

# Stakeholder Engagement and Open Innovation: A Range of Community Engagement Approaches

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December 16, 2021



# Objectives



- Provide a rationale for engaging stakeholders;
- Describe definitions, examples, important considerations, recommendations; and
- Discussion - Identity, disclosure, trust

## Acknowledgements

- Our funders include PCORI, NLM, NIDILRR, NSF.
- Our teams are diverse & inclusive; always include individuals with lived experience.
- Our partners include academic institutions, community agencies, advocacy groups, allies, & individuals.
- We are committed to translating research findings into accessible, useful resources to inform decision-making.
- Our dissemination modes include social media, videos, toolkits, technical assistance, etc., as well as journal articles.

## Key words to keep in mind: The proposed PCORI Research Agenda

- Inclusion
- Diversity
- Equity
- Disparities
- Health drivers where people live, work, learn, play
- Implementation
- Communication
- Access, understand, act

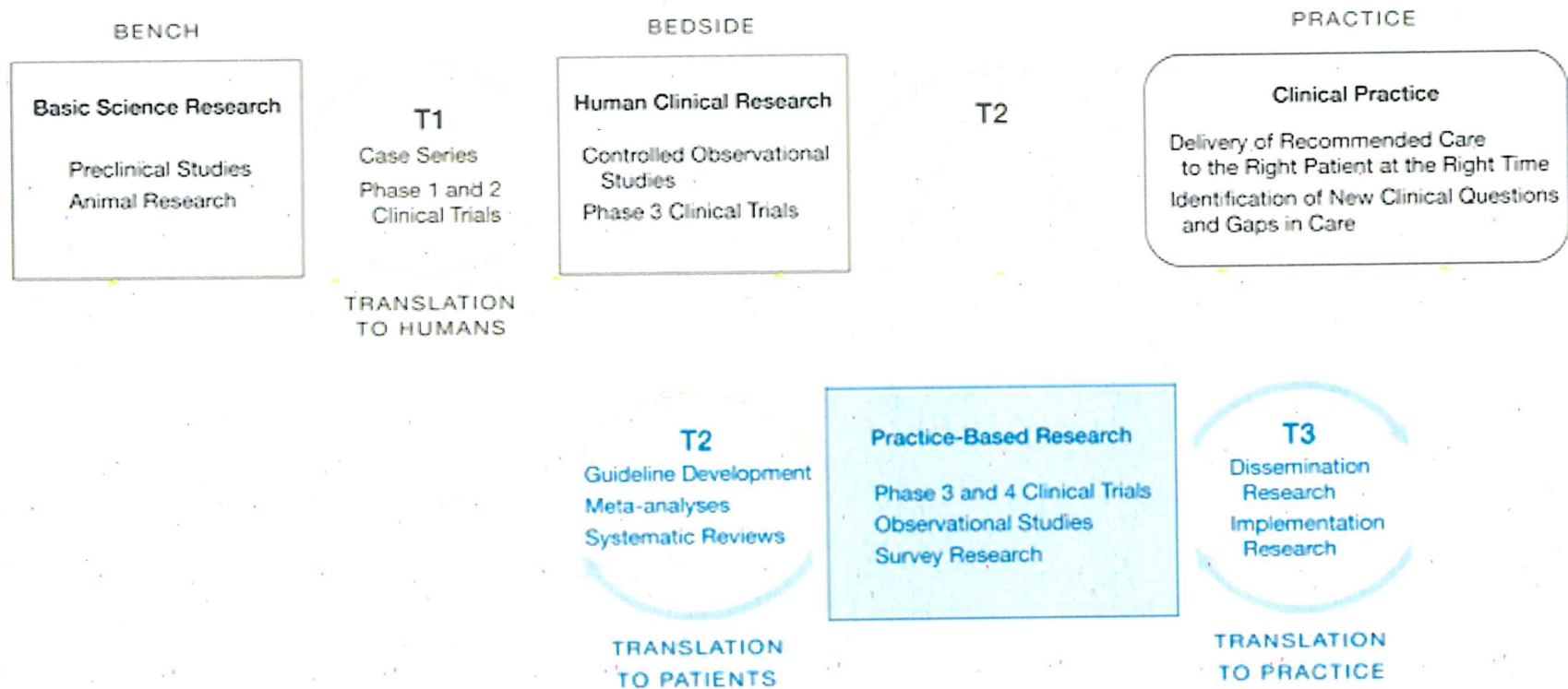


## What is Engagement in Research?

The meaningful involvement of *patients*, caregivers, clinicians, and other healthcare stakeholders throughout the entire research process--  
from planning the study, to conducting the study, and disseminating study results.

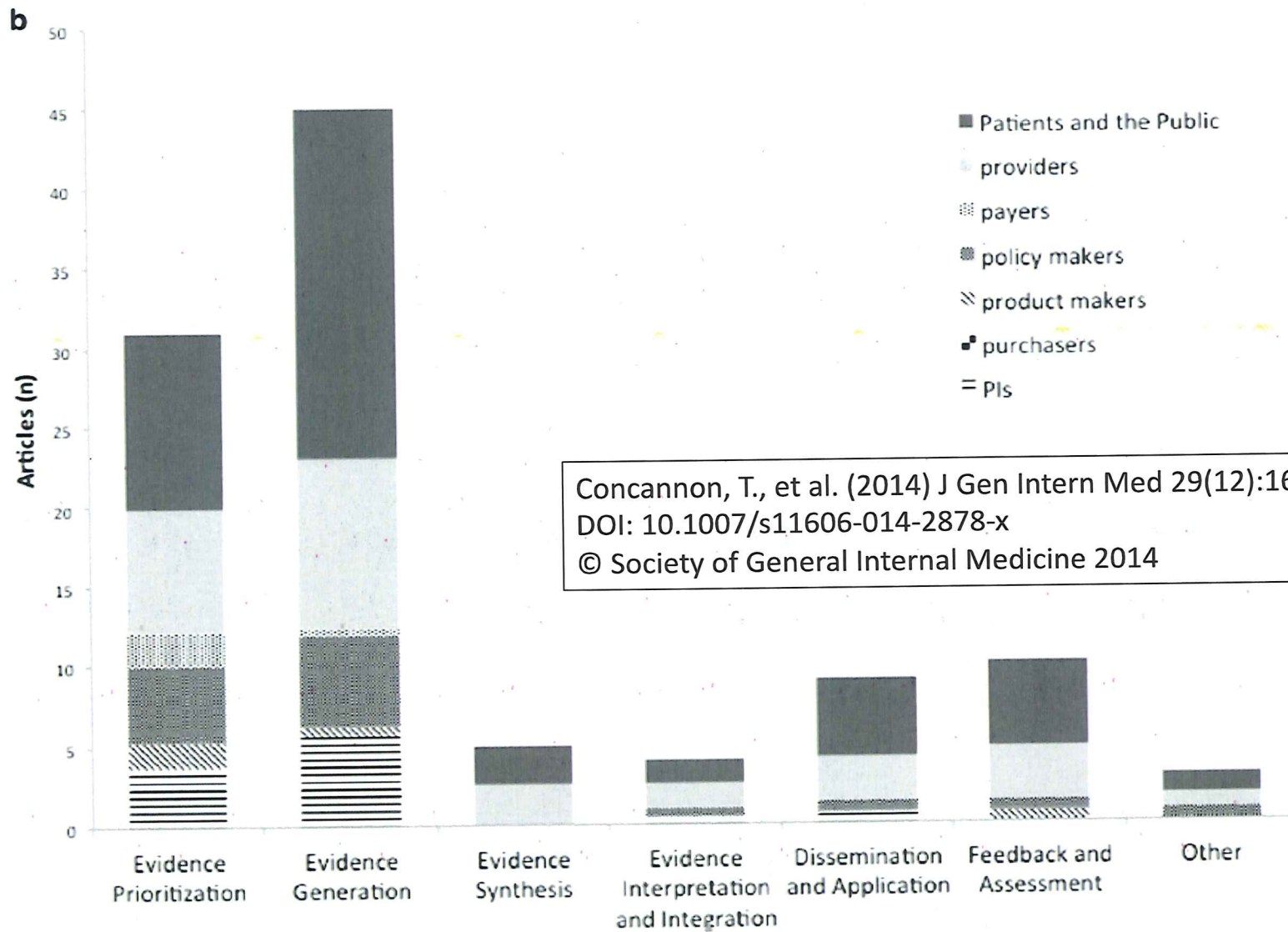
<https://www.pcori.org/engagement/value-engagement>





## US NIH. Blue Highways for Translation Research\*

\*(Westfall, Mold & Fagnan (2007). JAMA Jan 24;297(4):403-6.)



Concannon, T., et al. (2014) *J Gen Intern Med* 29(12):1692–701  
 DOI: 10.1007/s11606-014-2878-x  
 © Society of General Internal Medicine 2014

**What is Co-Production?**

A photograph of a piece of paper with the words "Co-Production" written in a typewriter font. The paper is slightly textured and has some faint, scattered red and yellow specks. The text is centered on the page.

Co-Production

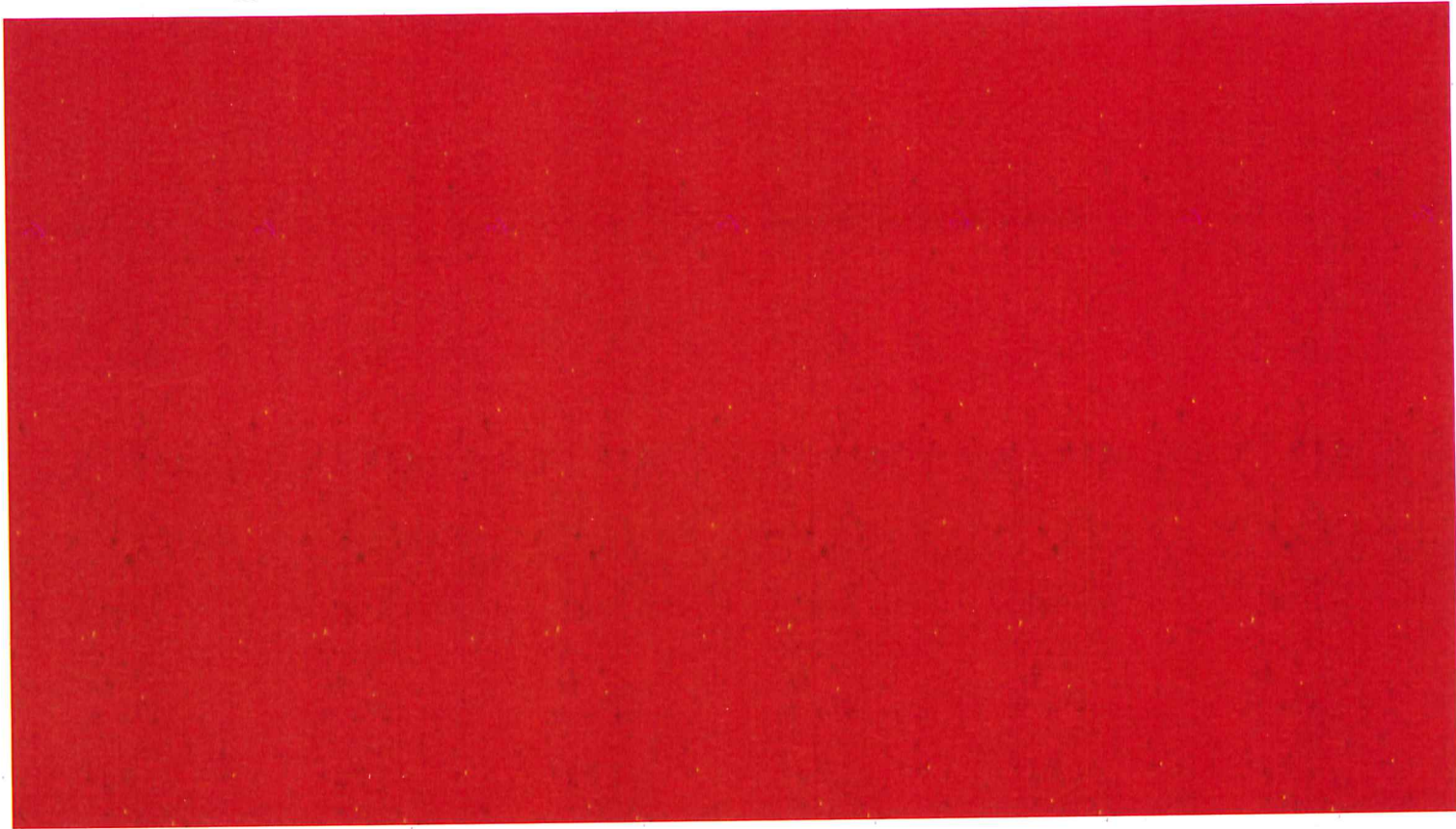
## What is Open Innovation?

Coined by Berkeley professor Henry Chesbrough, the term “open innovation” refers to the collaboration between companies, individuals and public agencies to create innovative products and services and, in the process, share its risks and rewards....This approach has yielded significant benefits in many fields, including healthcare, IT business models and public policy.

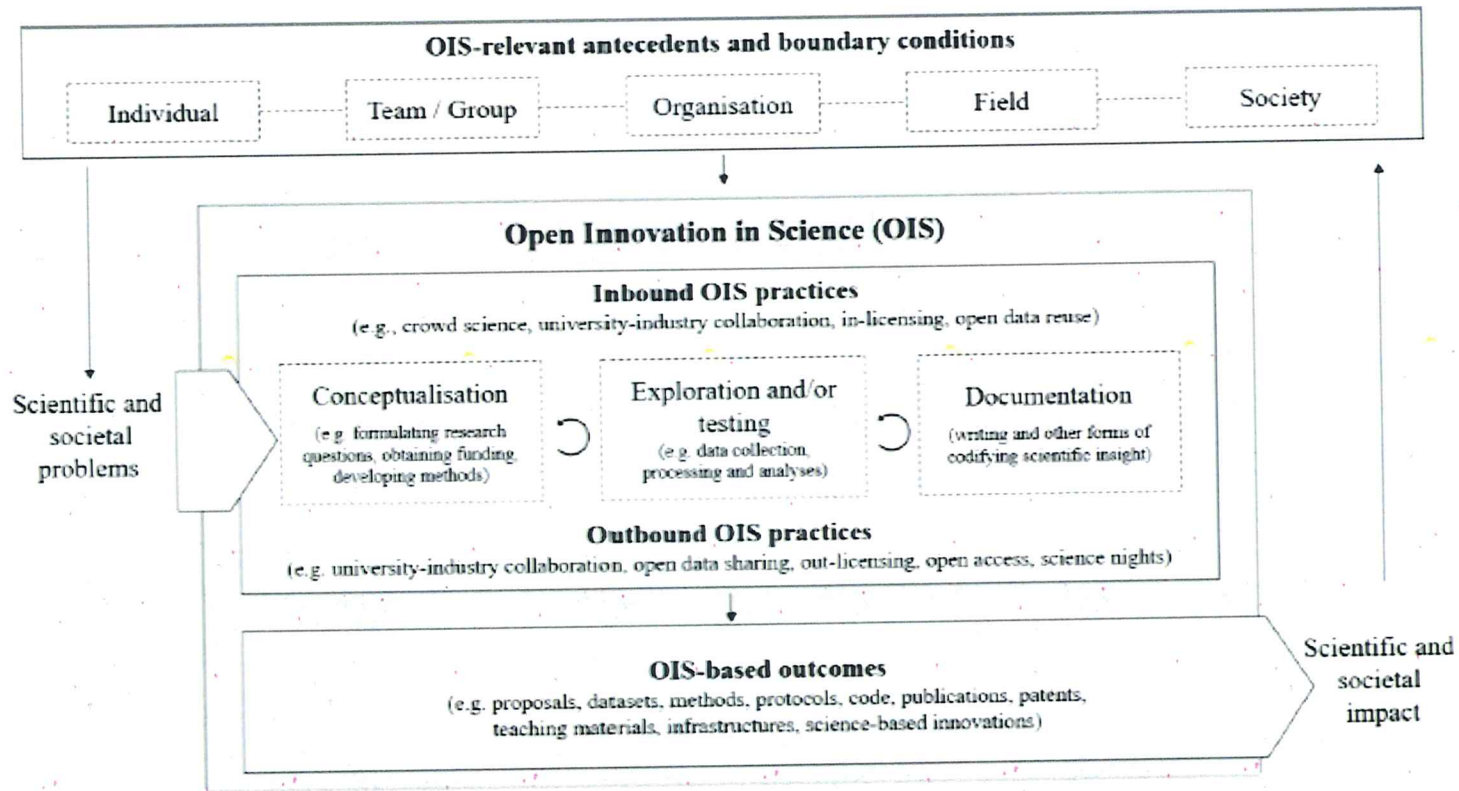
(e.g., West, J., Salter, A., Vanhaverbeke, W. & Chesbrough, H. (2014). Open innovation: The next decade. *Research Policy*, 43, 805-811.)



Breaking down walls...



Beck, et al. (2020). The open innovation in science research field: A collaborative conceptualization approach. *Industry and Innovation*. <https://doi.org/10.1080/13552716.2020.1792274>.



**Figure 1.** The OIS research framework. Note: 1) OIS is embedded in the wider context of science, including problems, antecedents and boundary conditions, and scientific and societal impacts. 2) OIS approaches scientific knowledge production and dissemination as an iterative process, meaning that scientific and societal impacts feed back into problems as well as antecedents and boundary conditions.



## The Costs\*

- Practical costs: administrative burden
- Personal costs to researchers: interpersonal conflict, burnout, stress
- Professional costs to researchers: independence & credibility questioned
- Costs to research *per se*: takes time, effort; no guarantee of outcome
- Costs to stakeholders: takes time from day job or home activities
- Costs to the research profession: credibility & utility of evidence questioned

\*(Oliver, K., Kothari, A. & Mays, N. (2019). The dark side of coproduction: Do the costs outweigh the benefits for health research? *Health Research Policy and Systems*, 17 (33). <https://doi.org/10.1186/s12961-019-0432-3>.)

## Why bother? The Benefits: Four Main Arguments\*

1. Substantive: to improve the quality of the research.
2. Instrumental: to see research findings utilized in effective ways.
3. Normative: there's intrinsic value (i.e., sharing expertise & power is more fair, more ethical.
4. Political: users (of research findings) feel empowered & included &, therefore, are more likely to act on findings.



\*Oliver, K., Kothari, A. & Mays, N. (2019). The dark side of coproduction: Do the costs outweigh the benefits for health research? *Health Research Policy and Systems*, 17 (33). <https://doi.org/10.1186/s12961-019-0432-3>.

## Funders may require engagement: PCORI Review Criteria

### **Criterion 6. Patient and stakeholder engagement**

“The application should demonstrate the engagement of relevant patients and other stakeholders (e.g., patients, caregivers, clinicians, policy makers, hospital and health system representatives, payers [insurance], purchasers [business], industry, researchers, and training institutions) in the conduct of the study.

Quality of engagement should be evaluated based on scope, form, and frequency of patient and stakeholder involvement throughout the research process.”

## PCORI (cont'd.)

### Engagement Plan

“Effective engagement of patients and stakeholders in research requires a well-thought-out plan. Therefore, all applications for PCORI research funding must include an Engagement Plan that outlines how stakeholder partners will be involved in all phases of the study.”

(<https://www.pcori.org/funding-opportunities/merit-review-process/merit-review-criteria/merit-review-criteria-broad-pfa>)



## Journals may require engagement: BMJ

“BMJ encourages active patient and public involvement in clinical research as part of its patient and public partnership strategy. To support co-production of research we request that authors provide a **Patient and Public Involvement statement** in the methods section of their papers, under the subheading ‘Patient and public involvement’. We appreciate that patient and public involvement is relatively new and may not be feasible or appropriate for all papers. We therefore continue to consider papers where patients were not involved. Please note that this practice is only applicable for Research Articles, Study Protocols, and Cohort Profiles.”

<https://bmjopen.bmj.com/pages/authors/>

Table 2   GRIPP2 short form		
Section and topic	Item	Reported on page No
1: Aim	Report the aim of PPI in the study	
2: Methods	Provide a clear description of the methods used for PPI in the study	
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	
4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	
5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	
PPI=patient and public involvement		

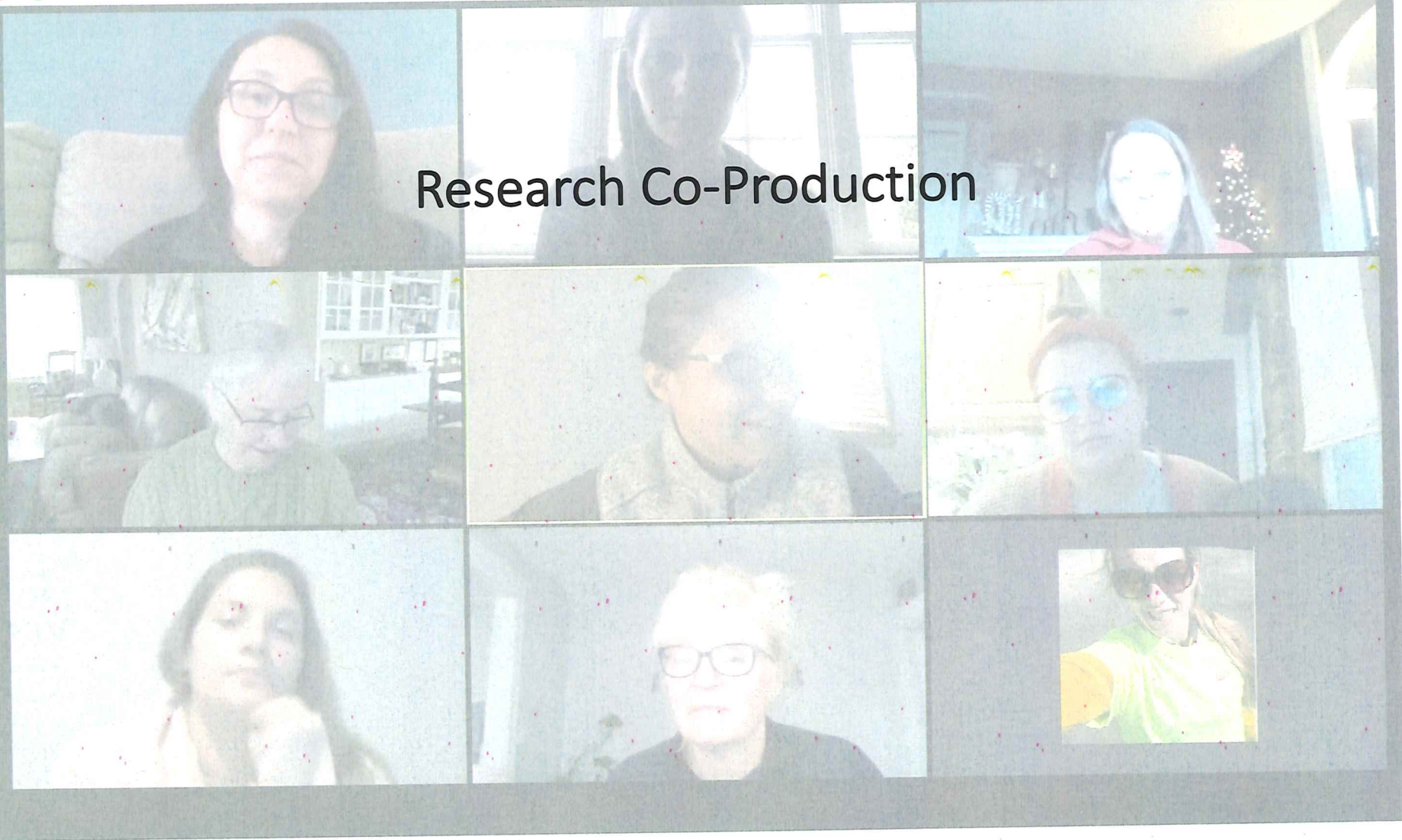
## Guidance for Reporting Involvement of Patients and the Public

Staniszewska, S., Brett, J., Simera, K., et al (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *BMJ* 2017;358:j3453 | doi: 10.1136/bmj.j3453





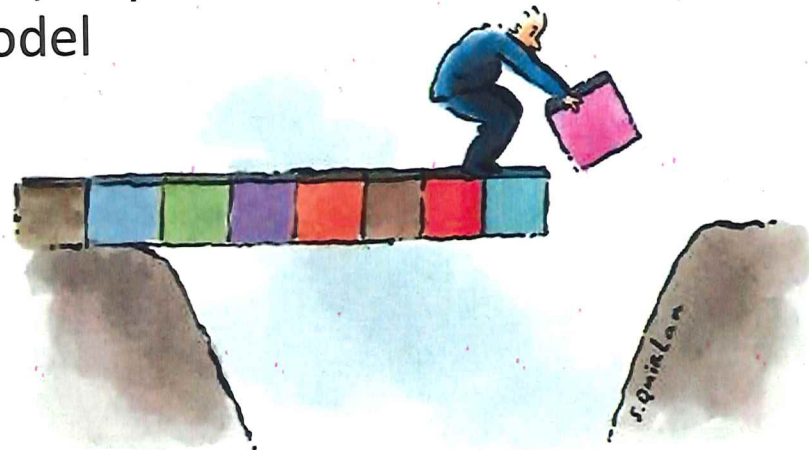
# Research Co-Production



## Mothers, Mental Illness & Opioids Projects

- To engage mothers & researchers in virtual community development (*research4moms.com*)
- To provide online resources & infrastructure for knowledge exchange
- To implement a tailored, in-person community engagement studio model

Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Awards (#8285-BU) and (EAIN-00147).



## How to engage mothers with mental health, opioid/substance use challenges & researchers in the MMHRC community?

- How to address mothers' concerns, e.g., privacy, confidentiality?
- How to provide researchers with community engagement resources & support?
- Benefits & costs of virtual vs. in-person connections?

Note: PMADS = postpartum mood & anxiety disorders



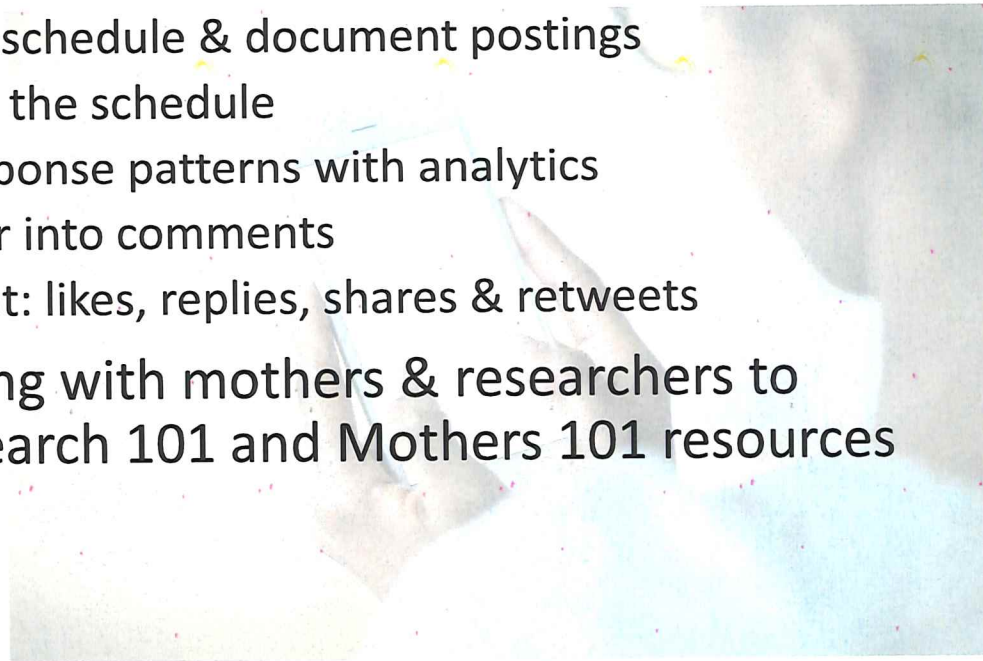


## Our approach:

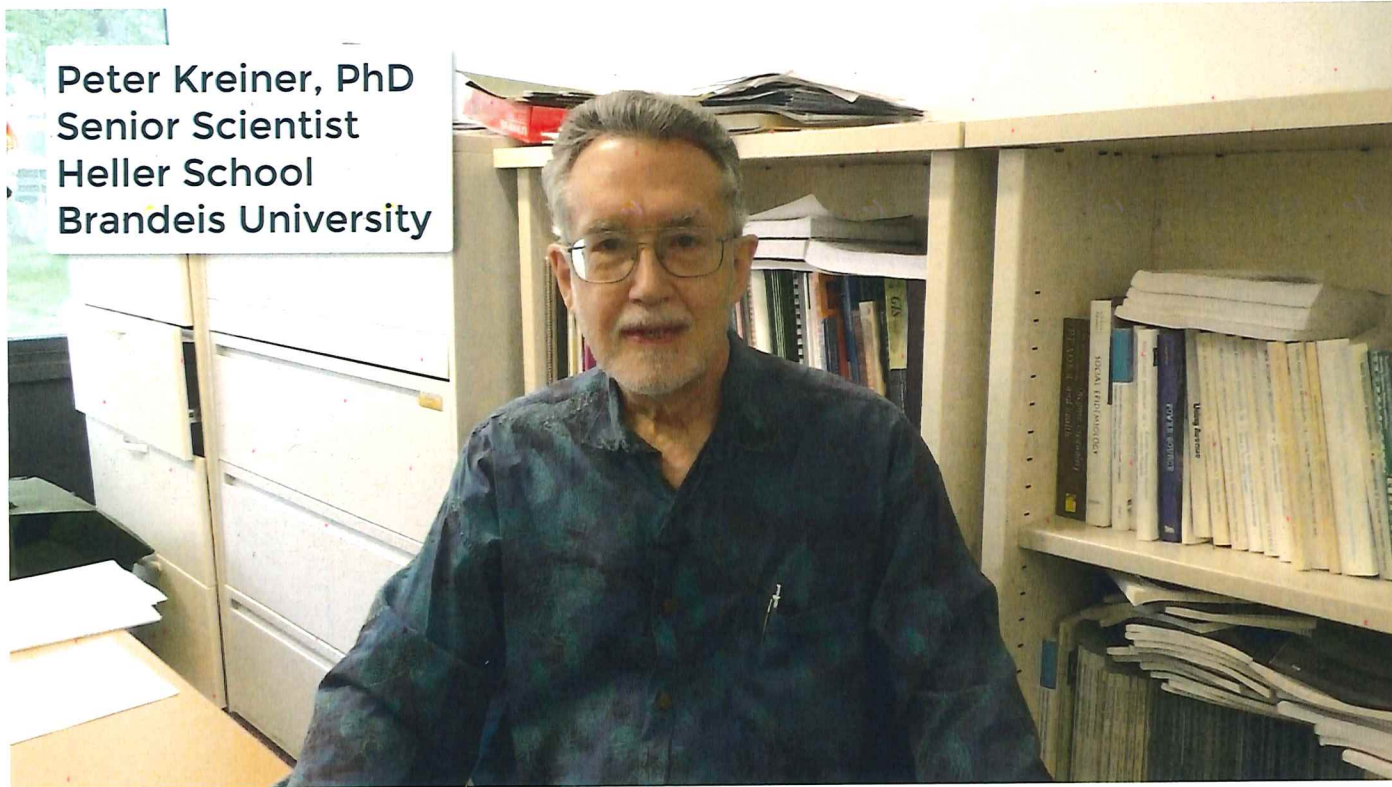
- Co-design teams to bring mothers, providers and researchers together in small co-design teams to reflect on their experiences, identify priorities, & devise & implement change.
- Leveraging social media to promote engagement.
- Clear process design & facilitation, a multi-disciplinary support team.
- Develop tools & resources to build bridges between researchers & communities.
- Community Engagement Studios – toolkits.

## Community Engagement Strategies

- Social media initiative
  - Categorize, schedule & document postings
  - Manipulate the schedule
  - Explore response patterns with analytics
  - Dive deeper into comments
  - Engagement: likes, replies, shares & retweets
- Crowdsourcing with mothers & researchers to develop Research 101 and Mothers 101 resources



## Identity – Meaning, Connection



Peter Kreiner, PhD  
Senior Scientist  
Heller School  
Brandeis University

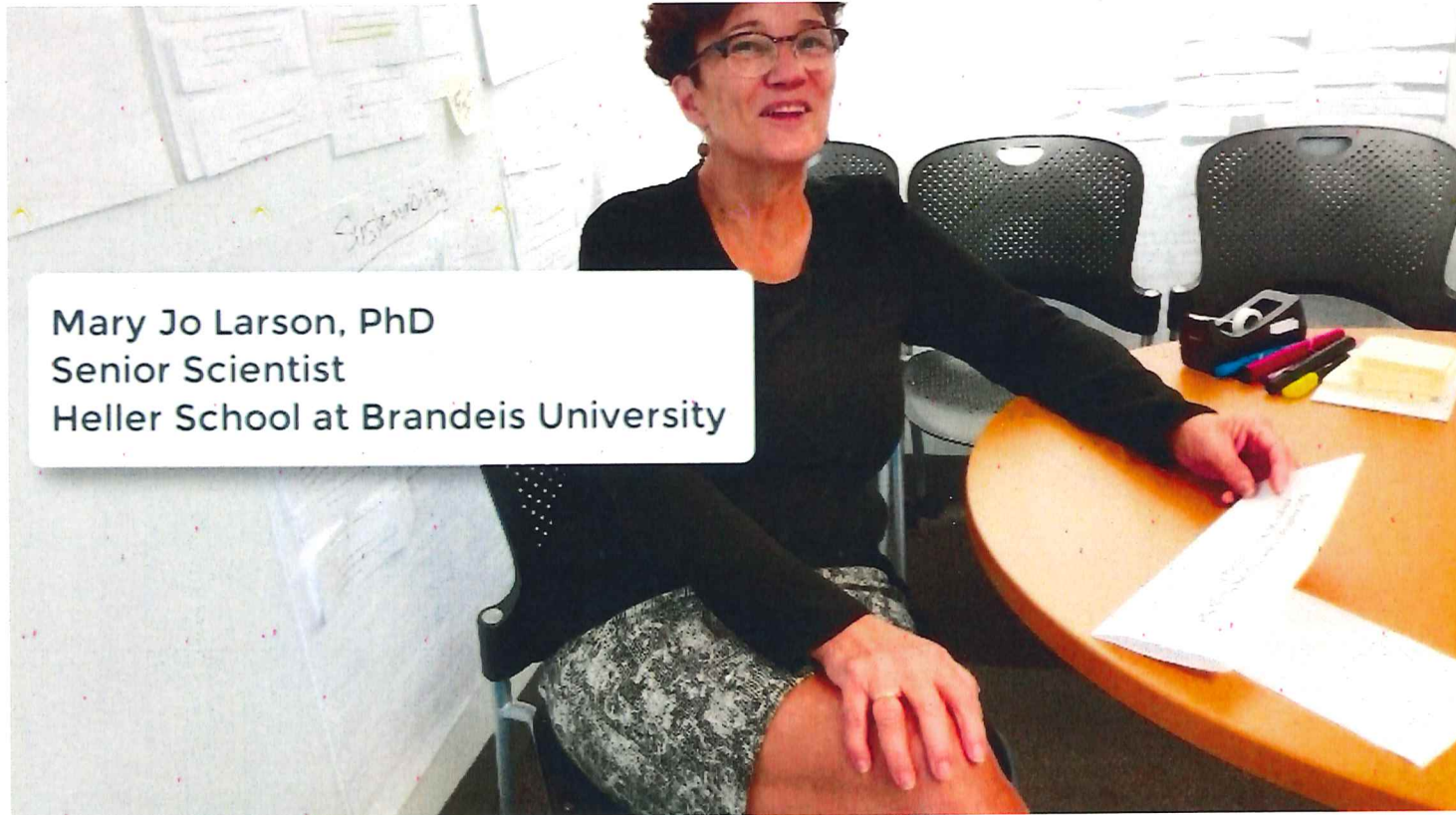
What matters?

Robin



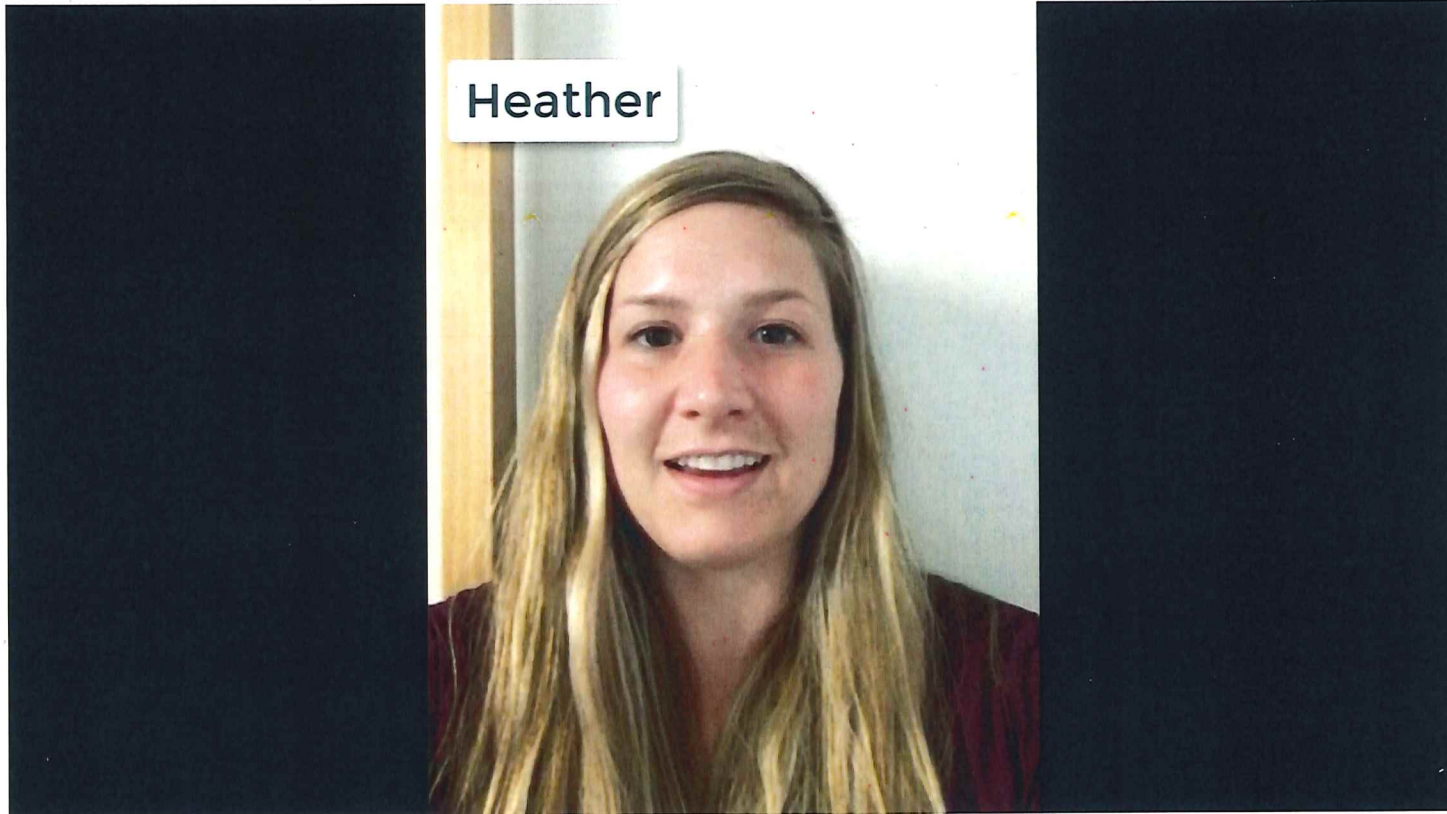


## Disclosure – Intention, Choice



Mary Jo Larson, PhD  
Senior Scientist  
Heller School at Brandeis University

The opportunity to have a choice...



## Trust – Respect, Safety

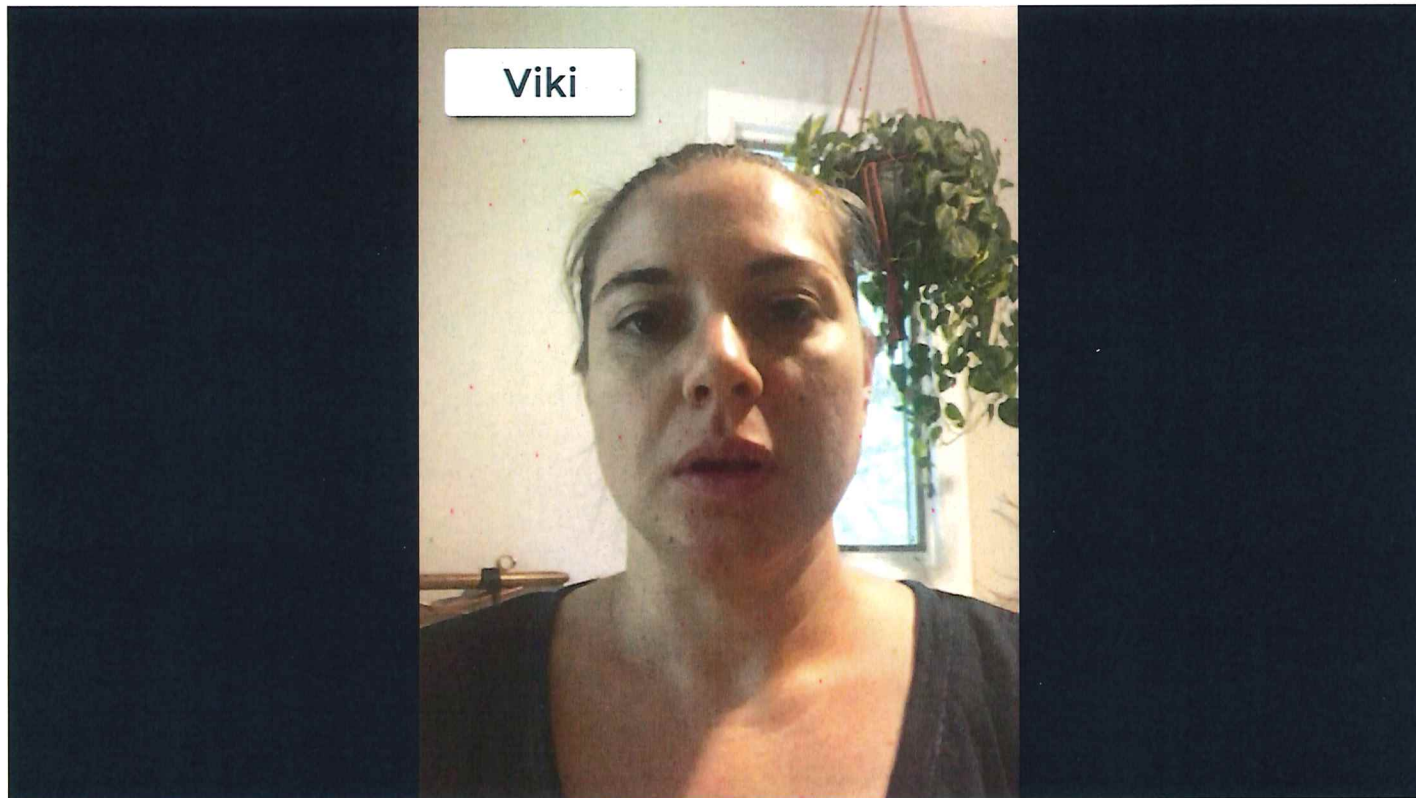


Mary Brolin, PhD  
Scientist  
Heller School  
Brandeis University

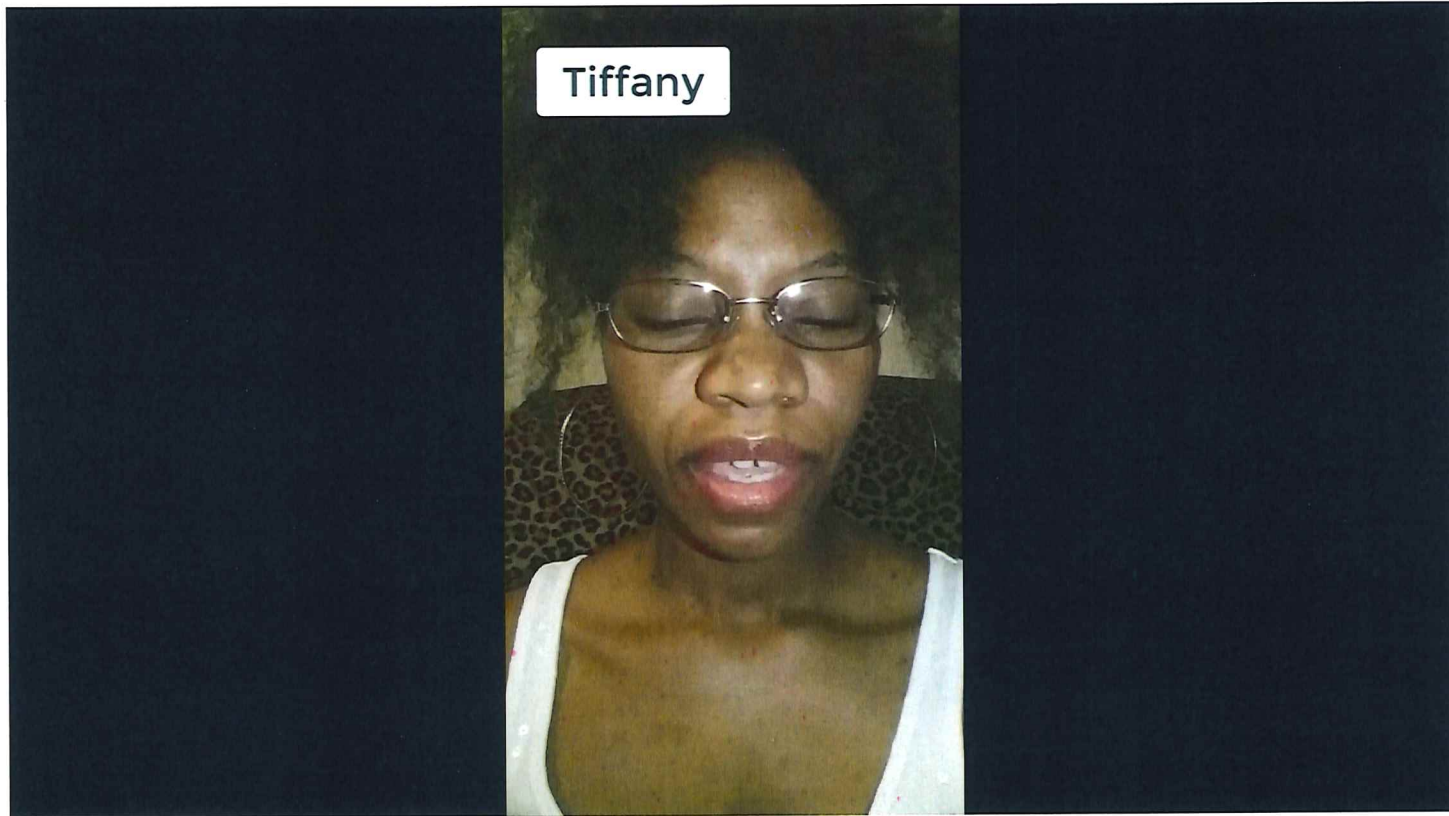
Who knows who is  
in the research  
study?



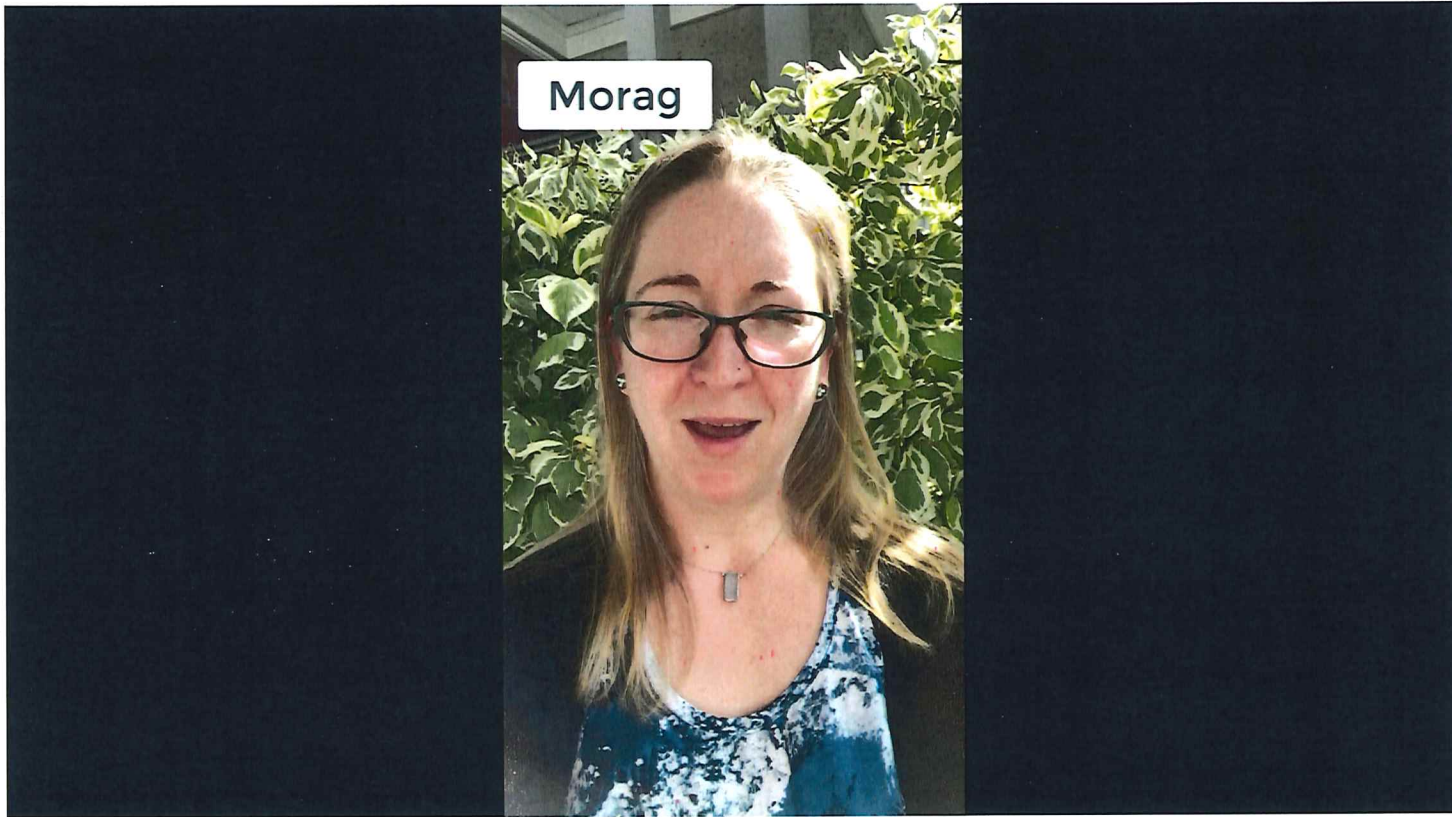
This clearly matters.



The opportunity to have a voice...

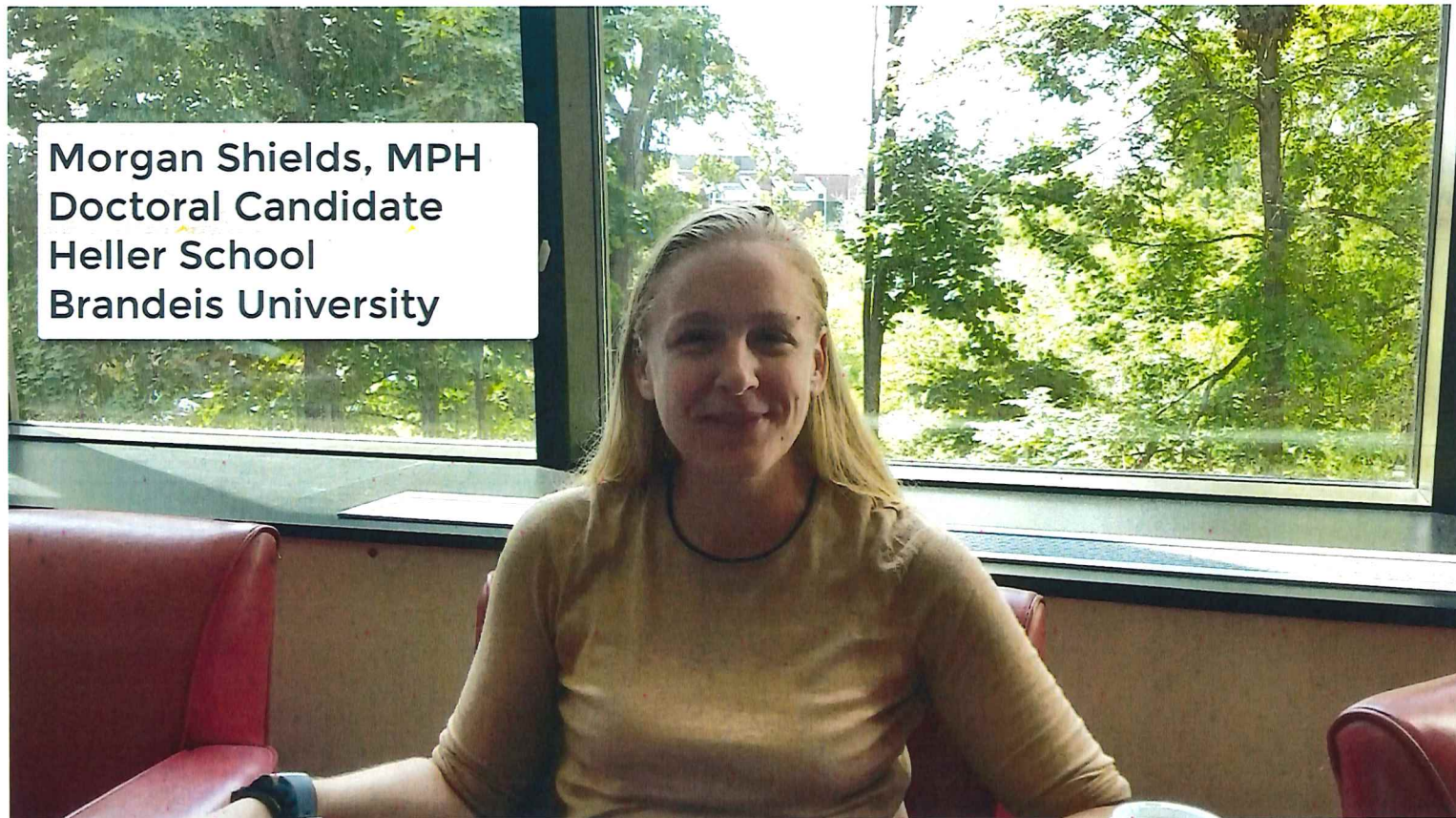


The opportunity to make a difference...





## How do we define success?



**Morgan Shields, MPH**  
**Doctoral Candidate**  
**Heller School**  
**Brandeis University**



## Things to think about: Power – respect & use

- What is your superpower?
- How to complement what you bring to the table?
- What can we learn from our community engagement efforts that is transferable to a larger diversity, equity, & inclusivity (DEI) agenda?
- What can we infuse into the way we work to enhance DEI, research implementation, evidence & impact?



## Resources

- <https://www.pcori.org/engagement/engagement-resources>
- <https://www.tuftsctsi.org/research-services/stakeholder-community-engagement/>
- <https://www.who.int/hiv/pub/6.pdf>
- Google scholar - key words

