

To Empower... or to Give (Up) Power?

Redistributing research authority with people affected by leprosy in India.

What would be the most radical form of participation?



Sharing "rivers of life" during training

The Challenge

The structures that historically excluded people affected by leprosy from social and political life also shape their exclusion from producing research knowledge about their own lives. Addressing this requires more than the language of "empowerment" or "consultation": it requires those holding institutional power to give some of it up — over agendas, over funding, over who is recognised as a legitimate knowledge producer.

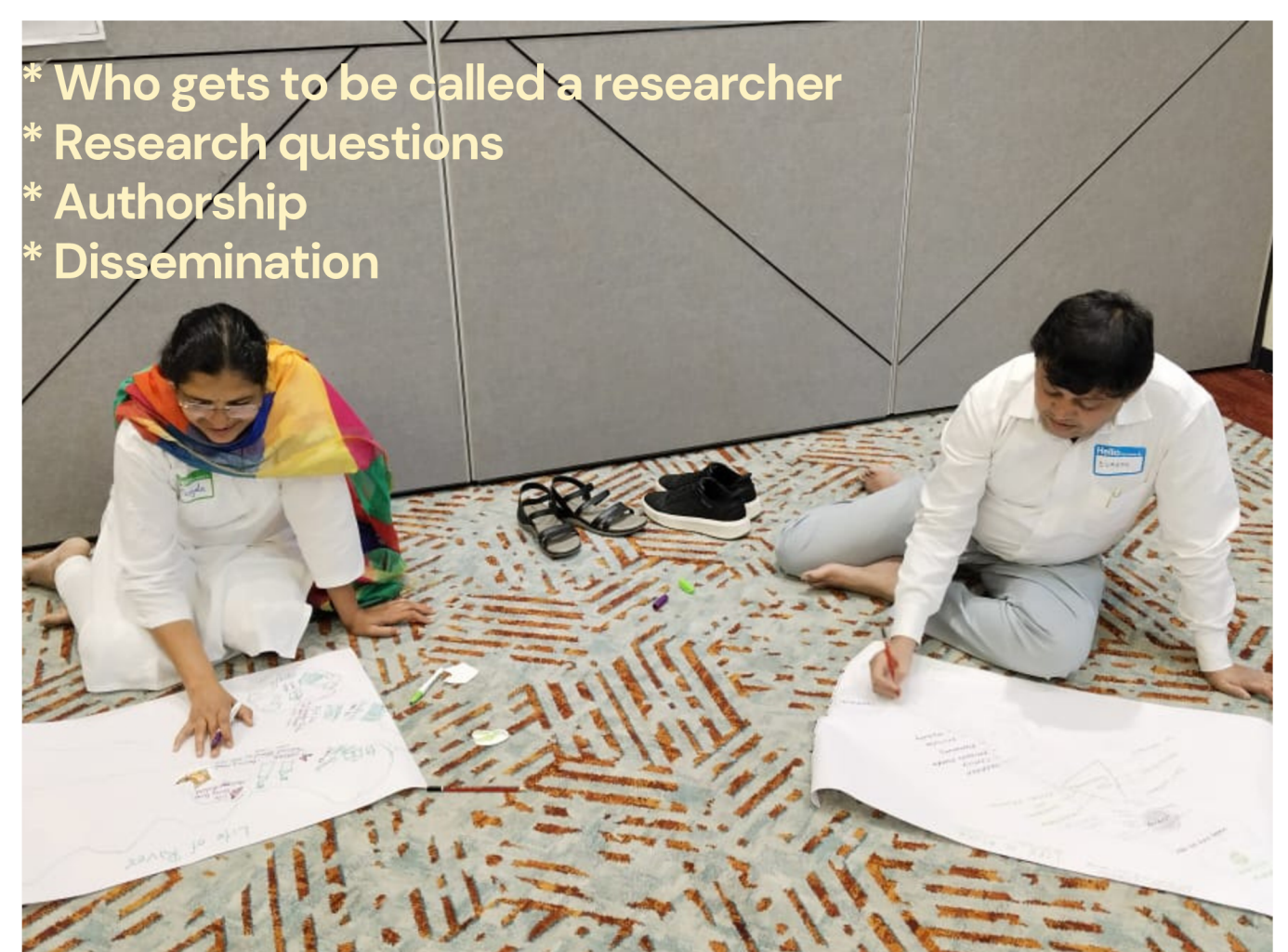


New researcher presenting ideas for research questions

The most radical form of participation would be for people affected by leprosy to set their own agendas, define questions, and conduct research themselves.

What We Learned

Participants quickly learned to do high quality qualitative research. The greatest change, however, was confidence and identity—they began to see themselves as **researchers**. Inclusive research isn't about inviting people into existing research systems. It is about sharing the authority to produce knowledge, whether in India or in the ARC KSS region. That means sharing decisions about:



- * Who gets to be called a researcher
- * Research questions
- * Authorship
- * Dissemination

"Do not be afraid. Research is not only for highly educated people." *One new researcher's advice for others.*

Our Approach.

Through practical, participatory training, people with lived experience of leprosy in India led every stage of the research process. They identified the issues that mattered to them, developed their own research question, designed interview guides, collected and analysed qualitative data, and presented their findings nationally and internationally.

- 15 new researchers given practical training
- 1 new Principal Investigator with lived experience
- 1 ethics board exposed to research led by people with lived experience
- 4 international conference presentations

The Team

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