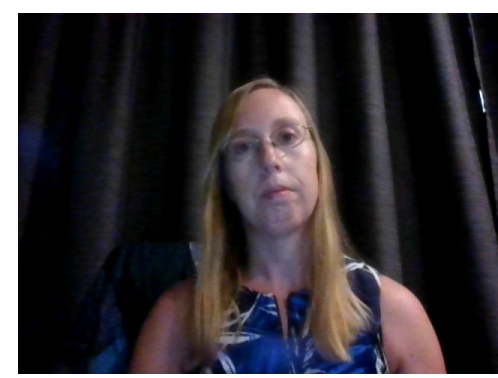
Diversity and mass

- **Meaningful engagement practice:**
- Achieving range means that participants span a wide spectrum of roles in a community and include those considered disadvantaged, lower status, or marginalised within the community.
- To ensure that the powerful and/or those who typically have a voice in health research do not dominate decision-making by force of numbers, it is necessary to balance power through equality or slight inequalities in numbers.
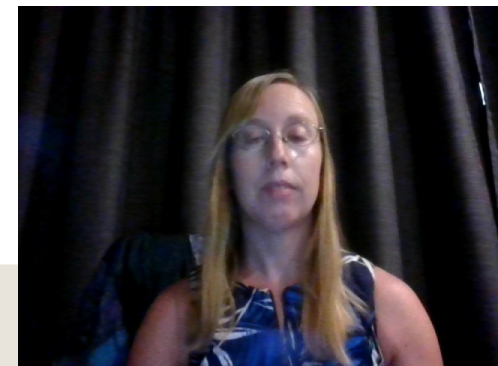
Dilemma

- A community organization was given leadership but, as a result, diversity of community and mass were not achieved.

- In the context of a maternal and child health research project in India, a community organization was given the power to identify the maternal and child health service access problems facing their community and to identify interventions to address the problems. But the community organization consisted of many more men than women. While data on problems was collected from a diversity of women in the community, no women participated its analysis or in the final selection of the intervention and few were present at the deliberative workshop to prioritize amongst the identified problems (i.e. 3 women and 57 men).

- **Question: If your longstanding community partner had such weaknesses in terms of representation, what would you do?**

Papers about navigating ethical dilemmas that arise when sharing power with communities
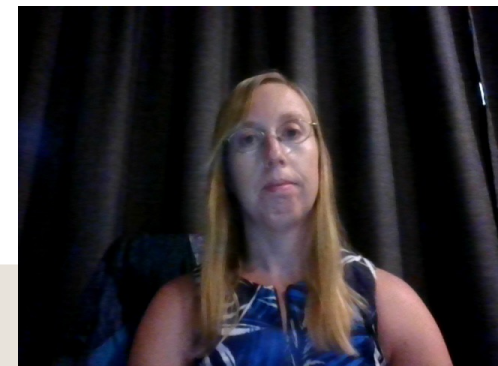
Pratt, B., Seshradi, T, & Srinivas, P.N. (2022). "Overcoming structural barriers to sharing power with communities in global health research priority-setting: Lessons from the Participation for Local Action project in Karnataka, India." *Global Public Health*, DOI: 10.1080/17441692.2022.2058048

Pratt, B., Seshradi, T, & Srinivas, P.N. (2022). "How is inclusiveness in health systems research priority-setting affected when community organizations lead the process?" *Health Policy and Planning* https://doi.org/10.1093/heapol/czac012

Take home messages

- There are a lot of ethical considerations involved when seeking to share power with communities in setting research topics and questions and in decision-making in health research projects.

- The **ethical toolkit** can help you and your partners think through these considerations to design a priority-setting or decision-making process where power is more evenly shared.
  - https://www.researchforhealthjustice.com/r4hj-framework

- Ethical dilemmas will arise when trying to share power and to address the ethical considerations in the toolkit.

- Sharing power is complicated! But ethically essential.

My email: bridget.pratt@acu.edu.au

Toolkit website: https://www.researchforhealthjustice.com/r4hj-framework