

# Take the next step on deepening lived experience expertise in social care research

SIREN National Research Meeting

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# Who are we?



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Independent Consultant



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# Workshop Goals

- Make connections and share learnings among individuals with a shared interest in deepening lived experience expertise in social care research.
- Whether that be...
  - o Taking the first step today
  - o Connecting around specific challenges or barriers
  - o Identifying the next step along the continuum of engagement

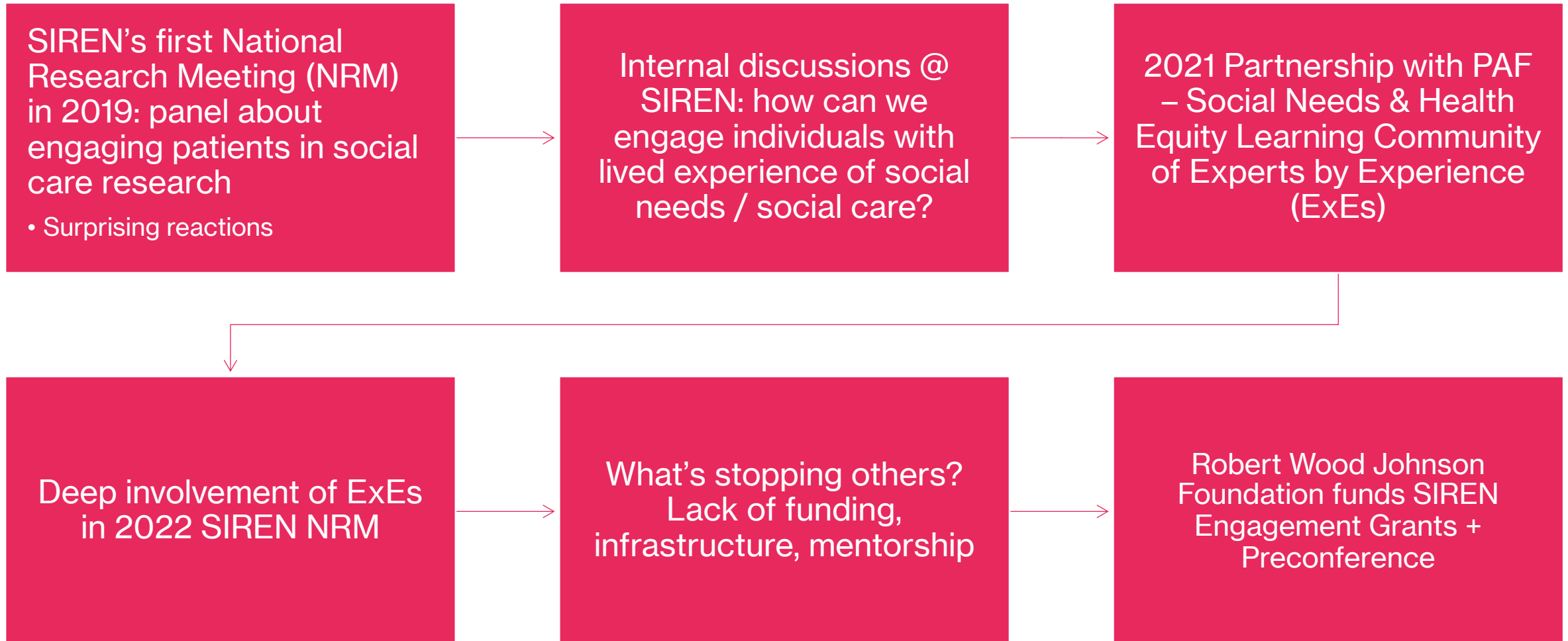
# — Agenda

- Introductions and level-set (15 min)
- Breakout groups (30 min)
- Room discussion (25 min)
- Closing (5 min)

# Why lived experience expertise is critical to social care research

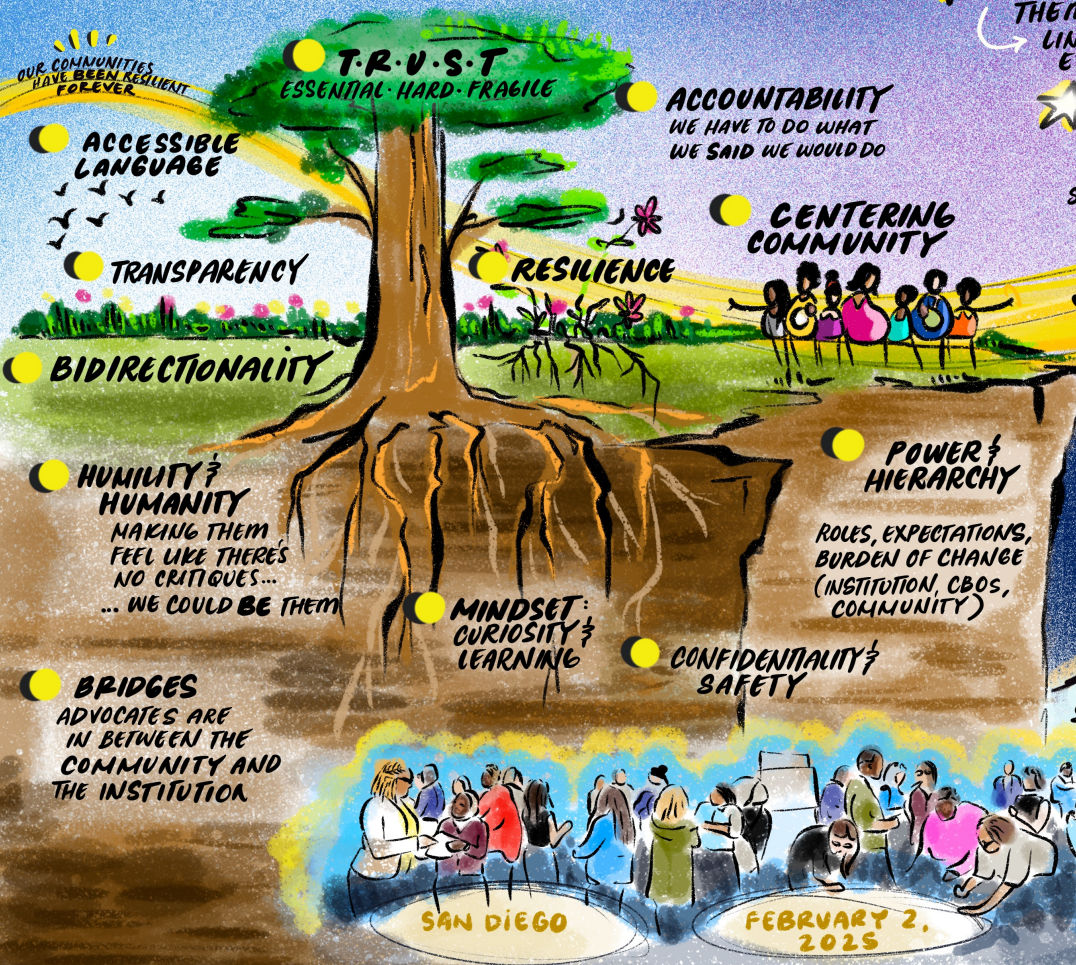
- Social care research aspires to address inequities, however achieving this requires researchers to improve and deepen their partnerships with individuals and communities impacted by social needs and interventions.
- Those most affected by these issues are the experts of their lived experiences and should play an active role in designing solutions.
- There is a larger movement with increasing energy to engage individuals with lived experience across all stages and activities of the research continuum.

# SIREN's engagement odyssey

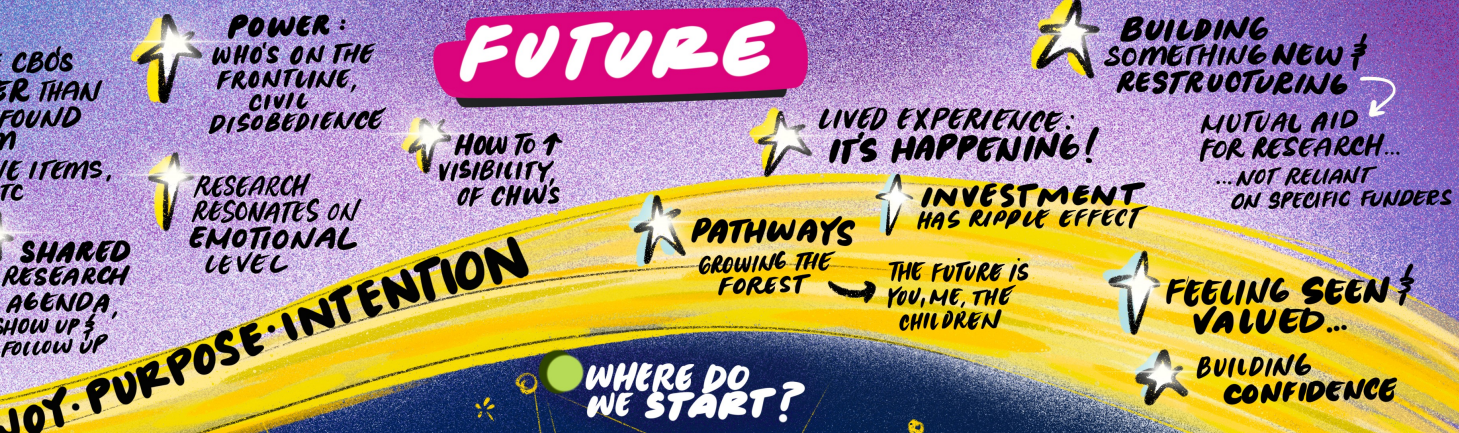


# SIREN SOCIAL CARE RESEARCH ENGAGEMENT GRANTS · GRANTEE CONVENING

## LEARNINGS



## FUTURE



## SOLUTIONS



## UNCERTAINTIES



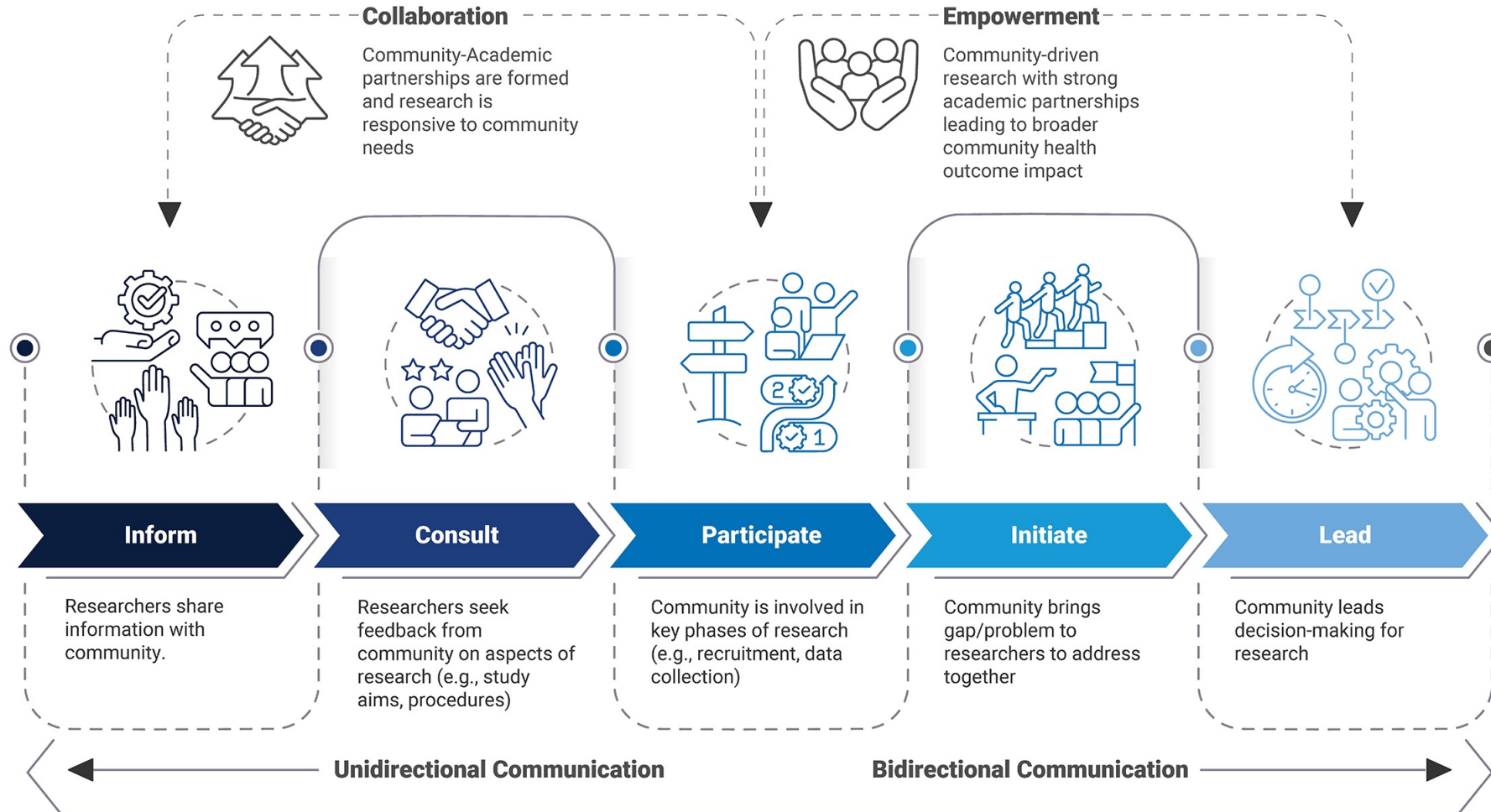


# QUICK POLL

1. What's your experience level?
2. What are your burning questions?



# The engagement continuum



# What are some of the different forms “engagement” can take?

- Focus group or key informant interviews
- Community advisory/advocacy board or workgroup
- Equal partner in developing and conducting research
  - o Develop research question
  - o Review questionnaires and interview guides
  - o Advise on recruitment and retention strategies
  - o Interpret findings
  - o Design infographics
  - o Co-author publications and other communications
- What to avoid: tokenism
  - o Strive to maintain environment of openness & learning, transparency & trust

PCORI is committed to Patient and Community involvement. They emphasize that interest holder engagement in research is early, ongoing, sustainable and meaningful.

## FOUNDATIONAL EXPECTATIONS FOR PARTNERSHIPS IN RESEARCH



# Recommended resources

- SIREN antiracism guidelines - <https://tiny.ucsf.edu/SIRENantiracism>
- Fair market value calculator or SOL wages <https://nationalhealthcouncil.org/fair-market-value-calculator/>
- PCORI Foundational Expectations - <https://www.pcori.org/engagement-research/engagement-resources/foundational-expectations>
- UCSF community engagement toolkit - <https://communityengagement.ucsf.edu/>
- Detroit Community-Academic Urban Research Center - <https://detroiturc.org/>



# **Time for breakouts!**

Sit at the table that best represents your experience level or interest!

Table facilitators will guide the discussion.

# Post-Breakout Discussion

- Something that challenged your way of thinking
- Something you didn't agree with or felt some tension about
- Something that felt inspiring or empowering

*Try to stick to sharing about just one thing and going deeper – this is not a report-back!*

# Closing exercise

- Write on your postcard:
  - What's one thing you are going to apply to your work?