



WELCOME to

*Get Engaged:
An ECHO to Increase Skills for
Community Engaged Research*

Funding Statement

This project was supported in part by Dartmouth SYNERGY with funding from the NIH National Center for Advancing Translational Science(UM1TR004772).

Created in Partnership with

Dartmouth Health Synergy Clinical and Science Translational Institute

Dartmouth Health Center for Advancing Rural Health Equity

Dartmouth Health Center for Rural Health Care Delivery Science

Dartmouth Learning Health System Embedded Scientist Training and Research Center

Dartmouth Health NNE Primary Care and Behavioral Health Post-Doctoral Research Training Program

Series Learning Objectives

After participating in this activity, learners will be able to:

1. Describe key principles, values, and practices of community-engaged research.
2. Conduct community-engaged research that provides positive experiences for community members and improves research design and outcomes.
3. Identify resources, colleagues, and community members to enhance their community-engaged research.

Series Sessions

Date	Session Title
2/25/2025	<u>Community Engagement Definition, Principles, and Practices</u>
3/25/2025	<u>Pre-research Engagement</u>
4/22/2025	<u>Infrastructure for Working with Community Members</u>
5/27/2025	<u>Research Implementation</u>
6/24/2025	<u>Ethical Considerations in Working with Communities</u>
7/22/2025	<u>Analysis/Dissemination</u>

Get Engaged ECHO:

An ECHO to Increase Skills for Community Engaged Research

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February 25, 2025



Overview

- What is Community Engaged Research?
- Why is Community Engaged Research Important?
- Community Engaged Research Steps and Principles
- Case Presentation
- Discussion

Community Engagement in Research

**A Fundamentally Different
Approach to Research**

Community Engagement

“Nothing about us, without us”-include the people and groups to inform decision-making processes related to work you are doing that will impact them (research, program, policy etc.)

“The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. “

Updated in 2025 to include: “The process should be enduring, equitable, and culturally sensitive to all participants, with a shared goal of addressing the concerns of the community.”

(CDC, 1997, p 9 – published in CDC, *Principles of Community Engagement* UPDATED in 3rd Edition, 2025; <https://www.atsdr.cdc.gov/communityengagement/>)

Traditional vs. Engaged

(from Principles of Community Engagement, 2025)

	Traditional Research	Community Engaged Research	
Research Objective	Based on epi data & funding priorities	Community input in identifying locally relevant issues	
Study Design	Based entirely on scientific rigor and feasibility	Researchers work with community to ensure study design is culturally acceptable and relevant	
Recruitment & Retention	Based on scientific issues & “best guesses” regarding how to best reach target community	Instruments adopted from other studies and tested/adapted to fit local populations with community guidance	

Traditional vs. Engaged

	Traditional research	Community Engaged Research	
Instrument design	Instruments adopted/adapted from other studies. Tested chiefly with psychometric analytics methods	Instruments adopted from other studies and tested/adopted to fit local populations with community/input guidance	
Data collection	Conducted by academic researchers or individuals with no connection to the community	Community members involved in some aspects of data collection	

Traditional vs. Engaged

	Traditional research	Community engaged research	
Analysis and interpretation	Academic researchers own the data, conduct analysis and interpret the findings	Academic researchers share results of analysis w/ community members for comments & interpretation	
Dissemination	Results published in peer-reviewed academic journals	Results disseminated in community venues as well as academic journals with community guidance	

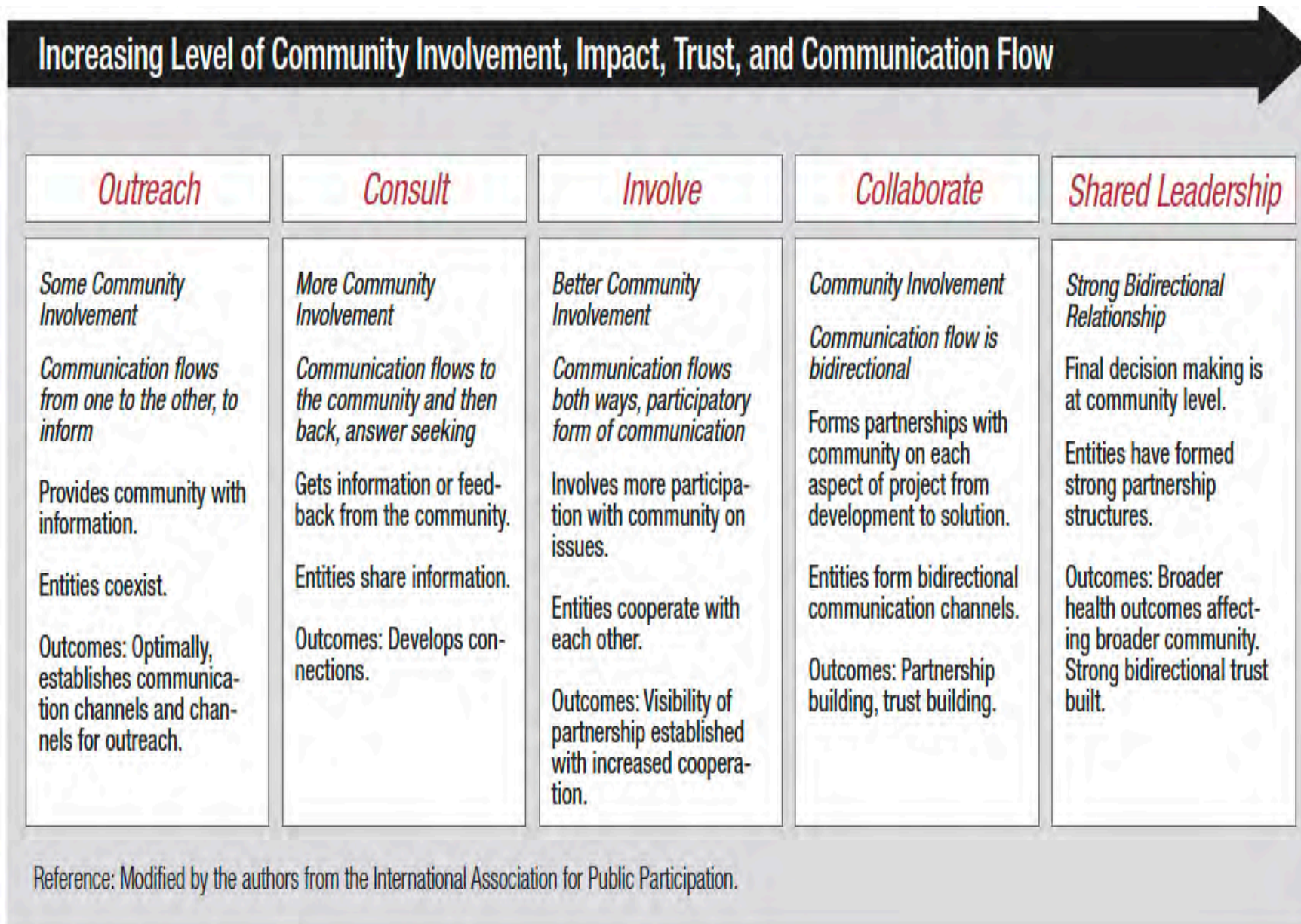


Figure 1.1. Community Engagement Continuum

Examples of Community-Engaged Research

- Intervention development
 - Focus groups with teens to identify sources of stress and appealing strategies to address stress in schools
- Developing research objectives
 - Clinical Trials Network (CTN) patient/clinician and policy stakeholder groups
- Study implementation partnership
 - Advisory board including clinicians, administrators and patients to guide and inform study
 - Board workgroups to develop assessment battery and devise recruitment strategies
 - Johnson et al 2022 <https://doi.org/10.2217/cer-2022-0090>

Examples of Community-Engaged Research

- Digital intervention design
 - Extensive user input in developing design of technology based interventions (user-centered design)
- Study design development
 - Surveys, focus groups & qualitative interviews with clinicians and patients to identify appropriate research design to test interventions for pregnant women with OUD

FIGURE 1 Community Engagement Impacts in Research Taxonomy: a taxonomy of standard terms for areas of community stakeholder impact in research. Domains are in all-capital letters and white text. Dimensions (topical clusters of subcodes) are preceded by a ">" symbol and are in black text



Fig 1 from Stallings S et al. A taxonomy of impacts on clinical and translational research. Health Expectations 2019

Why Community Engaged Research?

Community-engaged clinical research is consistent with ethical principals for research involving human participants, particularly marginalized populations.

“The traditional research approach has considered individuals and communities to be “subjects” or “objects” of health research.

Current developments in ethics, and research methods, and an expanding recognition of what constitutes expert knowledge, justify the heightened participation of individuals and communities.”

Tindana P, et al. Grand challenges in global health: community engagement in research in developing countries. PloS Medicine, 2007. 4(9): p. 1451-1455.

Values Connected

The values are organized as a continuous cycle that begins with inquiry and empathy before coming to action. They are interconnected and meant to be revisited as there is no linear path through engagement.



Potential Benefits of Community Engaged Research

4 Rs of research are enhanced by CSeR

- **Relevance** of research to the needs of those who could benefit by involving both people and investigators in identifying the most important research questions.
- **Rapid** pace is achieved by involving community members in developing the optimal research designs and recruitment strategies to address these questions and by leveraging collaboration and creative potential of different academic disciplines, organizations, provider and patient groups to maximize success.
- **Rigor** is enhanced by use of innovative methods and regional practices.
- **Relational** nature of research occurs by building equitable and respectful relationships across scientific disciplines AND between researchers and community members.
- AND **Reduce harm** through these practices

Riley et al., 2013;

Tebes, Thai, and Matlin, 2014; Green et al., 2001



U.S. CENTERS FOR DISEASE
CONTROL AND PREVENTION
AGENCY FOR TOXIC SUBSTANCES
AND DISEASE REGISTRY

Steps and Principals in Community Engagement

<https://www.atsdr.cdc.gov/community-engagement-playbook/php/about/index.html>

1. **Plan for community engagement from the beginning:**
 - timeline, decision-making processes, communication, and budgets
 - often involves extra time, resources, and steps to consider in advance
2. Be clear and transparent about:
 - **purposes or goals** of the engagement effort
 - population or community to engage
 - **decision making processes**

Steps and Principals in Community Engagement

3. Be aware of power and positionality

- take time to reflect on power dynamics that may exist among the community and the research entity
- address dynamics throughout the engagement
- especially important when working with communities that have been historically marginalized

4. Become knowledgeable regarding

- community's culture, economic condition, social networks, political and power structures, norms and values, demographic trends, history, and experience with efforts by outcomes groups to engage it in various programs
- **community's perceptions** of researchers initiating the engagement activities

Steps and Principals in Community Engagement

5. Develop a plan to **compensate community members** for their time and expertise whenever possible
6. Take steps to actively **remove barriers to community engagement** such as transportation, meeting times, childcare
7. Go to the community, establish relationships, build trust, work with the formal and informal leadership, and
*seek commitment from community organizations and leaders to create processes for mobilizing the community
8. Accept that collective **self-determination** is the responsibility and right of all people in a community

Steps and Principals in Community Engagement

9. Once all this preparation is completed, you are ready to **partner with communities**
10. As you partner, continue to **recognize and respect the diversity of the community**
11. To sustain engagement, identify and mobilize assets and strengths, develop capacity and resources to make decisions and take action

Steps and Principals in Community Engagement

12. Be prepared to **release control** of actions or interventions, be flexible enough to meet its changing needs
13. Make a **long-term commitment** to engagement
14. **Demonstrate trustworthiness** – critical to sustained engagement
15. **Establish and follow clear processes about how your community partners can provide feedback or raise a concern** about their experience. Ensure that the research team and community participants are aware of the processes

Key Characteristics of Authentic Community Engagement & Partnership

- Reciprocity
- Power-sharing
- Cultural humility
- Sustained commitment
- Measurable impact

Resources

1. Dartmouth Community Engaged Scholarship Hub

This comprehensive resource is designed to foster effective and consistent community engagement practices within Dartmouth Health and Dartmouth College.

[Community Engaged Scholarship Hub | Center for Rural Health Care Delivery Science | Dartmouth Health](https://www.dartmouth-health.org/rural-healthcare-science/community-engaged-scholarship) <https://www.dartmouth-health.org/rural-healthcare-science/community-engaged-scholarship>

2. Updated textbook: Principles of Community Engagement, ATSDR at CDC, 2025

3. CDC Community Engagement Playbook

<https://www.atsdr.cdc.gov/community-engagement-playbook/php/about/index.html>

4. Urban Institute: Exploring Individual and Institutional Positionality, A Tool for Equity in Community Engagement and Collaboration

[Exploring Individual and Institutional Positionality.pdf](#)



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Session 2, Pre-research Engagement, March 25, 2025

BMJ

3461-40 No 7908 ISSN 1759-2151
18 May 2013 | bmj.com

Safeguarding adults at risk of abuse
Better management of multimorbidity
How safe is sitagliptin?
Autologous blood for tendinopathy



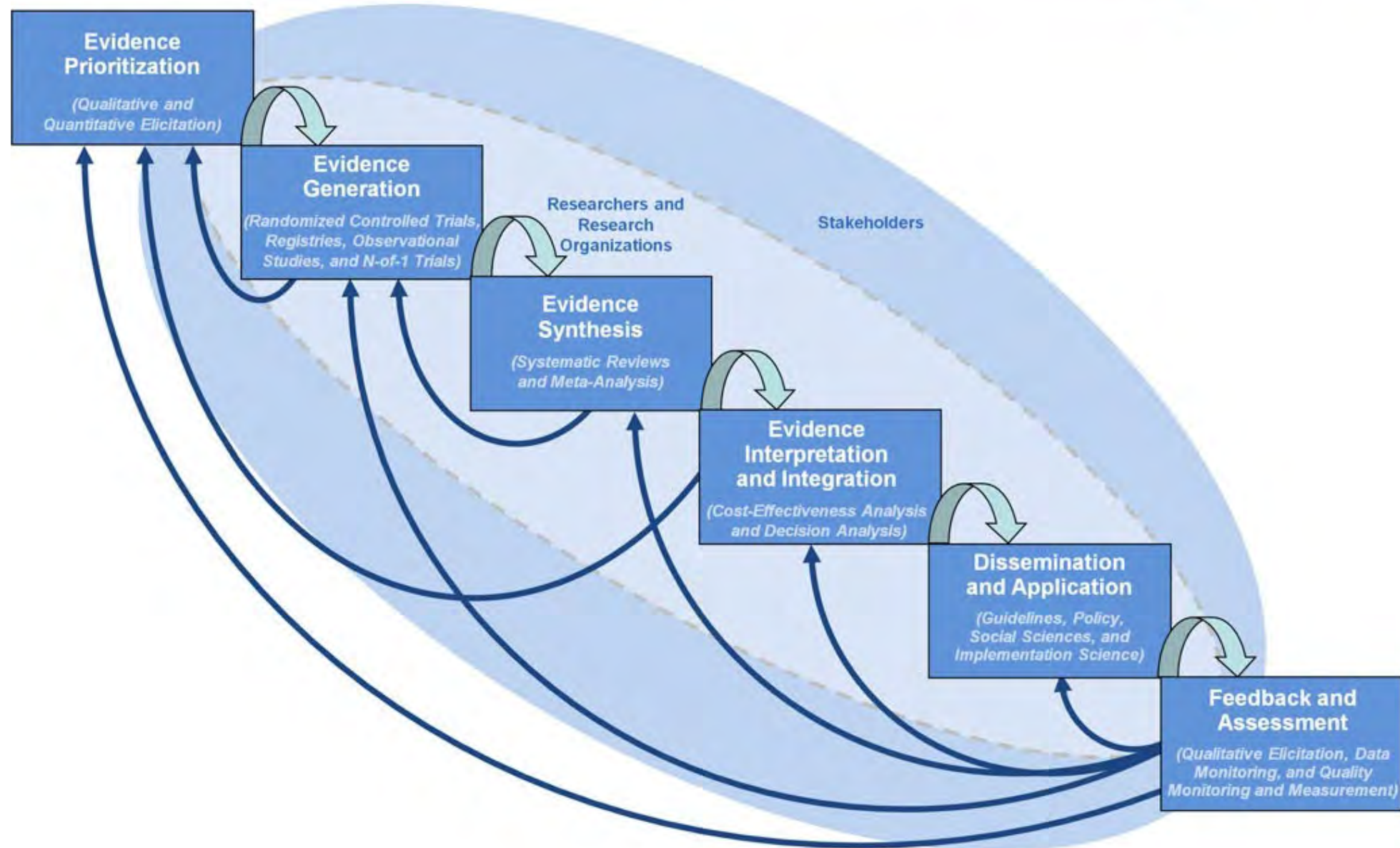
ECHO

Session 2.

**Patient Engagement in Research
Community Engagement Studios**

Paul J. Barr@dartmouth.edu

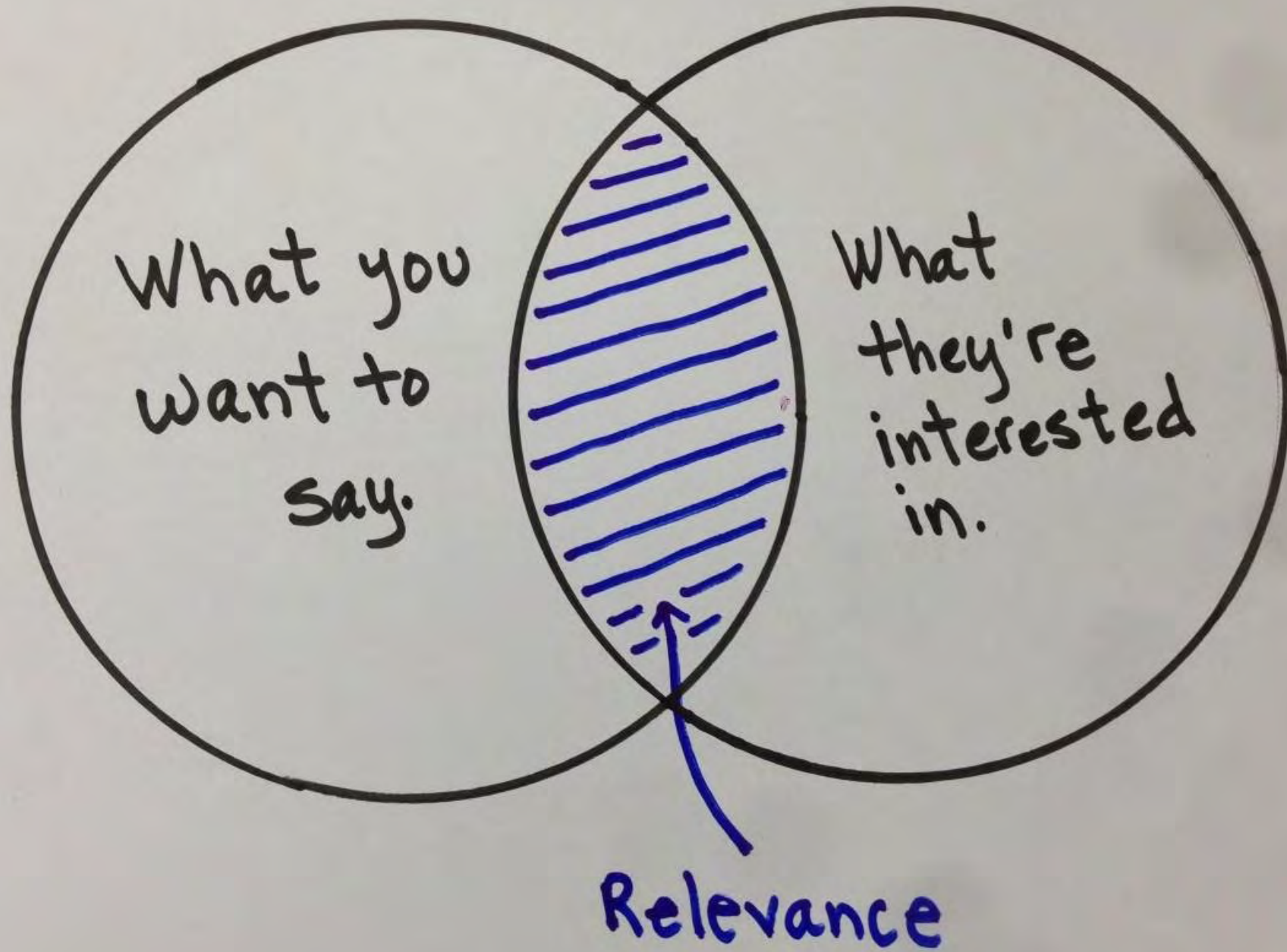
Translational Spectrum of Comparative Effectiveness Research at Tufts CTSI



WHY?



Increase the
quality of research



MIND THE GAP





Community Engagement Studio

“Many researchers are not prepared to identify, recruit, convene and engage these stakeholders or prepare them for participation in research in an advisory capacity or as part of a research team. The CE Studio creates a framework for stakeholders to provide immediate feedback to the researcher on specific areas of concern before the research project is implemented.”

Israel et al. CE Studio toolkit 2.0



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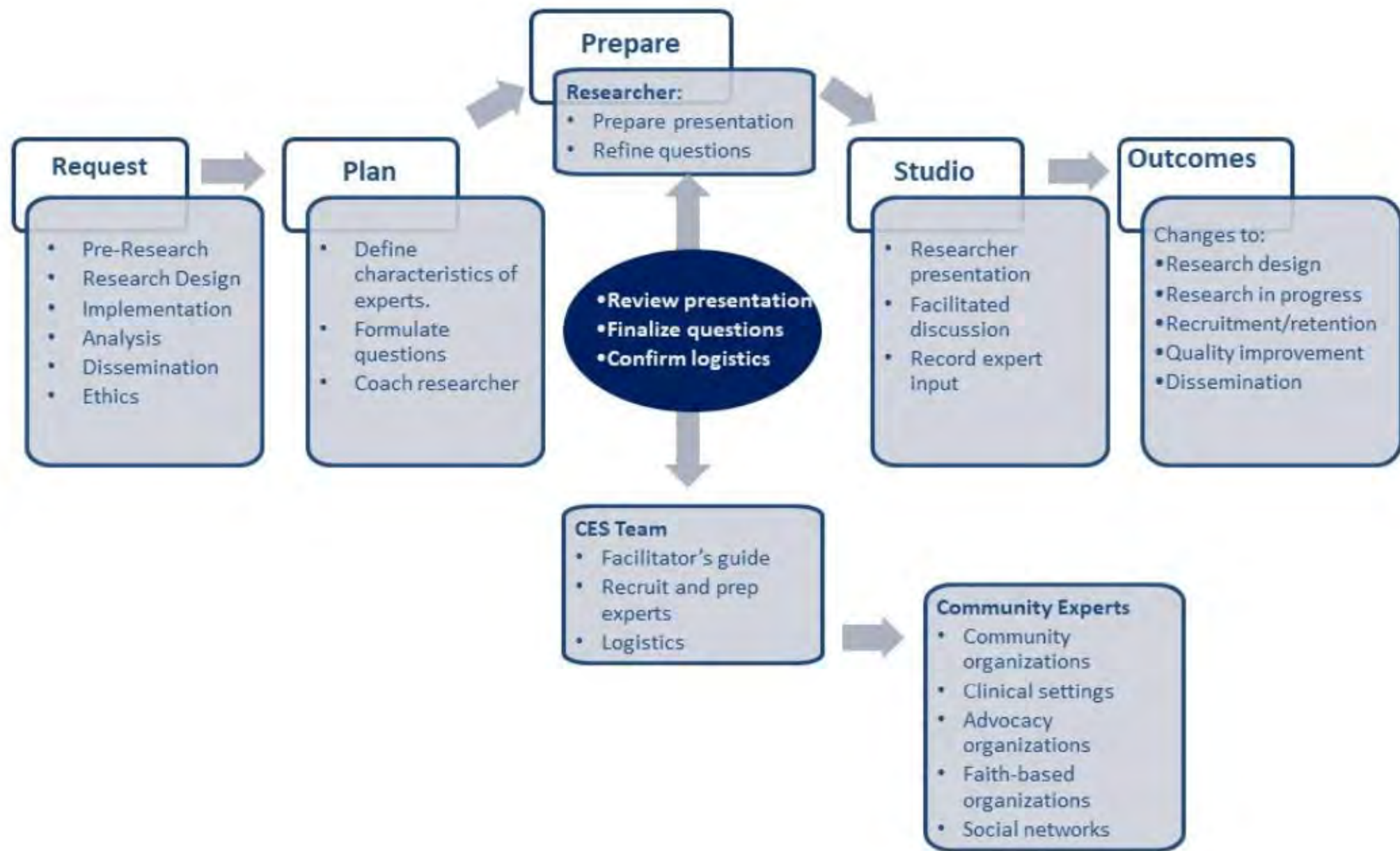
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Community navigator

- running the planning meeting with the researcher/research team
- identifying and preparing the community experts
- managing logistics
- following up on any resulting actions and recommendations
- documentation (summary of CE Studio, W9s etc)

*Hiring from the community puts into practice fundamental principles of community engagement such as mutual benefit, respect and community capacity building.



Facilitator



The facilitator's job is to create a neutral environment that allows for open and frank discussion and guide the conversation between the researcher and community experts.



A skilled facilitator does not interject his or her opinions or biases into the conversation.



Ideally, the facilitator has received relevant training that prepares them to work with groups of individuals representing a wide range of social-economic backgrounds and have varied learning and communication styles.



Researcher

Meet with CE Studio team:

- help the researcher clarify the questions that will be posed to the expert panel
- discusses potential probing and follow-up questions for the facilitator to use to engage panelists
- generate a 10 min presentation using a template and facilitation guide
- In preparing the presentation, the researcher must remember community experts need to know:
 - What the researcher is trying to find out, and why it is important.
 - How the planned research might impact people who would serve as research subjects
 - What kind of advice the researcher needs.

Join at menti.com | use code 4415 5802

Mentimeter

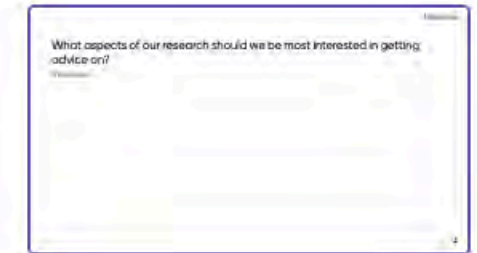
Menti

Untitled presentation



What aspects of your research would you be most interested in getting advice on?

Choose a slide to present



Sample of notes collected and analysis

CE Studio Summary and Recommendations Personalized HIV Care

Recommendations	
Elements important in personalized care: <ol style="list-style-type: none">1. Consistent and open communication between provider and patients.2. Continuity of providers is essential; doctors, nurses and staff.3. Incorporate holistic approach to care that includes mental health needs.4. Take into account the variety of cultural variances across all patient populations.	How EHRs are used in personalized care: <ol style="list-style-type: none">1. Genetic testing should be a part of PC with a focus on inter-provider and patient education to maximize impact.2. Take extra care in educating patients about their own genetic testing results.3. Use EHR data with patient permission and full transparency to address concerns regarding privacy, insurance, etc.
Recruitment and Messaging: <ol style="list-style-type: none">1. Raise awareness of opportunities to participate by building collaborations with community partners, i.e. community organizations, faith community, caregivers, etc.2. Get the word out via patients or advocates who are active in the LGBTQ or HIV+ community.3. Utilize multiple forms of outreach: people networks, social media, traditional media, and providers.	

Community Engagement Studio Conversational Summary

Initial thoughts about this project?

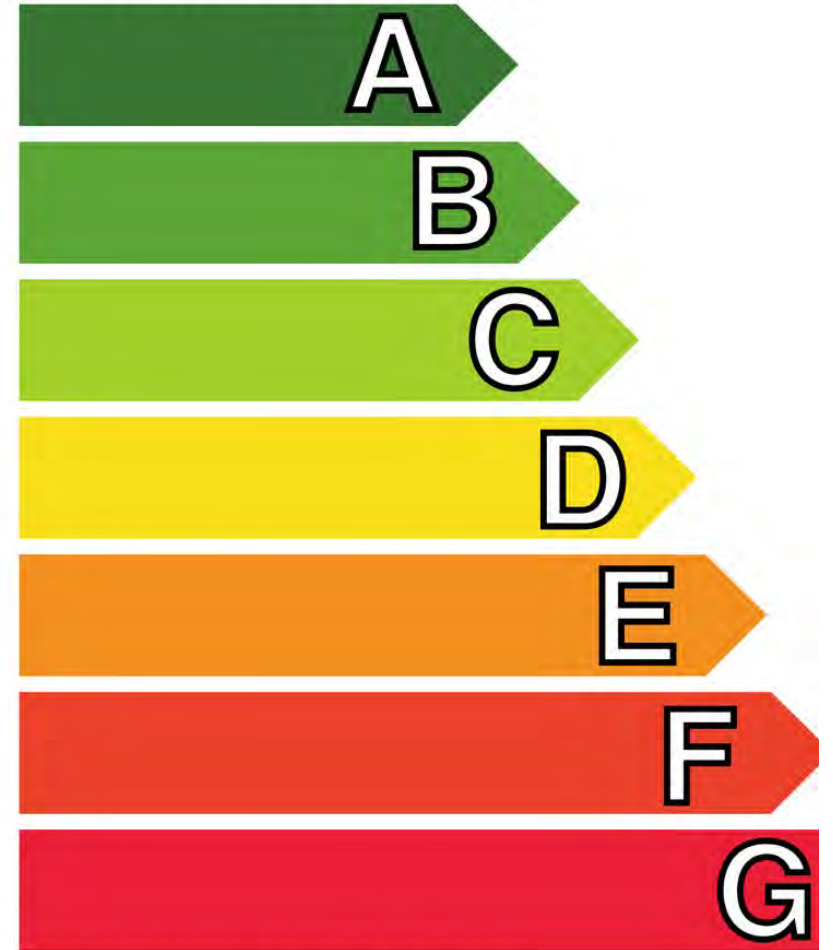
- This is an awesome idea.
- The project could be very informative.
- I appreciate all of the work that goes into HIV care. This would complement it.
- I love to be involved in work that uses lab/science.
- This sounds very educational and interesting.
- This focus could require lots of time to truly personalize (patient volume issues).
- I like that you are listening to us who are actually go through HIV to shape the project.

Minimize burden | Maximize efficiency

Researchers work with experts in community engagement

- Identification of stakeholder
- Recruitment
- Prepare the investigator for the session
- Facilitate the CE Studio session

More efficient



Less efficient

WHAT IS THE DIFFERENCE BETWEEN A COMMUNITY ENGAGEMENT STUDIO AND A FOCUS GROUP?

Purpose	Inform development, implementation or dissemination of research	Qualitative data collection
Approach	Bi-directional discussion	Uni-directional
Participants	Consultants Identified as experts based on lived experience	Research subjects Screened, consented
Facilitator	Neutral – could be community member Not affiliated with research project Uses techniques to balance power Uses guide for conversation: can diverge if relevant	Research team member Uses pre-approved script: cannot diverge
Preparation	Coaching for research team Orientation for community experts	IRB approval Consenting of research subjects
Compensation	Consulting fee	Participant incentive
Use of input	Participant comments and recommendation summarized CE Studio Team may help researcher interpret and apply recommendations	Participant comments transcribed Transcription qualitatively analyzed

[Acad Med](#). 2015 Dec, 90(12): 1040–1050.

Published online 2015 Nov 25. doi: [10.1097/ACM.0000000000000794](https://doi.org/10.1097/ACM.0000000000000794)

PMCID: [PMC4634204](#)

NIHMSID: [NIHMS689532](#)

PMID: [26107879](#)

Community Engagement Studios: A Structured Approach to Obtaining Meaningful Input From Stakeholders to Inform Research

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This article has been [cited by](#) other articles in PMC.

Problem

Go to: 

Engaging communities in research increases its relevance and may speed the translation of discoveries into

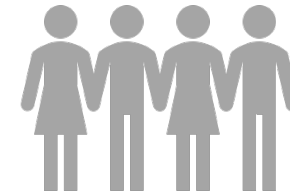
RECOMMENDED



Impact of CE Studio



**Improved project feasibility, recruitment
and dissemination strategies**




Recommendations focused on:

patient centeredness
cultural relevance
accessibility to potential research participants

A large orange circle is positioned on the left side of the slide, partially cut off by the edge.

Impact of CE Studio

The researchers reported that they used the stakeholder input to:

- refine research proposals
 - revise recruitment materials
 - modify consent forms
 - add / increase participant compensation.
- 
- A yellow dashed line is located in the bottom right corner of the slide, consisting of several short, curved segments.

Post CE Studio



half of the researchers made changes to an existing research project



36% submitted grants



18% used the stakeholder input for quality improvement activities

TABLE 5.3 ● Challenges Implementing Community Engagement Studios

Institution	<ul style="list-style-type: none">• Funding support• Inadequate infrastructure• Lack of coordination of community-engagement support services
Community engagement studio team	<ul style="list-style-type: none">• Recruiting finite or hard to engage populations• Fostering researcher humility• Facilitation
Researcher	<ul style="list-style-type: none">• Understanding of community-engaged research• Community input not valued• Communicating with lay public• Interpreting community input• Power dynamics (sharing power)
Community	<ul style="list-style-type: none">• Readiness to serve in research advisory roles• Power dynamics (taking power)

Joosten YA, Israel T, Dunkel L, Sims J, Hopkins Wilkins C. 2021 *The Community Engagement Studio: Tapping Into the Lived Experience of Community Members to Enhance Research*. In: Zimmerman. *Researching Health Together: Engaging Patients and Stakeholders, From Topic Identification to Policy Change* (Chapter 5). Sage Publications.



Q & A with
Sheri and
Paul

Today's Case

Journal of Clinical and Translational Science

www.cambridge.org/cts

Research Article

Cite this article: Masel MC, Cavanaugh KL, Croisant SP, Bohn K, Goodwin JS, Bruce ML, and Barr PJ. Community Engagement Studios to advance multi-site research with older adults. *Journal of Clinical and Translational Science* 8: e186, 1–7. doi: [10.1017/cts.2024.630](https://doi.org/10.1017/cts.2024.630)

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Community Engagement Studio; RCT; multi-site; communication; audio recording

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Meredith C. Masel and Kerri L. Cavanaugh are co-first authors.

Community Engagement Studios to advance multi-site research with older adults

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Abstract

Introduction: Operationalizing multi-site Community Engagement (CE) Studios to inform a research program is valuable for researchers. We describe the process and outcomes of hosting three CE Studios with Community Experts aged 65 years or older with chronic conditions and care partners of older adults. Experts gave feedback about processes for testing the feasibility, efficacy, effectiveness, and implementation of audio recording clinic visits and sharing recordings with patients who have multimorbidity and their care partners. **Methods:** The CE Cores of the Clinical and Translational Science Awards Programs at three academic health science centers created a joint CE Studio guide. Studios were conducted iteratively by site. Following receipt of the final reports, responses were compared to find themes, similarities, and differences on four topics in addition to overall commentary: Recruitment and Retention, Study Protocol, Study Reminders and Frequency, and Recording Technology. **Results:** Eighteen older adults and care partners in three states provided valuable feedback to inform multi-site trials. Feedback influenced multiple aspects of trials in process or subsequently funded. Experts provided critique on the wording of study invitations, information sheets, and reminders to engage in study procedures. Experts were concerned for participants being disappointed by randomization to a control arm and advised how investigators should prepare to address that.

Audio Trial

Paul J. Barr, Meredith Masel, Kerri Cavanaugh

The Dartmouth Institute, Lebanon NH
University Texas Medical Branch, Galveston TX
Vanderbilt University Medical Center, Nashville TN

National Institute on Aging (NIA), R56AG061522



Barr, Paul J., et al. "The feasibility of sharing digital audio-recordings of clinic visits online with older adults in primary care settings: A multisite trial." *Patient Education and Counseling* 131 (2025): 108574.

Masel MC, Cavanaugh KL, Croisant SP, Bohn K, Goodwin JS, Bruce ML, Barr PJ. Community Engagement Studios to advance multi-site research with older adults. *Journal of Clinical and Translational Science*. 2024 Jan;8(1):e186.

Specific Problem Study will Address

- Up to 80% of clinic visit information is forgotten immediately by patients.
- Older adults have:
 - Complex care plans and
 - May have more difficulty remembering care plans/changes to their care



After Visit Summary

know your test results and keep a list of the medicines you take.

How can you care for yourself at home?

Test, Joe (65016801-6) DOB: 09/17/1950 Printed at 12/12/16 3:56 PM

Page 4 of 5

Page 5 of 5

- Take an over-the-counter pain medicine, such as acetaminophen (Tylenol), ibuprofen (Advil, Motrin), or naproxen (Aleve), if your arm is sore after the shot. Be safe with medicines. Read and follow all instructions on the label.
- Give acetaminophen (Tylenol) or ibuprofen (Advil, Motrin) to your child for pain or fussiness after the shot. Read and follow all instructions on the label. Do not give aspirin to anyone younger than 20. It has been linked to Reye syndrome, a serious illness.
- Put ice or a cold pack on the sore area for 10 to 20 minutes at a time. Put a thin cloth between the ice and your skin.

- Diagnoses
- Medications
- Allergies
- Clinician Visited
- Visit Summary

Same medical appointment

What the doctor writes
aka **notes**

ASSESSMENT and PLAN:

38yr old female with past medical history notable for astrocytoma s/p 2 surgical removals (OSH), migraines, and epilepsy presenting to clinic today complaining of L knee pain and L heel pain.

(M25.562, G89.29) Chronic pain of left knee (primary encounter diagnosis)

(S83.8X2A) Meniscal injury, left, initial encounter

Comment: Chronic L anterior knee pain for >1 year. No trauma or acute injury, but movements associated with hyperflexion aggravate her pain. Does have mild medial/lateral joint line tenderness and moderate crepitus with passive movements. Xrays overall reassuring without signs of patella-femoral pain syndrome, mild lateral joint space narrowing. Suspect possible medial vs lateral meniscal injury because history notable for mild "catching" like sensation only with hyperflexion movements of her knee.

Plan: - reassured patient no MRI was indicated today

- recommended patient work with gym trainer on knee core strengthening exercises for injury prevention
- recommended avoiding hyperflexion movements (squatting) of her knees to prevent worsening injury
- overall symptoms are mild, consequently, no restrictions in activity levels are recommended today
- can try OTC ibuprofen for pain relief but patient wants to avoid medications.

(M72.2) Plantar fasciitis of left foot

Comment: Mild in nature

Plan: - recommended heel & calf stretches

vs. What the patient sees



Appointment Details

Salmi, Elizabeth
12/26/2017 Office Visit
MRN [REDACTED]

Location: FAM ACC
Dept: Primary

Description: Female DOB: 7/18/1979
Provider: [REDACTED]

Most recent update: 12/26/2017 9:56 AM by [REDACTED]

Vitals This Visit

BP	Pulse	Temp	Resp	HI	WT
123/76	52	36.6 °C (97.9 °F) (Tympanic)	16	1.702 m (5' 7")	72.1 kg (158 lb)
BMI	24.9 kg/m2				

Visit Diagnoses

Chronic pain of left knee - Primary
Meniscal injury, left, initial encounter
Plantar fasciitis of left foot

Your Doctor has provided these instructions for you to review and take action on after your visit.

Did you know that you may have access to an **Advice Nurse 24 hours a day** through your insurance provider and **you can go to an urgent care** without asking for approval from your Primary Care Provider?

Call or go online with your insurance plan for a list of Urgent Care centers covered by your insurance and ask about their Advice Nurse Services.

For life threatening emergencies you should call 911 or go to the closest emergency room.

BLAH BLAHBLAH
EBOLA BLAH
MUCOUS MEMBRANE
BLAH BLAH BLAH BLAH...



THE
DAILY
PANIC

SOMETHING ABOUT BODILY FLUIDS...

STUFF & THINGS & STUFF & THINGS & STUFF & THINGS & STUFF & THINGS & STUFF & THINGS & STUFF &

► TEEVEE ◀



HEALTH | The Appointment Ends. Now the Patient Is Listening.

The Appointment Ends. Now the Patient Is Listening.



Paula Span

THE NEW OLD AGE AUG. 18, 2017



Sheri Piper visiting with her doctor, James Ryan, earlier this month in Ludington, Mich. With permission, Dr. Ryan records appointments so his patients can listen whenever they need to recall what they discussed with

Research Questions

Does providing an audio recording of a clinic visit with older adults with multimorbidity (2 or more conditions) improve their ability to self-manage and their quality of life compared to usual care?

Population

Including people who are:

Adults aged 65 and older with two or more chronic diseases (including diabetes and high blood pressure) managed in primary care.

Speak English or Spanish

Excluding people who are:

Patients with substance use disorder, psychosis, those who are deaf or blind, or those who live in a skilled nursing facility



Study Design

Aim 1 Conduct a three-site pilot trial in primary care where older patients (90 total; 30 per site) will be randomized and followed for 3 months.

- 1st group – Usual care. Typically get an after visit summary
- 2nd group – (AUDIO + Notes) All patient visits with study clinicians will be audio-recorded over 3 months, using HealthPAL(a recording system). Participants in the AUDIO arm will receive orientation to HealthPAL, including how to listen to and share their recordings



Intervention

Recording clinic visits for a three-month period

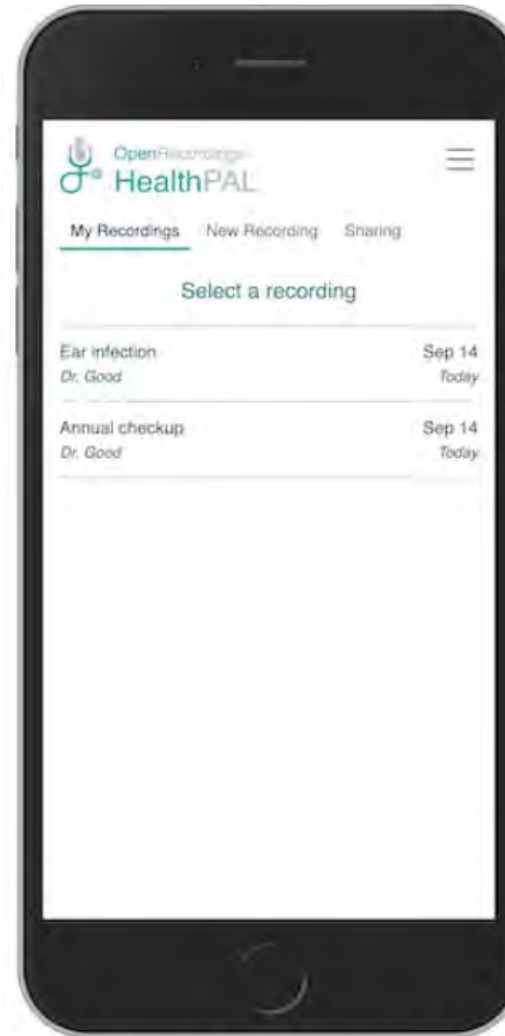


Figure 5: My Recordings

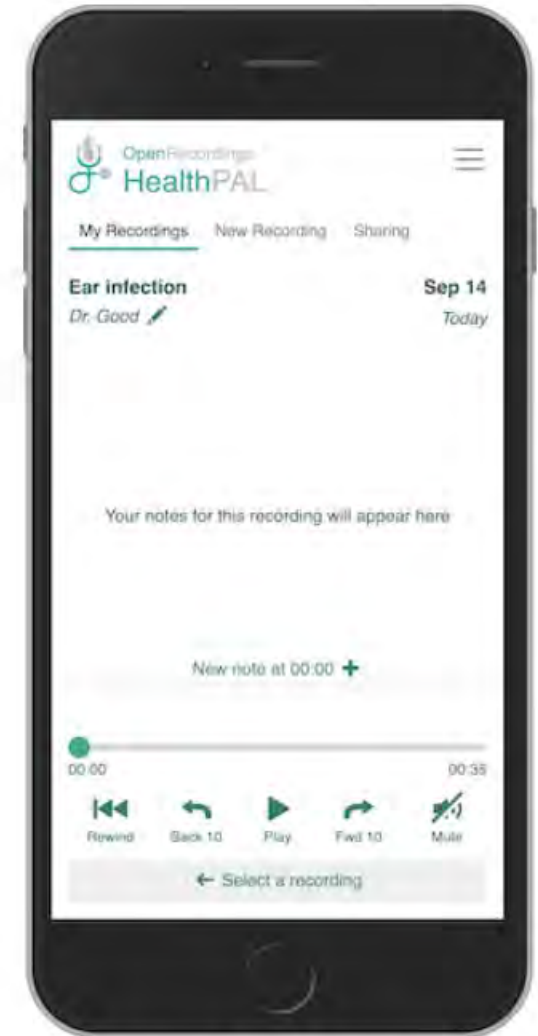


Figure 6: Playback Screen

Study Design

Reminders and agenda setting

Patients will be asked to review their visit information (open notes; open notes and audio) within 24 hours of the visit (recall), at one week (refresher) and prior to the next visit (question prompting). We will also encourage patients to share recording with caregivers.

Three day prior to their visit next visit, patients will also be asked to create an agenda based on notes or notes and audio from their prior visit



Study Design



***Aim 2** Identify barriers and factors that support the feasibility and acceptability of audio recordings among patients, caregivers, clinicians and clinic staff.*

Study Assessments

A trained research assistant will collect data by electronic tablet or paper form if the patient prefers, and in a private clinic room prior to the visit. Patients can also choose to complete assessments on their own at home using a computer.

Patients will be assessed (complete surveys) at:

- Baseline,
- immediately after their visits,
- 1 week from their visits
- 3 months



Outcomes

Our primary outcome is self management ability as measured by the patient activation measure (PAM-SF)

Secondary outcomes are patient-reported and include: Global PROMIS-10, a 10-item patient reported measure of quality of life that produces both physical and mental functioning scores, adherence to medication, satisfaction with care, Communication and Shared Decision Making

Keeping participants in the study



Participants will receive reminder a week prior to scheduled outcome assessments



Participants will receive a tailored schedule, based on their preferences and Research Assistants will offer study visits at the same time as clinic appointments, whenever possible



Participants will provide the contact information of a family member or caregiver



Participants will be compensated for their time: \$30 for initial recruitment and \$20 for each follow-up assessment.

How will findings be used?

Patient and Advocacy Organizations. We will work with patient and advocacy organizations to share the results of our study, including both national groups such as the Osher Lifelong Learning Institute and the National Council on Aging

Policy: the research team will present our findings at meetings that reach policy makers such as the American Geriatric Society

Peer-review Journals, scientific conferences and social media.



Over to you

Which type of community experts should we seek?	
Where should we conduct the studio?	
What time of day should we conduct the studio?	
What aspects of the research should we seek feedback on during the AudioTrial Studio?	
#1.	#2
#3	#4

Report out



Findings from our prior CE Studio

Hello,

Thank you for expressing interest in participating in our new initiative, the Community Engagement Studio. We have officially scheduled the Community Engagement Studio on the Audio Recording Trial and would love if you could join us as a Community Expert. Here are the details:

Date: Friday, March 6, 2020

Time: 8:30am – 11am (Breakfast and orientation will be from 8:30-9am; The Studio will be held at 9 and should last about 1 ½ to 2 hours.)

Location:

Details: You do not need to prepare or bring anything, just yourself! You are already an expert and will be asked to provide your feedback, insight, and recommendations to the researcher based on their questions.

As a reminder, the Studio is meant to serve as a guidance session for health researchers interested in getting feedback from patients or community stakeholders. Community members serve on expert panels to provide feedback on various aspects of the proposed or ongoing research project, including the design, intervention, communication materials, participant recruitment strategies, and applying research findings to practice. By working directly with patients and other community stakeholders, researchers are able to do so in a way that is culturally sensitive and in keeping with community priorities, values, and needs.

Please let me know if you are available to attend, or if you have any questions at all. We truly appreciate your participation in this initiative!

Community Expert's Characteristics	DH	UTMB Health	VUMC
Gender			
Male	2	2	2
Female	4	4	4
Age (years)			
<65		1	1
65+	6	5	5
Race/Ethnicity			
White	6	4	4
Hispanic		1	
Black		1	2

Note: DH = Dartmouth College; UTMB Health = University of Texas Medical Branch; VUMC = Vanderbilt University Medical Center.

Specific Recommendations	
Summary of general feedback: <ul style="list-style-type: none"> • People responded positively to this idea, and see it as a solution to current poor after visit summaries (4 participants would participate, 1 participant might participate) • How patients and caregivers will use recordings: <ul style="list-style-type: none"> ○ Call their doctors to clarify specific details ○ Review specific medication changes ○ Review before next visit as preparation ○ Sharing with caregivers may be one of the best parts of this – can listen together 	
Email reminders (see page 4 of this report for conversational summary details): <ul style="list-style-type: none"> • Participants recommended changing specific language • Email sender is important, and should be recognizable to participants • Participants want less communication if they complete what is asked of them in the first communication. Though the study team has reasons for the three reminders, the detail of this was lost and participants indicated they just wanted fewer emails. • There was a mix of preferring emails to texts or texts to emails 	Recruitment and compensation suggestions: <ul style="list-style-type: none"> • There was no single recruitment method that was preferable • A mix of all recruitment methods (ie, directly from doctor, waiting room flyers, emails, newspaper ads) was recommended • Feedback on compensation was mixed – there was no clear indication that it was too high or too low. • Compensation may be appropriate, but may still be a barrier for some participants
Transcription: <ul style="list-style-type: none"> • Multiple people requested transcriptions of the recordings in addition to the recording itself • Transcripts were viewed as a more efficient way of reviewing the visit 	Surveys: <ul style="list-style-type: none"> • Efficient delivery of the surveys is important • These participants valued a voice asking the questions (ie, in-person during/after a visit, or via an online survey with speech option)
General concerns to prepare for: <ul style="list-style-type: none"> • Requests for use of recordings in other types of visits (ie, outside of the primary care setting) • Concerns around confidentiality • Concerns of over-communication (ie, high frequency of reminders) – some participants reported already ignoring notifications from hospital portals • Concerns that providers may be changing their behavior because they are being recorded • Concerns about the ease of using the interface when accessing recordings online • Barriers to participating: <ul style="list-style-type: none"> ○ Participants' discomfort about listening to themselves on a recording ○ Time, internet access, too many demands on the user 	

Topic/sub-topic	Interview guide question (examples)	Community Expert responses	Research team actions
Recruitment	How would you prefer to hear about a study like this? How do you think people in your community will react to being in the [usual care] group?	"If the physician asked, I'd be more likely to say yes." "I think it could hurt some people's feelings to be in the control group."	Ensured that potential participants received a note from their provider about the study and that the provider was comfortable with their participation. Prepared study staff to be able to clarify that participation was voluntary in the case a person was randomized to an arm other than the one they wanted.
Materials	Regarding reminders for study activities, what text would be most impactful or motivating for you and people in your community How can we make the reminder most motivating for you to review you recording?	"Need to make sure it's not spam; it sounds like spam." "Sender matters – need to recognize or won't open" "Email 3: rephrase as final "opportunity" to visit recording. More personable and more inviting"	Changed the wording of automatic reminders to be more personable and reflect specific suggestions from the Experts. Ensure that study reminders come from an email address the patient is familiar with or has been prepared to look for.
Implementation	Recap technology. How do you think this might work for YOU and people in your community? How would a recording of your doctor's visit be useful for you?	"Can't picture the advantage of a recording because I am a very visual person, like another participant." "Technology use in elderly populations needs to be easy." "I think this is an awesome project, because my parents are 60 and 65 and my mom's response is always "they didn't say anything" when I ask about the Drs visits."	Performed field testing and a pilot trial to continuously improve the user interface for the intervention. Expand the research program emphasis on care partners.
Other	"What would you like to see the researcher do differently?"	"Add paper transcription/translation." "[Provide access] for other languages besides English to help clarify clinic visit information."	The intervention user interface was translated along with all final study materials. We continuously work to expand access and recruitment of Spanish-speaking study participants.



The feasibility of sharing digital audio-recordings of clinic visits online with older adults in primary care settings: A multisite trial[☆]

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Elizabeth Carpenter-Song^{a,h}, A. James O'Malley^{a,c}, Martha L. Bruce^{a,i}, James S. Goodwin^c,
Sunil Kripalani^{j,k}, Susan Tarczewski^b, Sonya Williams^l, Isamar Ortiz^l, Adam Wright^l,
Mukaila A. Raji^l, Hyunouk Hong^m, Parul M. Goyalⁿ, Kerri L. Cavanaugh^{j,o}

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ARTICLE INFO

Keywords:

Patient centered communication

Older adults

Technology

ABSTRACT

Objective: The objective of this trial was to determine the feasibility, acceptability, and preliminary effectiveness of sharing audio recordings of primary care visits with older adults with multimorbidity.

Methods: We used a two-arm, randomized, controlled, feasibility trial with 3-month follow-up. Patients aged ≥ 65 years—with diabetes and hypertension—were recruited from academic primary care settings in New Hampshire, Tennessee, and Texas. Patients were randomized to receive online access to audio recordings of scheduled visits for three-months or care as usual (after visit summaries). Primary outcomes were acceptability and feasibility assessed using several indicators: acceptability—recruitment of 90 patients; recording use; and the Appropriateness of Intervention Measure (AIM; >3), feasibility—retention rate; protocol adherence; and the Feasibility of Intervention Measure (FIM; >3). Interviews were conducted with clinicians ($n = 14$) and patients ($n = 19$). Exploratory outcomes included patient activation, satisfaction, adherence, and quality of life.

Results: We met recruitment ($n = 91$) and retention (98 %) targets and exceeded feasibility (Median FIM 4; IQR 3 – 4) and acceptability (Median AIM 4; IQR 3 – 4) metrics. Fidelity to protocol was high (92 %), and 40 of 45 patients (85 %) accessed their recordings. Interviewees noted the benefits of visit recording, including greater recall, understanding, and family engagement. Recording had little perceived impact on the visit interaction, and concerns about visit recording were minimal. Exploratory outcomes revealed better PROMIS Mental Health



The Effect of Clinic Visit Audio Recordings for Self-Management in Older Adults



PIs: Paul J Barr PhD MScPH, Kerri Cavanaugh MD MHS (VUMC), Dr. Meredith Masel PhD MSW (UTMB) National Institute on Aging (NIA), R01AG074959



Comparing Healthcare Visit Recording and Open Notes to Improve the Chronic Illness Care Experience for Older Adults



PI: Paul J Barr PhD MScPH; Site Pis: Kerri Cavanaugh MD MHS (VUMC), Dr. Meredith Masel PhD MSW (UTMB) Patient Centered Outcome Research Institute (PCORI)

A 7-Item Questionnaire for Reporting on Stakeholder Engagement in Research

-
1. What types of stakeholders were engaged?
 2. What were the a priori target number(s) for each type of stakeholder? Were targets met?
 3. How was balance of stakeholder perspectives considered and achieved?
 4. What methods were used to identify, recruit and enroll stakeholders in research activities?
 5. Did engagement occur:
 - a. before research began, during priority setting, topic development, question development, and research design;
 - b. during research activities, including enrollment of patients, conduct of data collection, analysis, and interpretation of findings; and
 - c. after research was concluded, including dissemination and implementation of findings, and evaluation of the research itself?
 6. What were the intensity, methods and modes of engagement?
 7. What, if any, was the impact of stakeholder engagement on:
 - a. the relevance of research questions;
 - b. the transparency of the research process; and
 - c. the adoption of research evidence into practice settings?
-

This figure presents a list of questions that may be used by researchers to guide future reporting on stakeholder-engaged research. These questions were co-developed with a stakeholder panel

Concannon, T. W., Fuster, M., Saunders, T., Patel, K., Wong, J. B., Leslie, L. K., & Lau, J. (2014). A systematic review of stakeholder engagement in comparative effectiveness and patient-centered outcomes research. *Journal of general internal medicine*, 29(12), 1692–1701. – 7 item survey of engagement



WELCOME to

*Get Engaged:
An ECHO to Increase Skills for
Community Engaged Research*

*Session 3, Infrastructure for Working with Community Members,
April 22, 2025*

Infrastructure for working with community members

Julie Bosak, DrPH, CNM
Cheri Bryer, CRC, CLC, CHW



Overview

- What are the aspects to consider when creating the infrastructure for working with community members?
- How do you determine when in the research process to engage community members?
- What level of engagement is most appropriate for your research?
- Case Presentation
- Discussion

FIGURE 1 Community Engagement Impacts in Research Taxonomy: a taxonomy of standard terms for areas of community stakeholder impact in research. Domains are in all-capital letters and white text. Dimensions (topical clusters of subcodes) are preceded by a ">" symbol and are in black text



Area of focus today

Fig 1 from Stallings S et al. A taxonomy of impacts on clinical and translational research. Health Expectations 2019

Why Community Engaged Research?

Infrastructure

This stage of research process focuses on:

- ❖ Logistics of the project
- ❖ Distribution of funds
- ❖ Research team members and roles
- ❖ Other planning decisions are made

Appropriate **structure and process** to support meaningful engagement:

- ❖ Governance
- ❖ Compensation
- ❖ Team Roles

Concepts that support meaningful engagement:

- ❖ Power Balance
-



Governance

What are the structures and processes that guide decision making and accountability within the community partnerships.

A well defined governance structure protects community interests


- ❖ How are decisions being made? Consensus?
- ❖ Who has the final decision power?
- ❖ Is it different dependent upon the content of the decision?

Factors that will influence best governance structure-

- ❖ What level of community involvement is reasonable and expected for your research?
- ❖ What is your capacity as a team for supporting levels of engagement?

Compensation

- ❖ **Not an incentive**, but appropriate payment for their expertise and time
 - ❖ Compensation should be adjusted based on level of involvement
 - ❖ Research appropriate amount to ensure sufficient coverage
- ❖ **Be transparent**
 - ❖ Clearly communicate compensation requirements, amount and timing
- ❖ Consider **unintended consequences** of increased income
- ❖ Operationally- part of your budget
 - ❖ System challenges -be aware of funder or institutional restrictions on processes
 - ❖ Might need to advocate for adaptation to existing policy



“HRSA prioritizes equitable compensation for community members involved in their community engagement efforts, recognizing the value of their time, expertise, and lived experiences.” –HRSA Maternal Child Health Bureau



Team Roles

- ❖ Clearly define responsibilities and scope for each team member and their interaction with community members
- ❖ Ensure capacity for supporting community participation
 - ❖ Is there additional time and funds needed for training internal team members and the community participants?
 - ❖ Additional time for extra support in preparing for meetings/ follow up?

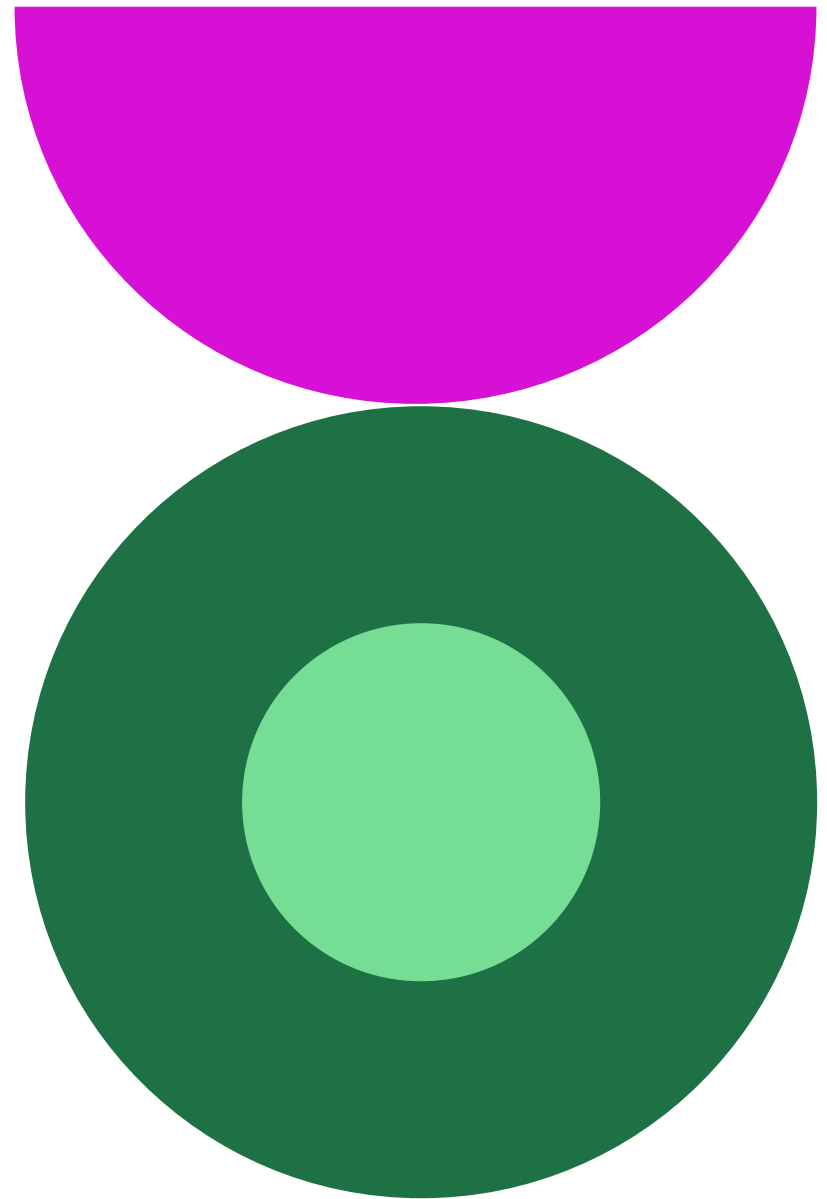
The power imbalance

- ❖ **Definition of power imbalance:** Existing difference between participants based on societal and organization norms (academic, socioeconomic)
 - ❖ **Understanding and managing the power balance?**
 - ❖ Recognize that one will always exist even with a fully shared leadership
 - ❖ Especially if the academic institution provides the finances
 - ❖ **Power balance will look different dependent upon your research community**
 - ❖ Community organization staff versus historically marginalized populations such as pregnant women in recovery
-

Steps to manage the power dynamic

Must intentionally work to create a more equitable and collaborative relationship

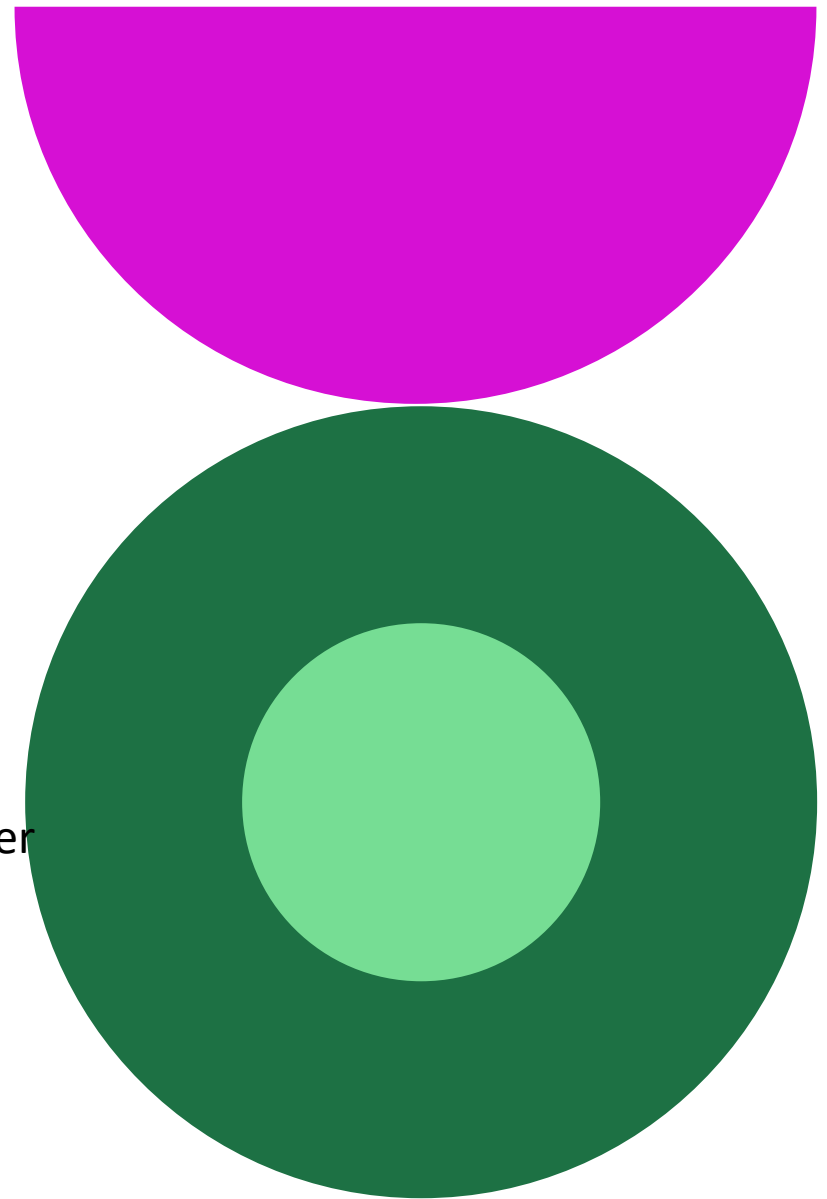
- ❖ Up front assessment of the dynamic- where are the inequities, biases, discrimination, racism, rank and privilege
- ❖ Thoughtful selection and conversations with your academic colleagues
 - ❖ Are they willing and able to “release power”
 - ❖ Do they truly see the community voice as an expert
 - ❖ Do they understand the complexities and vulnerability of community participants’ with lived experience and are willing/able to ensure extra support provided



Addressing the underlying influences of the power dynamic

Offer and encourage training on:

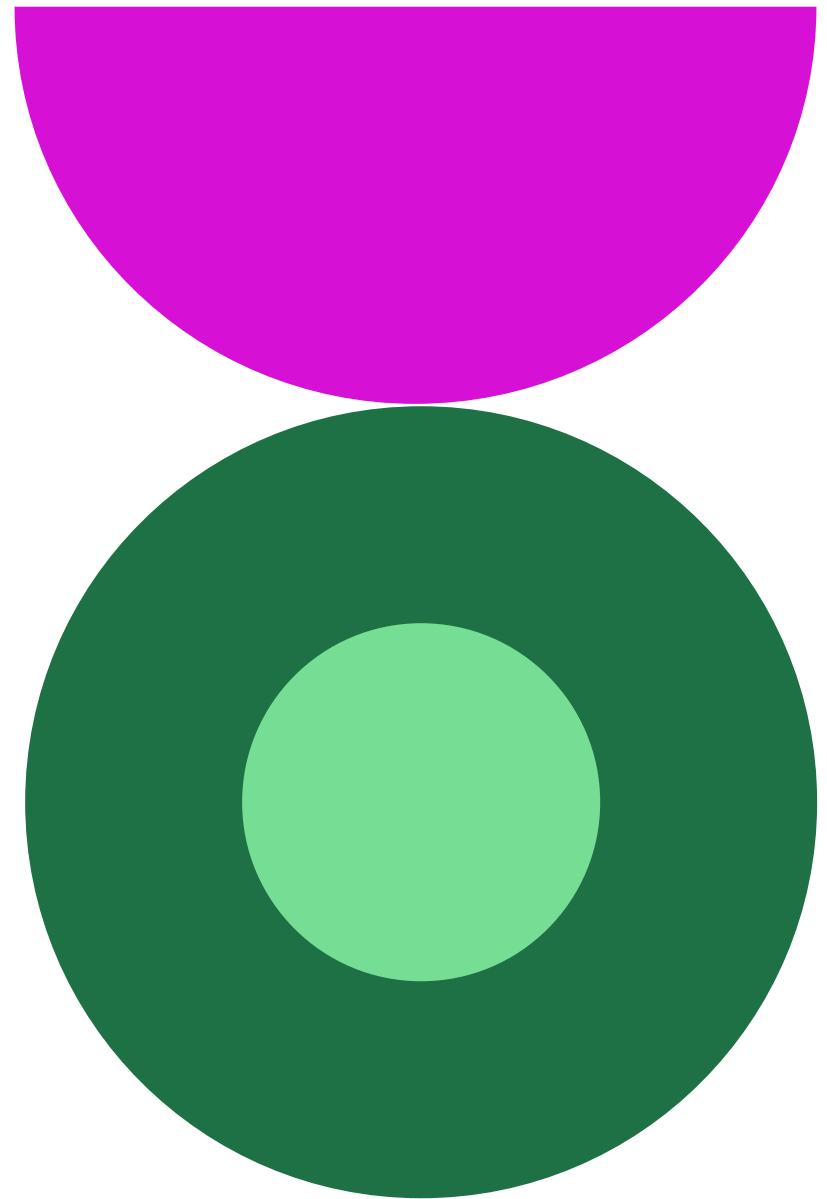
- ❖ **Implicit bias**
 - ❖ Participants ability to identify and address unconscious judgements based on historical stereotypes
- ❖ **Positionality**
 - ❖ Ones' ongoing awareness of their role and influence over the research due to their social status
- ❖ **Structural competency**
 - ❖ Recognizing and understanding the embedded system, institution and policy barriers based in historical inequities



Understanding the power dynamic

With historically marginalized populations

- ❖ Community members who have not historically had a seat at the table will need additional time to develop trust and fully engage
- ❖ Ideally have a trusted representative who can manage contact, ensure respectful communication and provide a safe connection
- ❖ Extra consideration for communication, ethics and compensation process



Structural options for including community members

Community
Members as part
of study team

**Integral part of the study
leadership team across all
phases of the study**

OR

During implementation
function as community
based researchers/outreach

Advisory Boards

**A structured group of
individuals who provide
guidance and advice on
a research study.**

Part of internal Study Team

April 2025

A fully participatory member of the organization's team

Governance

- ❖ Transparency about roles and decision making within the team- shared leadership
- ❖ Impact of hired staff versus consultant contract and their level of involvement with decisions



Part of internal Study Team

April 2025

Power Dynamic

- ❖ Still exists within the internal team
- ❖ There will still be a reporting structure of community member to the Principal Investigator (supervisory)
- ❖ Consider the scope of the role and how they will interact with the external community member participants in the research study

Compensation

- ❖ Dependent upon structure either as paid staff or with a consultant agreement
- ❖ Provides predictable income that supports a more sustainable, long term collaboration



A structured group of individuals who provide guidance and advice on a research study to full collaborative oversight

Governance

- ❖ Clearly delineate the role of the Advisory Board
- ❖ Ideally co-create a charter for the board that defines its role within the study and how it will function



Power Dynamic

- ❖ Choice of facilitator- culturally responsive approach
- ❖ Consider dynamic both between the advisory board members and between study staff and board
- ❖ Putting the time in up front to build relationships
 - ❖ Remote platform creates additional challenges

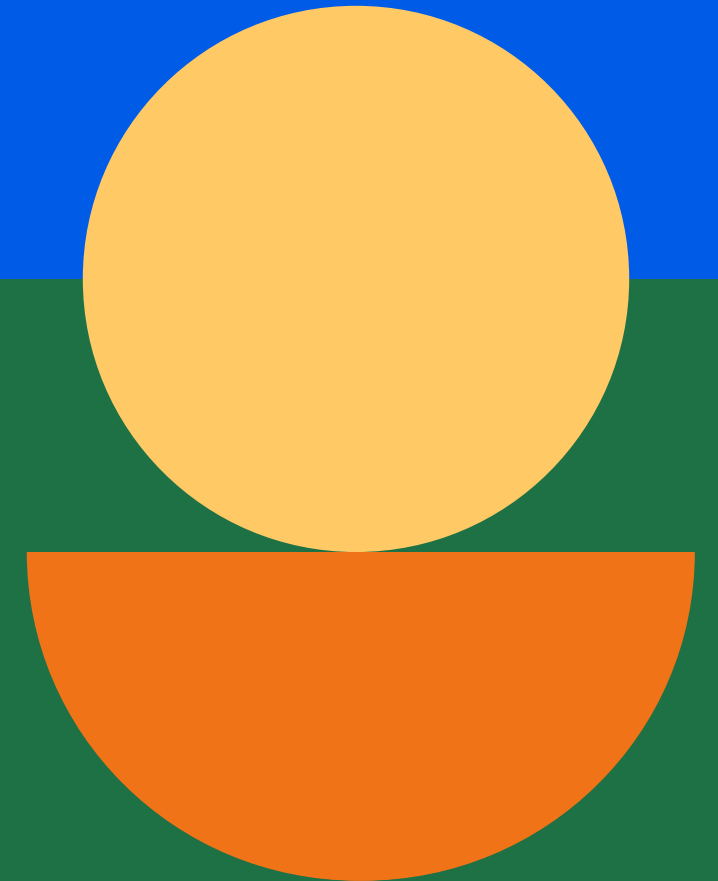
Compensation

- ❖ Funds to support their time
- ❖ Consider in between meeting prep work when identifying amount
- ❖ Additional efforts for the research evaluation- surveys, interviews

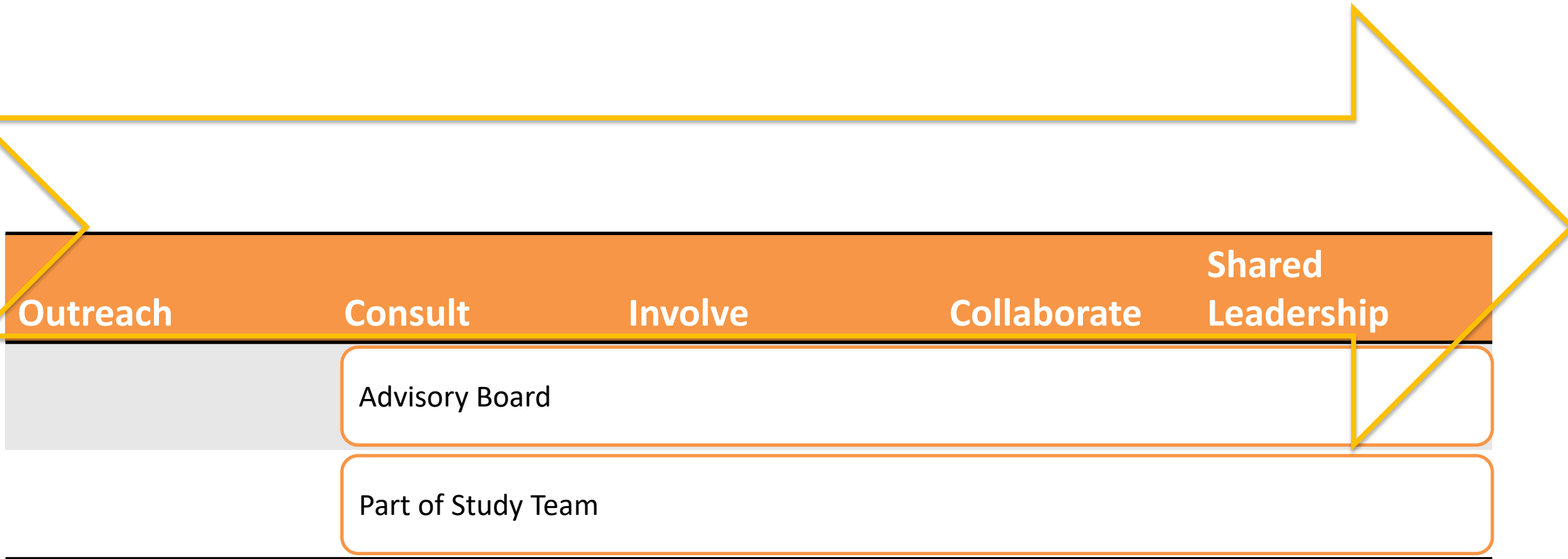


Considerations for community participation.

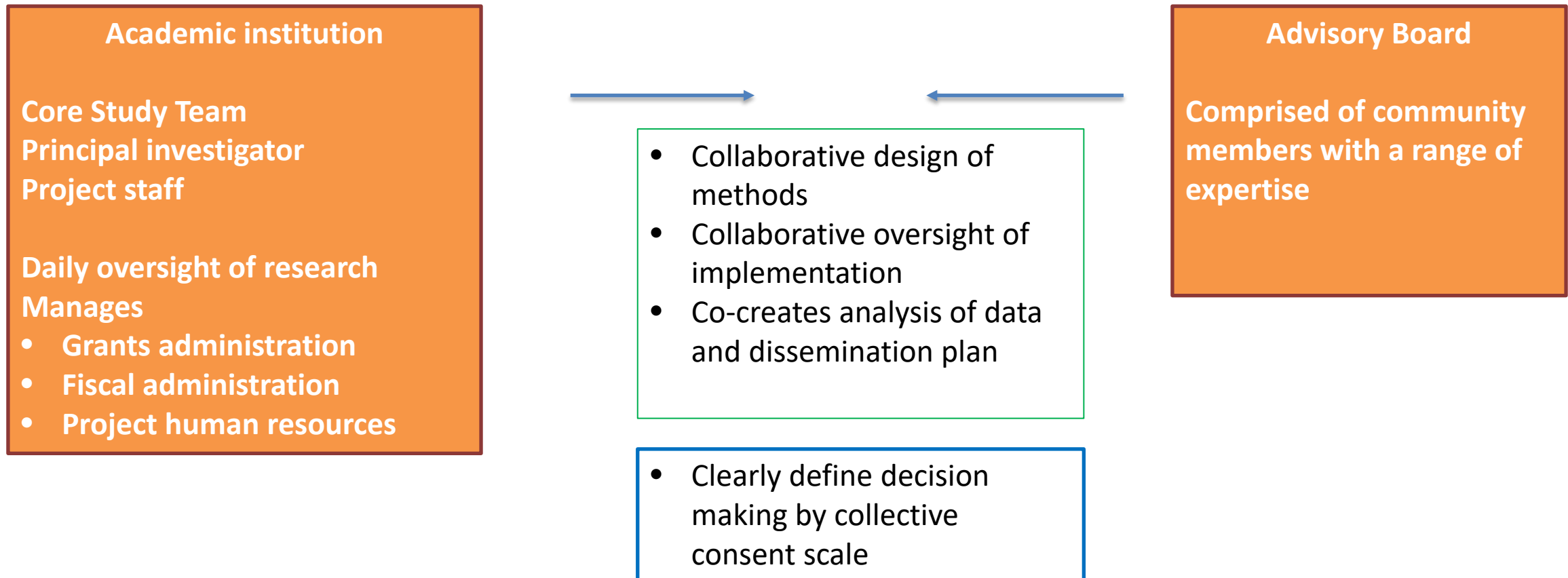
- ❖ When in the process would you like to engage community members?
 - ❖ What level of engagement do you have the capacity to support?
 - ❖ What is your “readiness status?”
 - ❖ Do you have existing relationships in the community- a champion?
 - ❖ Financial and staff capacity-
 - ❖ What can the budget manage for additional project staff to support facilitation and administrative needs
 - ❖ Significant planning and preparation work to ensure ethical and effective implementation –
 - ❖ Ideally co-create materials to ensure language and concepts accessible
-

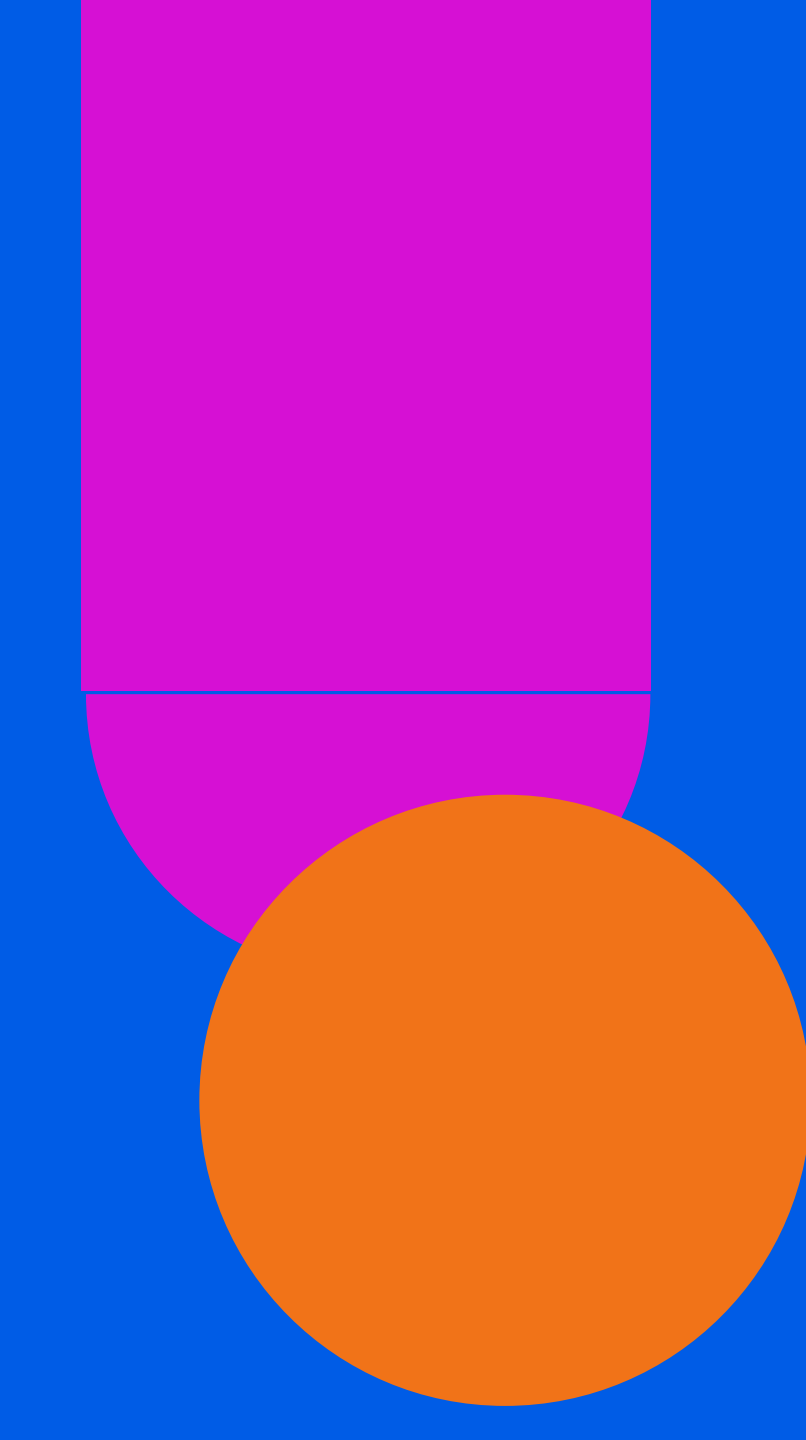


How do these different structural approaches align along the continuum of engagement?



Example of shared leadership governance structure for an advisory board



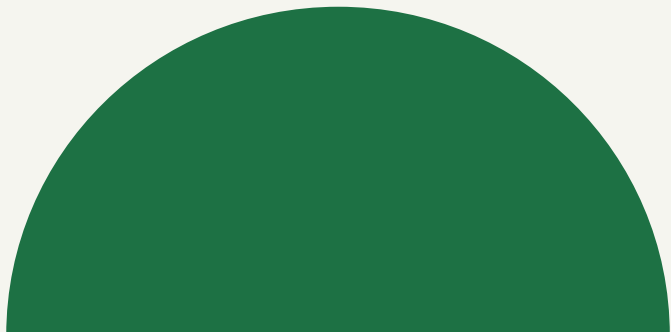


How do you operationalize an advisory board

- ❖ Determine membership composition goals (ideally collaboratively with some initial community members)
- ❖ Strategy for recruitment (open call versus invitation)
 - ❖ How to ensure broad representation
 - ❖ Clarity of expectations for time commitment
- ❖ Barriers to participation (transportation, childcare, technology)
- ❖ Defining governance and communication norms within the advisory board and the broader context of the study
 - ❖ Training plan to ensure meaningful participation

Small details that make a difference

- ❖ Focus on building trusting relationships
 - ❖ Lays the foundation for the work
 - ❖ Who does the initial outreach and communication?
- ❖ Be clear and then do what you say
- ❖ Things that seem small to us are consequential to participants
- ❖ Full transparency if adaptation necessary





Questions?

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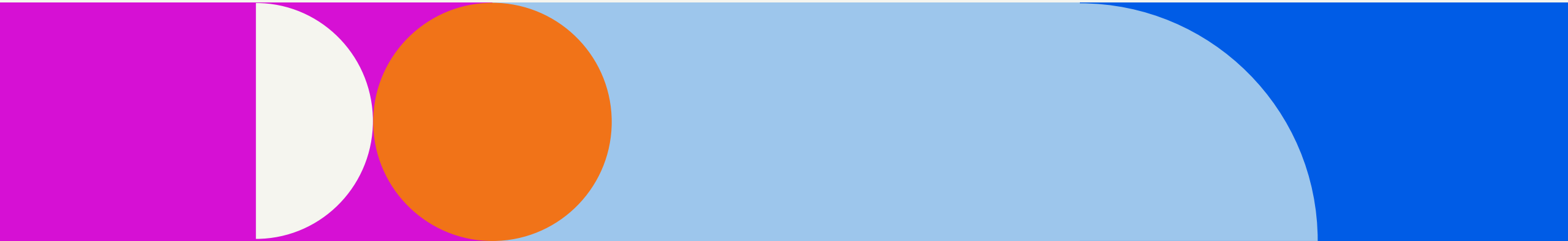
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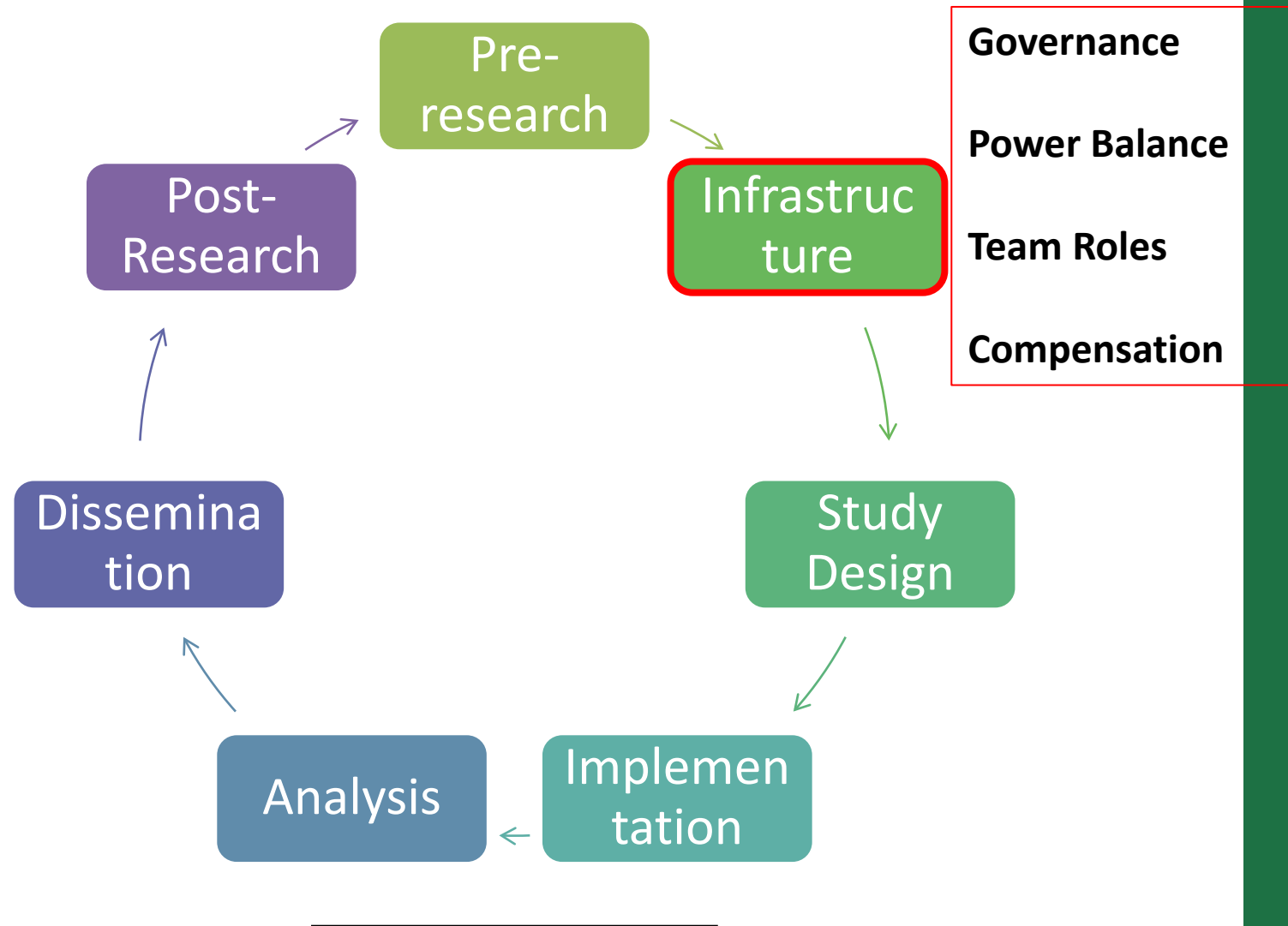
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The domain of infrastructure

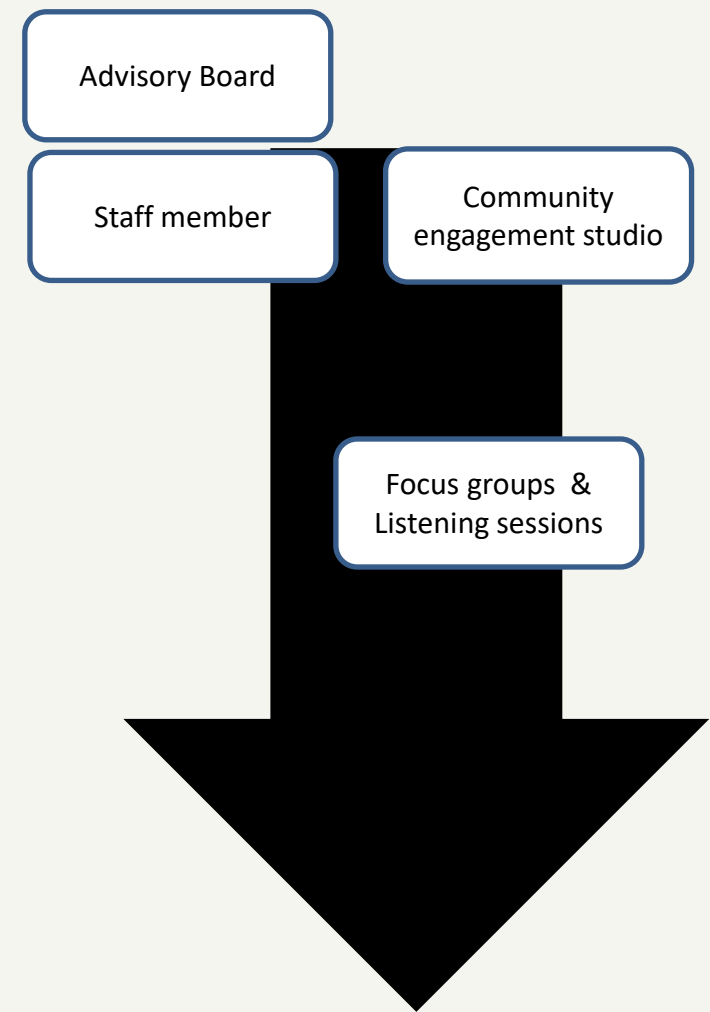
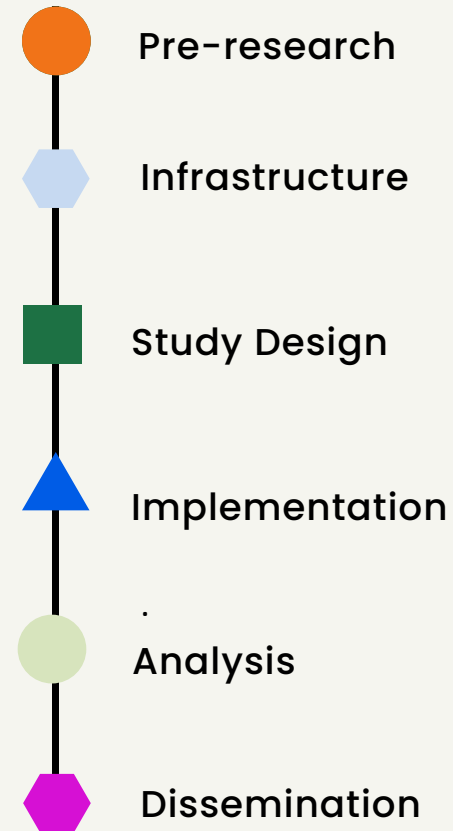




How do you decide on the level of engagement

- ❖ Assess your readiness as a team
 - ❖ Composition of your existing study team
 - ❖ Experience with CEnR
 - ❖ Assess your connection with the community
 - ❖ Do you have strong ties with the community already?
 - ❖ Do you have at least an existing champion?
-

Where in the Research Process do you involve community members?





WELCOME to

*Get Engaged:
An ECHO to Increase Skills for
Community Engaged Research*

Session 4, Research Implementation, May 27, 2025

Implementing Community Engaged Research: A Case Study

- ❖ **Meagan M. Adams, RSW, CHW,**
Doula/Recovery Support Worker
Dartmouth Health
- ❖ **Daisy J. Goodman, DNP, MPH, CNM, CARN-AP**
Associate professor of OBGYN
Geisel School of Medicine



Agenda

Implementing Community Engaged Research:
the MORE Study as a case example

- ❖ Study Advisory Group as framework for collaboration
- ❖ Community-led recruitment strategies
- ❖ Community-engagement data collection
- ❖ Analysis and interpretation



Gratitude

- For our Study Advisors, community members, clinical partners, and the study team whose dedication to community engaged research is a continual inspiration to us.
- Acknowledgement: The MORE Study is funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Award (MAT-2017C2-7717): Co-PIs S. Lord/D. Goodman).
- Disclaimer. The content of this presentation is solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.
- Today's presenters have no financial or other conflicts to disclose



A community-based study exploring the best methods of care for moms in recovery

MORE Study Aims

- **Aim 1 (*Clinical Outcomes*):** To use clinical record data to evaluate the comparative effectiveness of Integrated and Referral-based MAT care models on maternal and neonatal outcomes.
- **Aim 2 (*Patient-Reported Outcomes*):** To use patient-reported data to evaluate the comparative effectiveness of Integrated and Referral-Based care models on patient-centered outcomes.
- **Aim 3 (*Heterogeneity of Effects*):** To examine differences in treatment retention within condition by subgroups of patients based on: (1) psychiatric co-morbidity, (2) type of MOUD medication, and (3) addiction severity.

MORE Study Aims (cont'd)

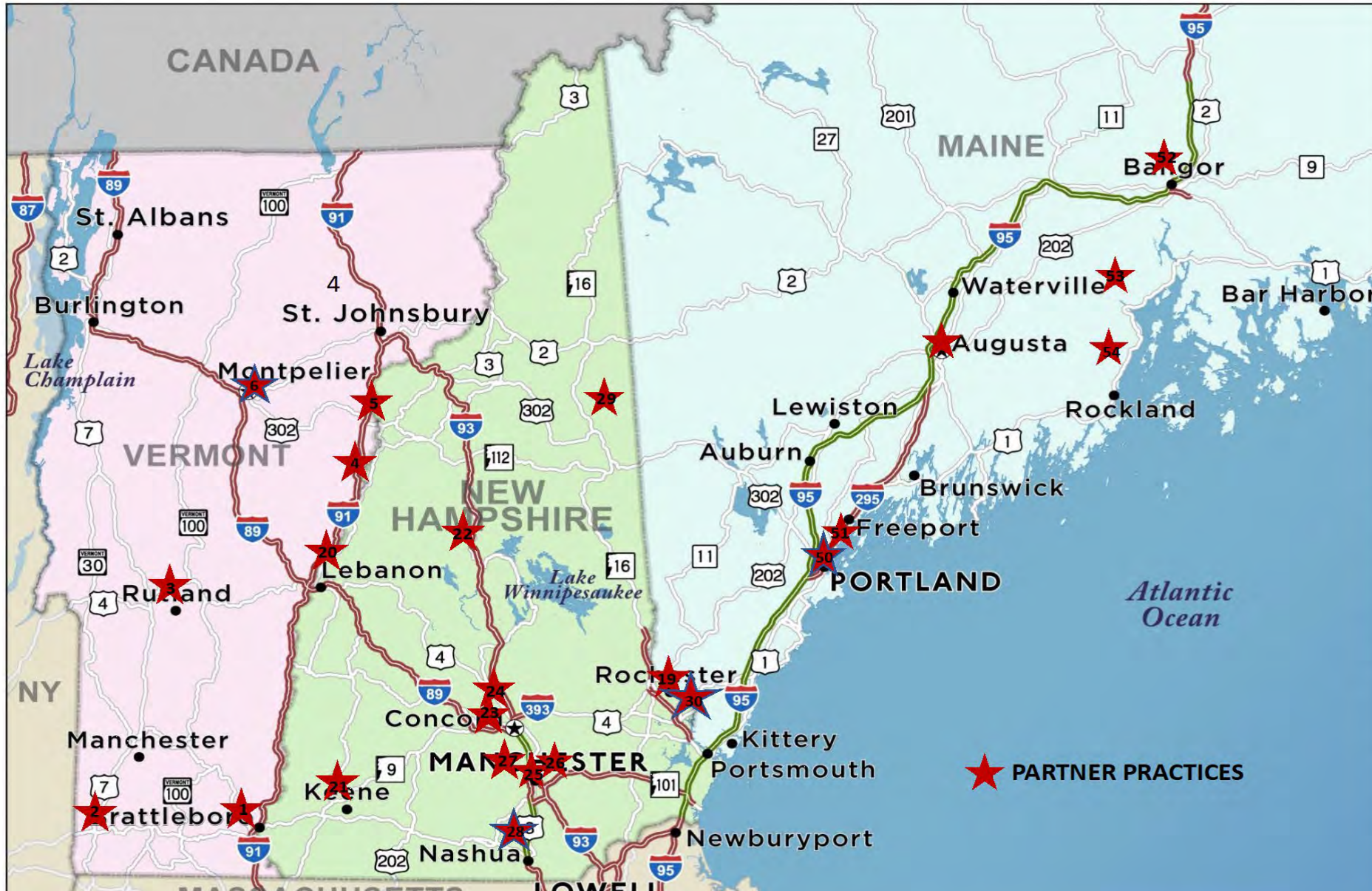
- **Aim 4 (*Specification of Services*):** To determine which services (psychosocial, case management, parenting education) are associated with better maternal and neonatal outcomes.
- **Aim 5:** To explore how provider attitudes about medication treatment for OUD and care of patients with OUD vary by care model and are associated with maternal outcomes

This study therefore had three key groups of stakeholders:

- ❖ Pregnant and postpartum people
- ❖ Clinicians (both perinatal and SUD treatment providers and administrators)
- ❖ Policymakers



MORE Study Partner Practices



VERMONT

- 1 – Brattleboro Memorial Hospital
- 2 – Southwestern Vermont Medical Center
- 3 – Rutland Regional Medical Center
- 4 – Little Rivers Health Care – Bradford
- 5 – Little Rivers Health Care – Wells River
- 6 – Central Vermont Medical Center

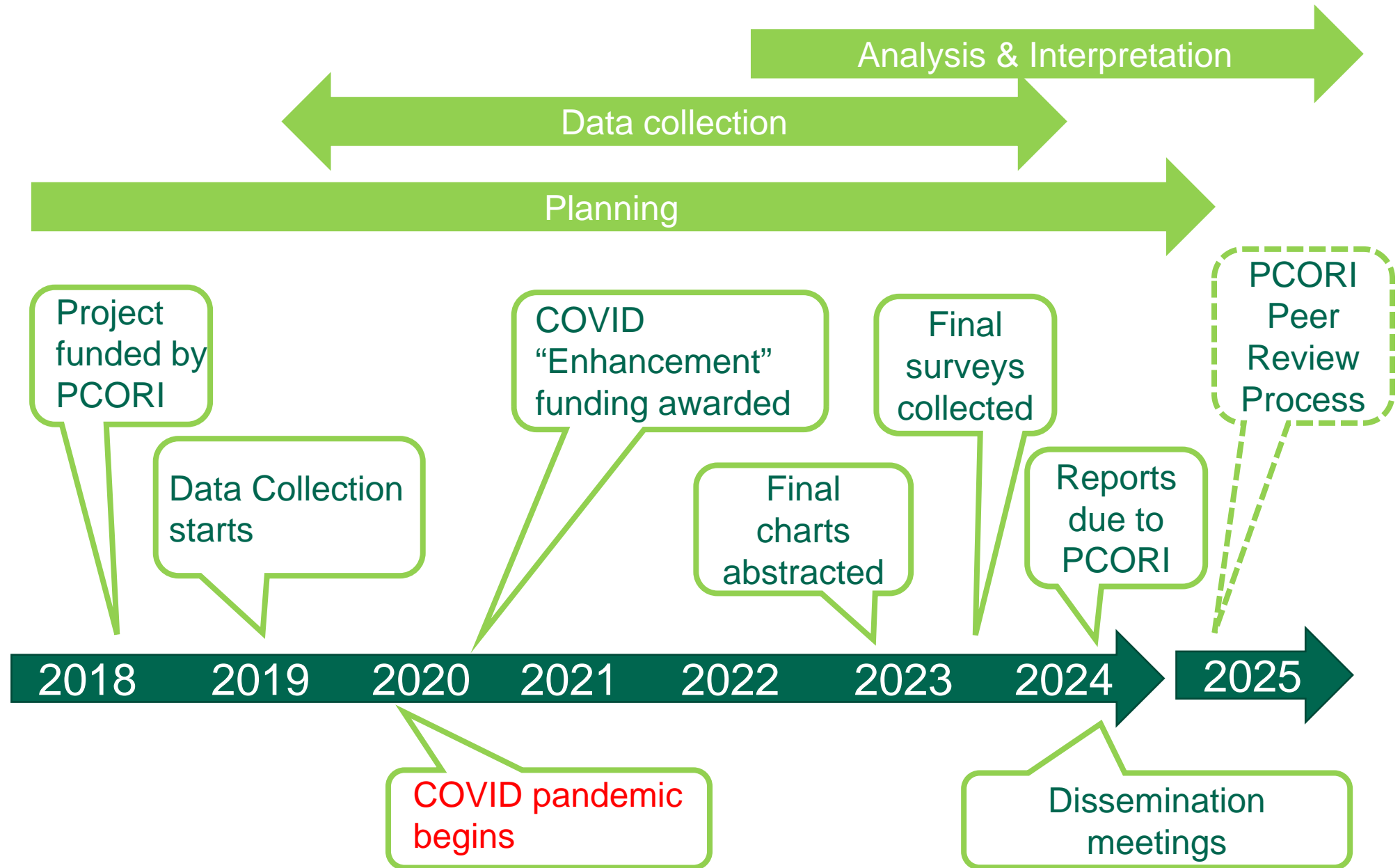
NEW HAMPSHIRE

- 19 – Avis Goodwin
- 20 – Dartmouth-Hitchcock Lebanon
- 21 – Women's Health, Cheshire Medical Center, Dartmouth-Hitchcock
- 22 – Plymouth OB/GYN, Speare Memorial Hospital
- 23 – Dartmouth-Hitchcock Concord, Department of Obstetrics, Gynecology & Nurse Midwifery
- 24 – Concord Hospital OB & GYN
- 25 – Amoskeag Health
- 26 – Dartmouth-Hitchcock Bedford
- 27 – Catholic Medical Center
- 28 – Dartmouth-Hitchcock Nashua
- 29 – Women's Health & OB/GYN, Memorial Hospital
- 30 – Garrisons Women's Health

MAINE

- 50 – Maine Medical Center OB/GYN
- 51 – Falmouth Family Practice
- 52 – Northern Light/Eastern Maine Medical Center
- 53 – Women's Health and Obstetrics, Waldo County General Hospital
- 54 – Pen Bay Women's Health Center
- 55 – Maine-Dartmouth Family Practice Residency

MORE Study Timeline



Framing Engagement: MORE Study Advisory Committee

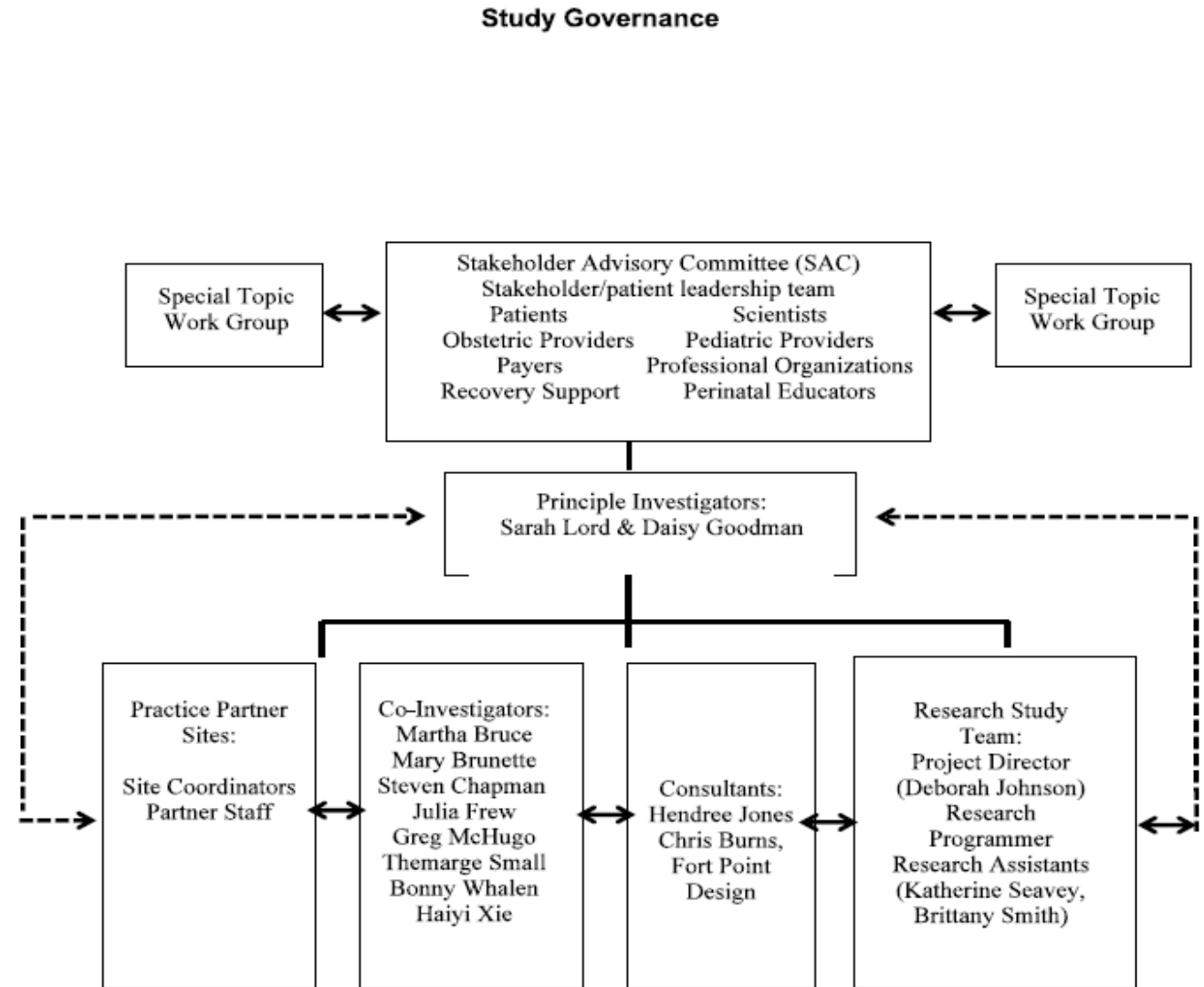
Role of Study Advisory Committee (SAC)

Provides oversight for all aspects of the study

Charter created collaboratively by SAC, project director, and mPIs

Establishes norms and responsibilities for both SAC members and study team during all phases of the study:

- Planning
- Conducting
- Dissemination

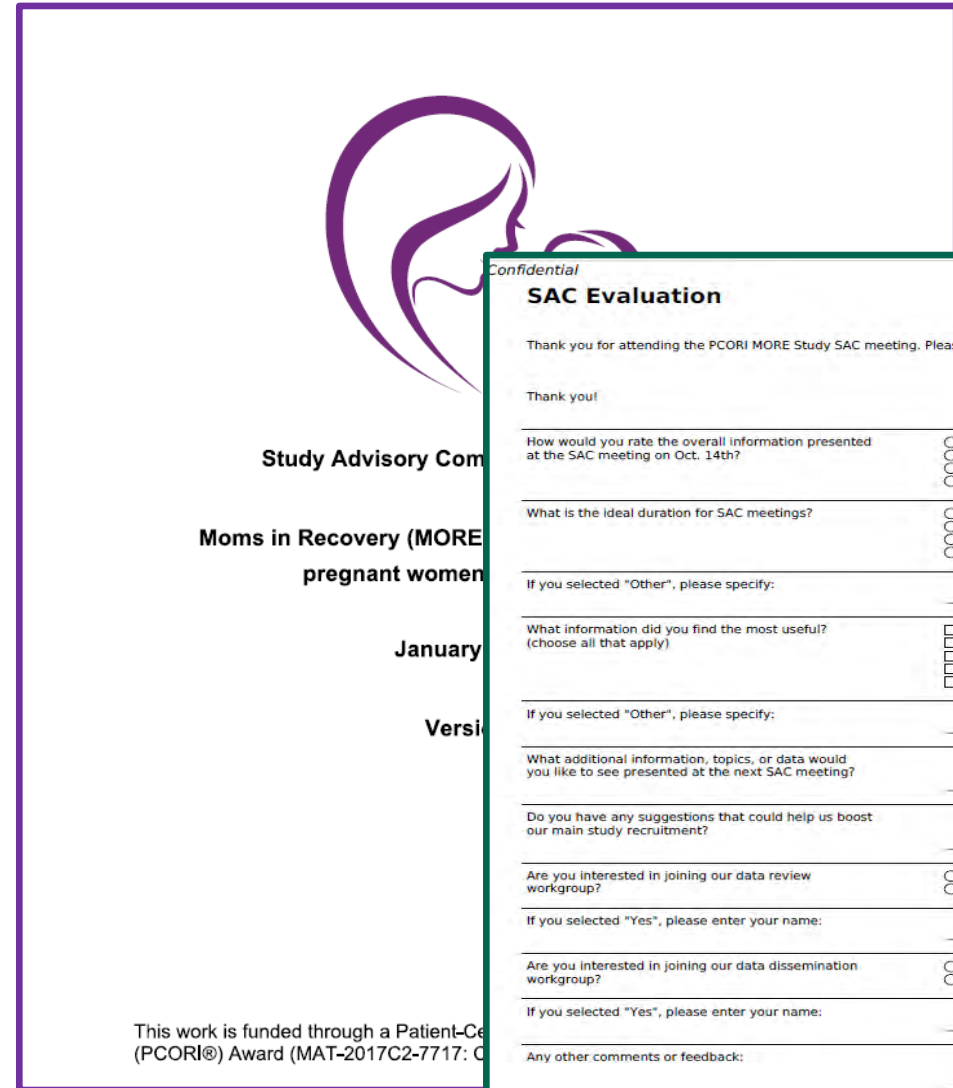


SAC Workgroups In Action



SAC Activities During Planning Year

- SAC Charter developed
- Research methodology training for SAC members, provided by PIs
- Group study for CITI training
- Formation of Workgroups
- Instrument development, consent, other study materials



Study Advisory Committee

Moms in Recovery (MORE)

pregnant women

January

Vers

This work is funded through a Patient-Centered Research (PCORI®) Award (MAT-2017C2-7717: C

Confidential

SAC Evaluation

Page 1

Thank you for attending the PCORI MORE Study SAC meeting. Please complete the survey below.

Thank you!

How would you rate the overall information presented at the SAC meeting on Oct. 14th?

☐ Poor
☐ Fair
☐ Good
☐ Excellent

What is the ideal duration for SAC meetings?

☐ 1 hour
☐ 1.5 hours
☐ 2 hours
☐ Other

If you selected "Other", please specify:

What information did you find the most useful? (choose all that apply)

☐ Main study recruitment updates
☐ Main study data updates
☐ COVID enhancement study data updates
☐ Main study recruitment challenges
☐ Other, please specify

If you selected "Other", please specify:

What additional information, topics, or data would you like to see presented at the next SAC meeting?

Do you have any suggestions that could help us boost our main study recruitment?

Are you interested in joining our data review workgroup?

☐ Yes
☐ No

If you selected "Yes", please enter your name:

Are you interested in joining our data dissemination workgroup?

☐ Yes
☐ No

If you selected "Yes", please enter your name:

Any other comments or feedback:

04/05/2022 9:37am

projectredcap.org

REDCap®

Data collection:

Instrument Design & Clinical Record Abstraction Tool

Study Outcomes:Aim I (Clinical)

Primary

- Illicit opioid use
- MOUD treatment retention prenatal to 6 weeks postpartum
- Perinatal complications

Secondary

- Other substance use
- Neonatal complications
- Treatment for neonatal opioid withdrawal

Other

- Health services utilization (including prenatal care)
- Mental health diagnoses and medication treatment
- Infectious diseases (e.g., Hep C, HIV)
- Social determinants
- Child protective service involvement

Study Outcomes:Aim 2 (Patient-Reported)

Primary

- MOUD treatment retention at 3- and 6-months postpartum
- Mental health: Depression, Anxiety
- Substance use

Secondary

- Patient-centered care experiences
- Quality of life
- Child custody
- Pediatric care visits

Other

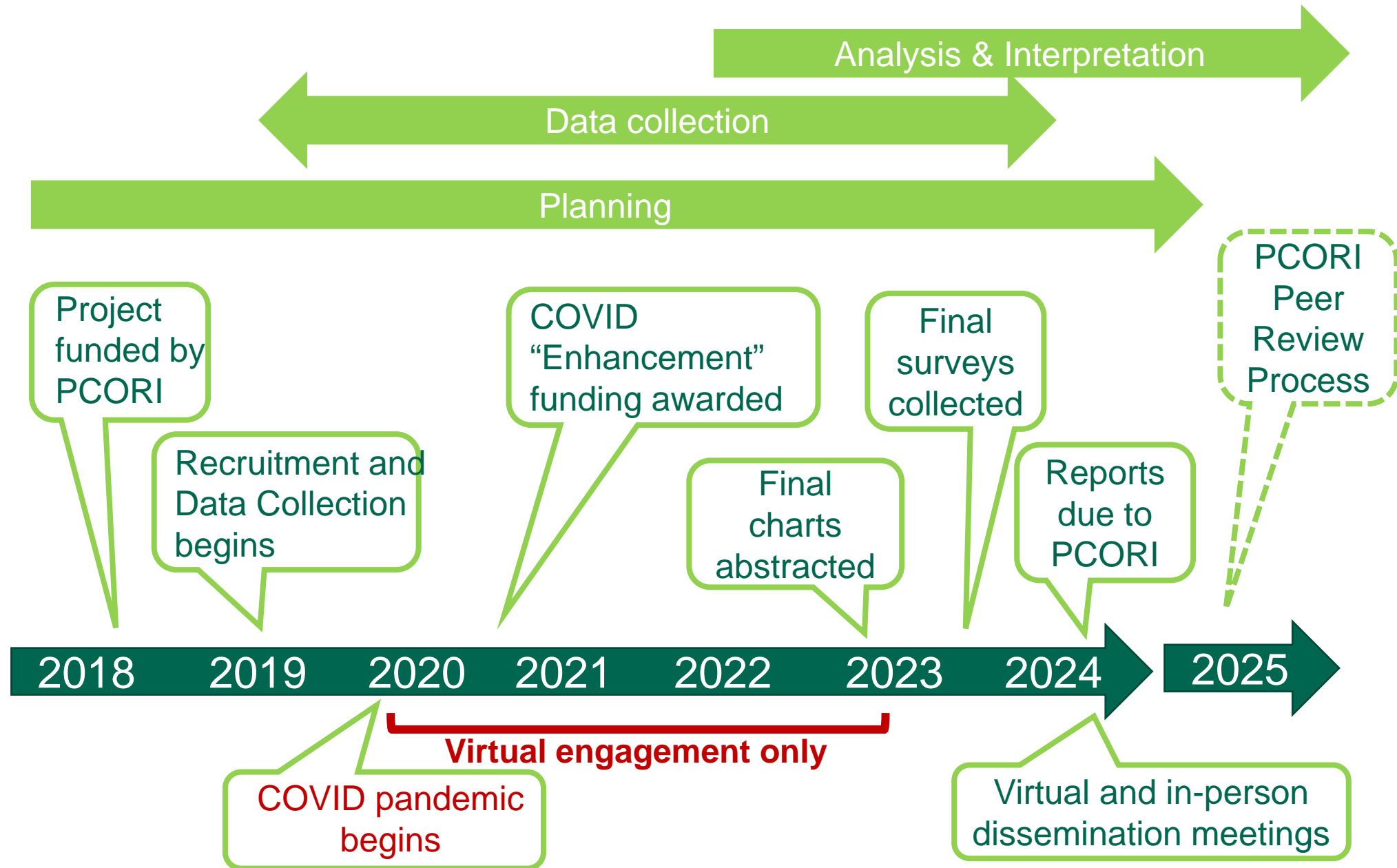
- Opioid use severity
- Social determinants
- Adverse childhood experiences
- Health services utilization
- Parenting efficacy

Engagement Of Key Stakeholders In Designing Data Collection Instruments And Approach

- Registered nurses and nurse midwife PI led development of clinical record data collection tool and approach to accessing data
- SAC Workgroup, Project Director, and PI collaborated to develop survey instruments for patient-reported outcomes
 - Reviewed available instruments
 - Provided guidance on instrument modification to improve community fit
 - Pilot tested instruments with group
 - Removed or adapted questions which were identified as problematic or triggering

Recruitment and Retention Strategies

MORE Study Timeline



Impact Of The COVID Pandemic On Study Approach To Recruitment

With the onset of the Pandemic, planned approaches to recruitment fell apart

- Patients were no longer coming to clinical settings regularly
- Everyone was struggling financially and emotionally
- Practices were overwhelmed

SAC Engagement allowed us to pivot

- Reliance on clinical staff for recruitment was transformed to reliance by community knowledge about how and where to reach people in pandemic conditions
- Reliance on community members' word of mouth, digital media, and community events
- Recruitment video featured SAC members
- Snowball strategy
- Incremental increases in compensation

Adaptation Of The SAC



MOns in REcovery (MORE) Study: Defining optimal care for moms and infants
Semi-Annual Study Advisory Committee (SAC) Meeting

Wednesday, October 28, 2020

1-3:30 PM

Via Virtual Zoom

Join Zoom Meeting

<https://dartmouth.zoom.us/j/94957297400?pwd=Z0ZhS1BzN3pDUVMrcU1GZlVTcE5Rdz09>

Meeting ID: 949 5729 7400

Passcode: 405141

+16465588656, 94957297400#,405141# US (New York)

Meeting Objectives:

1. Update on study activities.
2. Understand COVID's impact on the study.
3. Understand how COVID has impacted/transformed care.
4. Describe recruitment challenges and brainstorm solutions

AGENDA

- | | |
|---|----------|
| 1. Introductions | 10 mins. |
| 2. Meeting Guidelines | 2 mins. |
| 3. Overview of Meeting Agenda | 5 mins. |
| 4. Study Overview, Aims & Data Sources | 5 mins. |
| 5. Study Progress and Activities | 15 mins. |
| a. The impact of COVID on the study | |
| Break | 10 mins. |
| 6. COVID Enhancement Funding | |
| a. New funding | 10 mins. |
| BREAKOUT with focused questions | 30 mins |
| REPORT OUT & DISCUSSION | 20 mins. |
| Break | 10 mins. |
| 7. Recruitment Challenges and Solutions | 20 mins. |
| a. Group Discussion | |
| 8. Meeting Summary and Wrap-Up | 15 mins. |
| 9. Next SAC Meeting | 5 mins. |
| 10. Meeting Evaluation | 5 mins. |

Community Expertise Continues To Inform Analysis and Dissemination

Analysis and Interpretation

Study team and SAC worked together throughout to interpret study results

- SAC members with lived experience worked with study team to review thematic analysis and interpret qualitative data
- Regular SAC meetings reviewed and discussed implications of both qualitative and quantitative data
- SAC members involved in presentations and poster sessions, and as co-authors on publications

> [J Comp Eff Res](#). 2022 Oct;11(15):1085-1094. doi: 10.2217/ce-2022-0090. Epub 2022 Sep 1.

Promoting community stakeholder engagement in research on treatment for pregnant women with opioid use disorder

Deborah J Johnson ¹, Mary F Brunette ^{2 3 4}, Daisy J Goodman ^{5 6 3}, Meagan Adams ⁷, Cheri Bryer ^{6 8}, Julie R Doherty ¹, Victoria Flanagan ⁹, Julia R Frew ^{2 8}, Sarah Mullins ⁹, Farrah Sheehan ¹, Allison Tobar-Santamaria ¹, Sarah Whitney, Sarah Lord ^{1 2}

Affiliations [+ expand](#)

PMID: 36047333 DOI: [10.2217/ce-2022-0090](#)

[Free article](#)

Abstract

Aim: Community stakeholder engagement in research (CSER) can improve research relevance and efficiency as well as prevent harmful practices, particularly for vulnerable populations. Despite potential benefits, researchers lack familiarity with CSER methods. **Methods:** We describe CSER strategies used across the research continuum, including proposal development, study planning and the first years of a comparative effectiveness study of care for pregnant women with opioid use disorder. **Results:** We highlight successful strategies, grounded in principles of engagement, to establish and maintain stakeholder relationships, foster bidirectional communication and trust and support active participation of women with opioid use disorder in the research process. **Conclusion:** CSER methods support research with a disenfranchised population. Future work will evaluate the impact of CSER strategies on study outcomes and dissemination.

Keywords: comparative effectiveness research; methodology; stakeholder engagement.

Coproduced with
study team

Coping with Loss As a Research Community



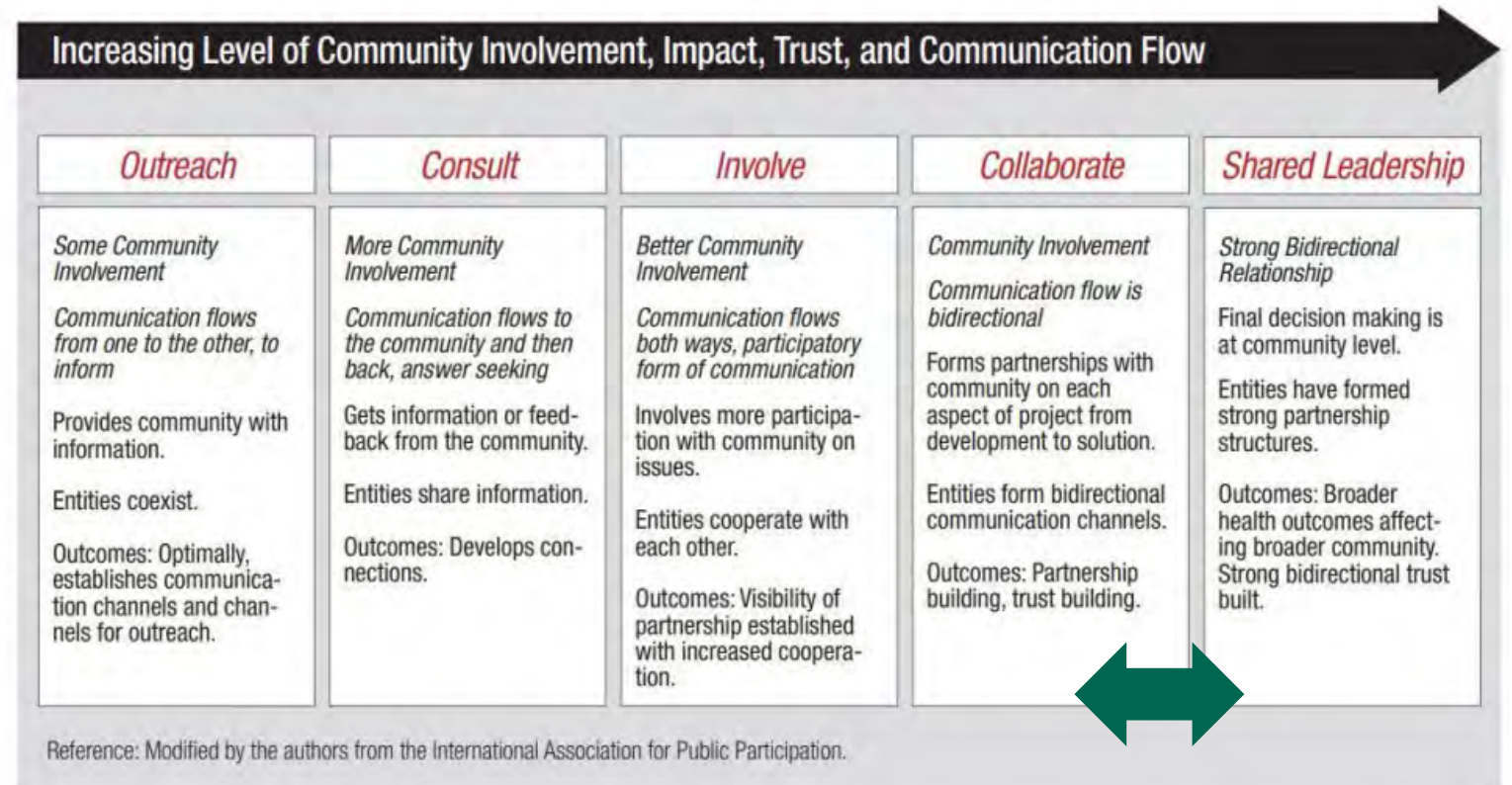
In loving
memory

*Jenel
&
Margo*



Summary

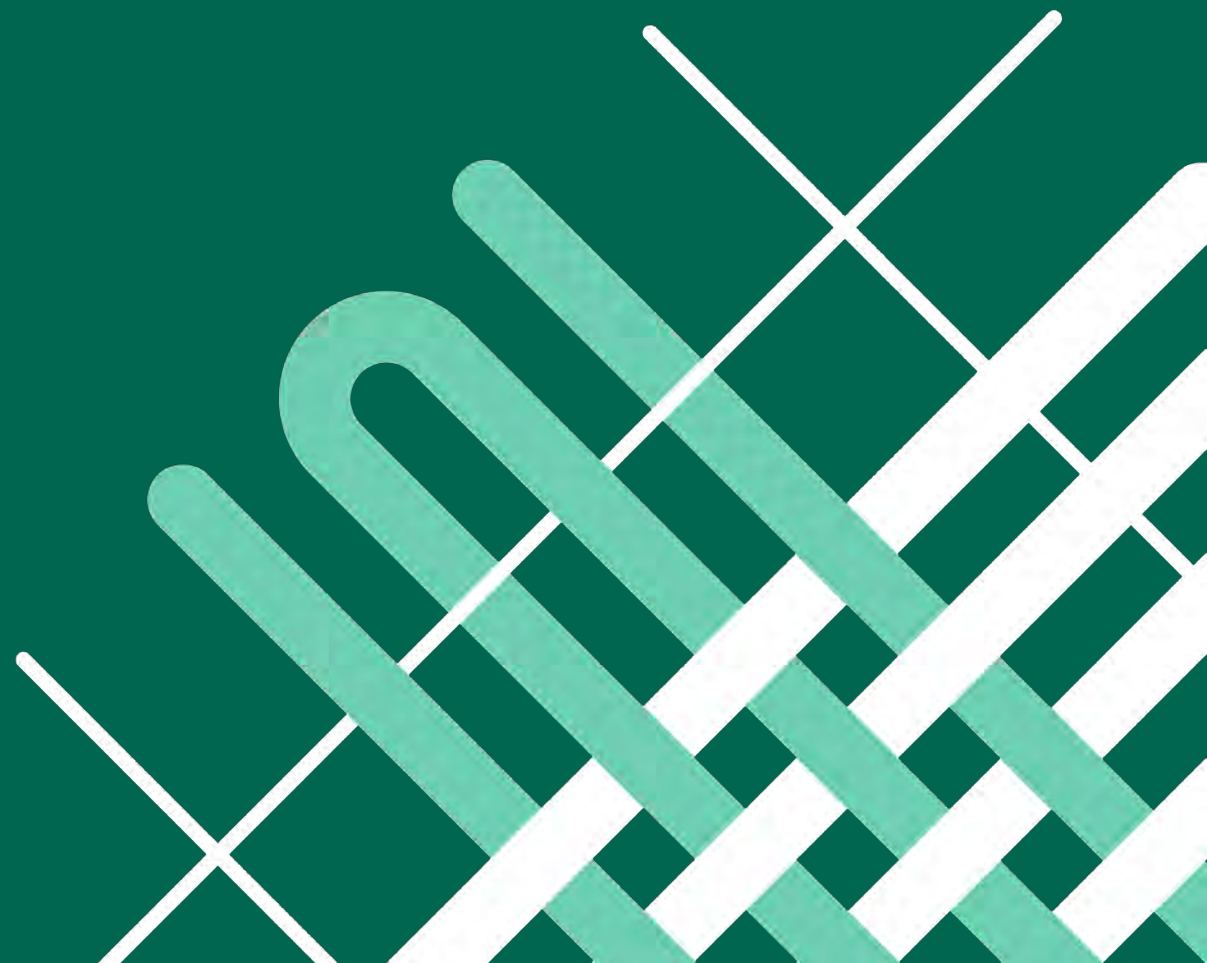
- Community engagement is an iterative process which can be facilitated by an intentional and inclusive framework (SAC)
- Self-reflection, humility and commitment to continual improvement on the part of study PIs and the research team are a necessary part of this process



Thank you

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meagan.m.adams@hitchcock.org





WELCOME to

*Get Engaged:
An ECHO to Increase Skills for
Community Engaged Research*

*Session 5, Ethical Considerations in Working with Communities,
June 24, 2025*

Ethical Considerations in Working with Communities

Jessica Maurer, Esq. (she/her)
Executive Director
Maine Council on Aging

Renée Pepin, PhD (she/her)
Assistant Professor
Community and Family Medicine
Geisel School of Medicine at Dartmouth and Dartmouth Health



Agenda

- Research Ethics
- Key Principles of Community Engagement
- Community Engagement Skills
- Community Engagement Tips
- Ethical Considerations in Working with Communities



Research Ethics

- Respect for people
 - Informed consent
 - Privacy
- Beneficence
 - Promote well-being and minimize potential harm
- Justice
 - Fair distribution of burdens and benefits
 - Equitable selection of participants
 - Protection of vulnerable populations

Potential Burden of Research Participation for Community Partners

- Lack of compensation for writing and submitting grants (that may not be awarded)
- IRB – CITI Training, Federal-Wide Assurance (FWA) and designating an IRB of record
- Timeline issues
- Administrative burden of paperwork, documentation, contracts, invoicing
- Financial risk
- Reputational risk for championing things that may not work
- Traditional academic “benefits” – may not be particularly beneficial like publication or other academic recognition.
- Incremental discoveries that move the field **slightly** forward may not be celebrated.

Key Principles of Community Engagement

- Focus on community perspectives
- Build on community strengths and resources
- Co-learning, co-benefit, co-capacity building
- Build and maintain trust
- Ongoing partnership
- Facilitate equitable partnership
- Partner input is vital
- Involve all partners in dissemination

Community Engagement Skills

- Listening
- Communicating
- Sharing power
- Sharing control
- Sharing resources
- Being humble

Community Engagement Tips for Everyone

- Be clear about motivation and expectation
- Participate
- Be generous
- Share: resources, decisions, credit
- Ask what is needed
- Build a relationship and stick with it

Community Engagement Tips for Researchers

- Go to the community, don't make community come to you
- Real people, real organizations, real communities
 - Offer real help
 - Commit to real action
- Don't over-promise and under-deliver
- Don't say “yes” if you mean “no”
- Understand processes **before** you start
 - Ask questions
 - Have contingency plans

Ethical Considerations in Working with Communities

- How do we engage community in an ethical way?
- How do we minimize community harm/maximize community benefit?
 - How do we know what may be harmful?
 - How do we know what may be beneficial?
- What if parties involved want different things?
- How do we repair harm?

Thank you

jmaurer@mainecouncilonaging.org
renee.l.pepin@dartmouth.edu





WELCOME to

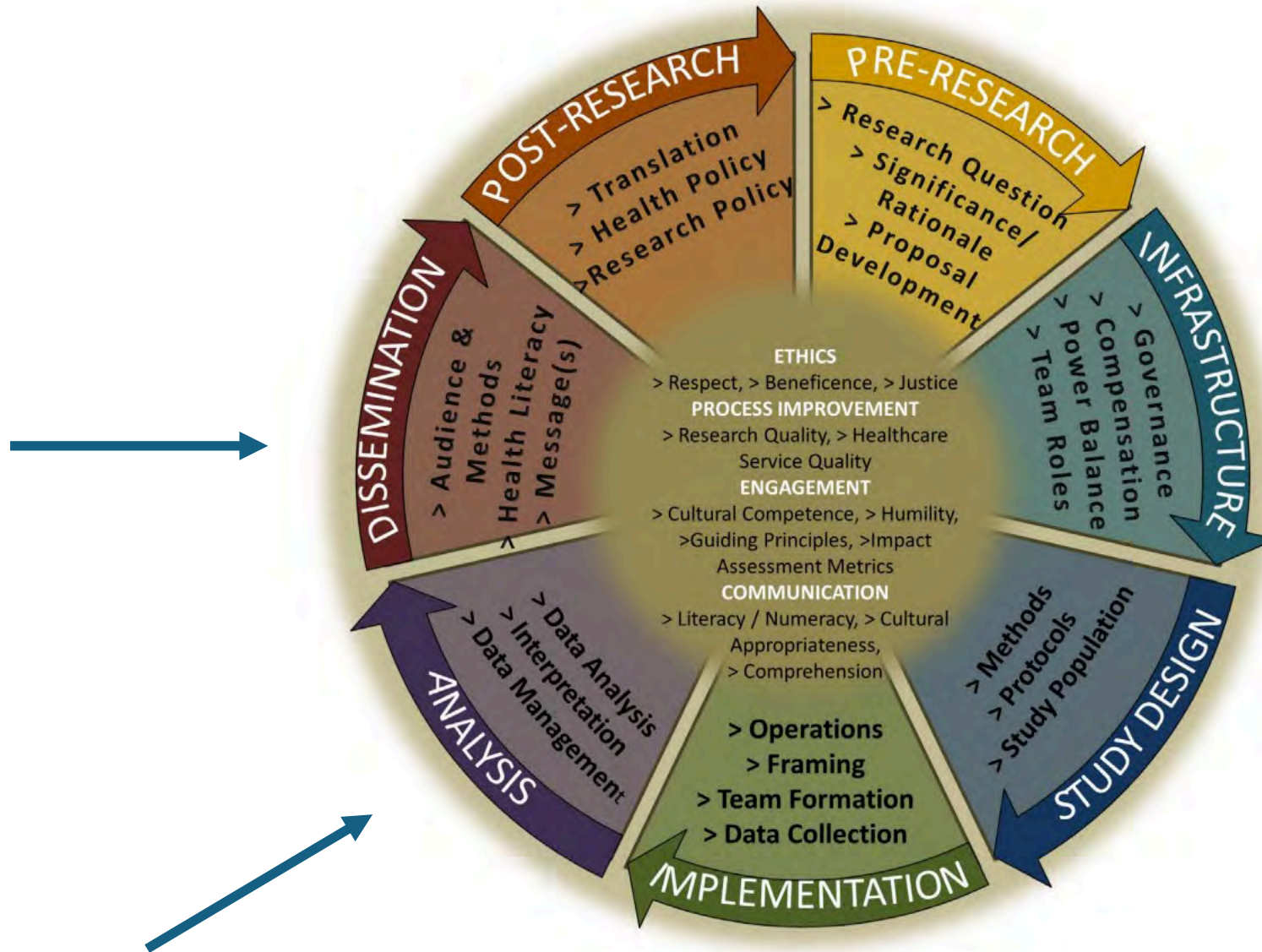
*Get Engaged:
An ECHO to Increase Skills for
Community Engaged Research*

Session 6, Analysis/Dissemination, July 22, 2025

Engaging Community Partners in Analysis and Dissemination of Research

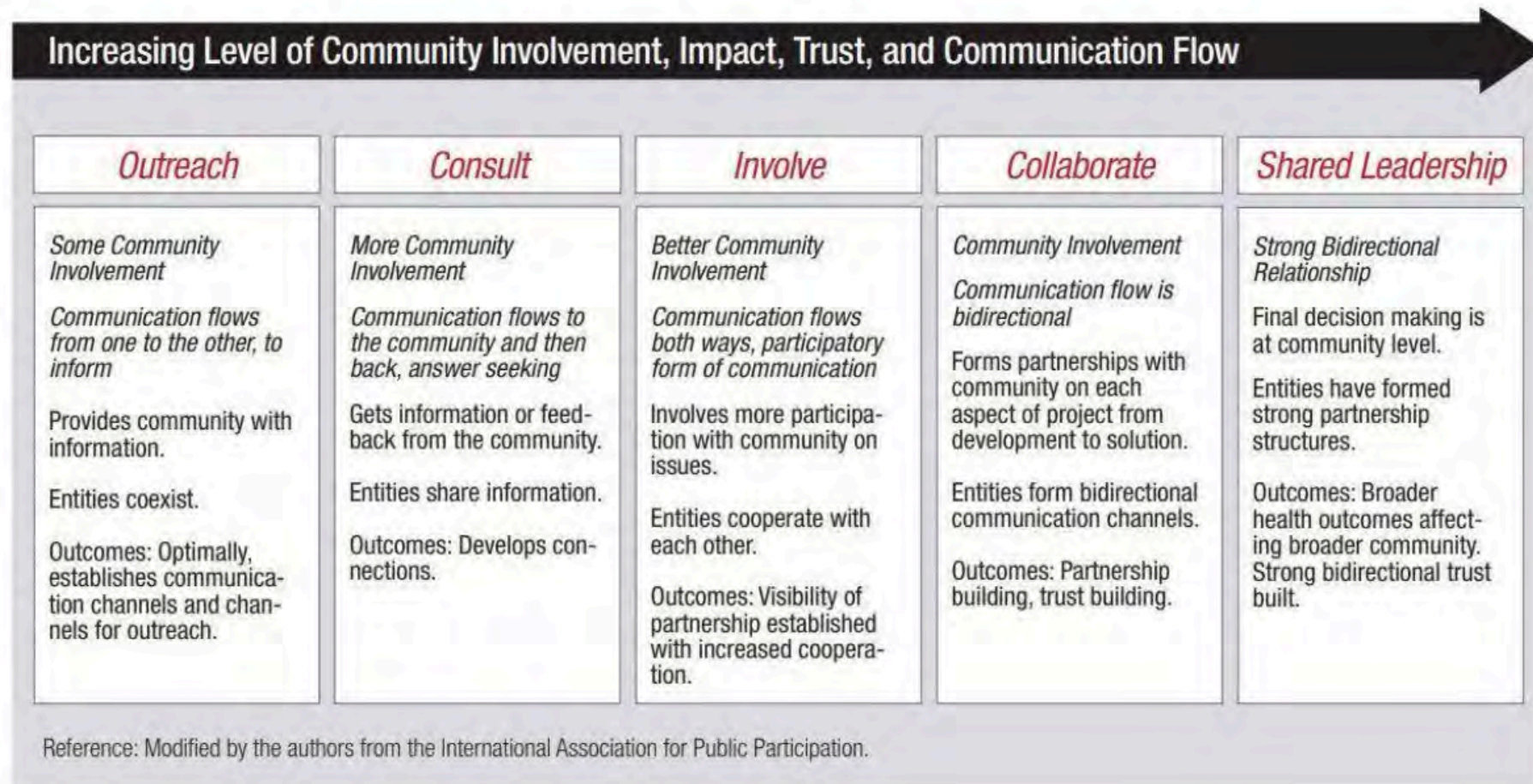
Sara Kobylenski, MSW, ACSW

Elizabeth Carpenter-Song, PhD



Stallings et al. (2019) A Taxonomy of impacts on clinical and translational research from community stakeholder engagement. *Health Expectations* 22:731-742.

Varying Levels of Community Engagement



Spectrum of Approaches to Engage Community Partners in Analysis & Dissemination

Less formal &
structured

More formal &
structured

Traditional v. Community-Engaged Research Approaches

COMPARISON BETWEEN TRADITIONAL AND COMMUNITY ENGAGED RESEARCH		
	Traditional Research	Community Engaged Research
RESEARCH OBJECTIVE	Based on epidemiologic data, prior research findings and funding priorities	Community input in identifying relevant issues and questions
STUDY DESIGN	Design based entirely on scientific rigor and feasibility	Researchers work with community to ensure study design is also culturally acceptable
RECRUITMENT AND RETENTION	Based on scientific issues and "best guesses" on how to best reach community members	Community provides guidance on recruitment and retentions strategies
INSTRUMENT DESIGN	Instruments adopted/adapted from other research and tested w/psychometric methods	Community provides guidance on instrument modification to improve community fit
DATA COLLECTION	Conducted by academic researchers or individuals w/no connection to the community	Community members involved in some or all of data collection
ANALYSIS AND INTERPRETATION	Academic researchers own the data, conduct the analysis, & interpret the findings	Academic researchers and community members work together to interpret results.
DATA COLLECTION	Results published in peer-review academic journals	Community assists in identifying additional appropriate venues for dissemination and results shared by researchers and community members



What are the benefits?

- Communities deserve access to research findings that are relevant to them
- Analysis and interpretation are enhanced by including multiple perspectives
- Collaboration with community partners creates opportunities to explore local implications of research findings and enhance the relevance of interventions for local communities

Self-reflection as skill building

- Recognize your multiple identities
- How would you like to be involved in research?
- What would you need to feel comfortable and confident to participate, to contribute to analysis and dissemination?
- How do you and others in your life like to learn and receive information?

Create opportunities for reciprocal learning


- Recognize that the “culture of research” is often quite different from the culture of the community
- Create opportunities to learn across these differences through openness and curiosity
- Researchers may need training and support to understand local context, what matters to community partners
- Community partners may need training and support to participate in a project with confidence

Clear intentions, expectations, and roles

- Be intentional about goals for collaboration in analysis and dissemination
- Be clear about expectations for involvement in analysis and dissemination
- Consider a range of ways that team members may be involved in analysis and dissemination
 - More formal and structured roles may require additional training (e.g., IRB certification)



What made this event possible?

A photograph of a paved road that curves gently to the right, disappearing into a dense forest. The trees on the left have vibrant autumn foliage in shades of orange, yellow, and red. The trees on the right are mostly evergreens, with some showing hints of yellow. The sky is a pale, hazy blue. The overall atmosphere is quiet and somewhat somber, fitting the contemplative nature of the text.

*Why do people with
significant mental health
challenges not use
available services?*

Mental Health at the Margins



Our partnership focused on 'surfacing' stories and experiences that are often hidden to improve mental health in our communities.

Participatory research designed to understand:

- Why do well-intentioned efforts to provide mental health services fall short?
- How might systems of care be redesigned to better meet the needs of community members?

Partnership Structure

- **Co-Project Leads:** Sara Kobylenski and Elizabeth Carpenter-Song
- **Mental Health at the Margins Advisory Board:** Clinical/Service Leaders and Providers, Researchers, Community Members
- **Co-designed Core Values:** (1) every voice matters; (2) respect for differences; (3) honest and open dialogue; (4) active listening; (5) responsiveness and accessibility; (6) willingness to ask questions; and (7) concern for sustainability.
- **Funding:** Dartmouth SYNERGY Community Engagement Award (NCATS 1UL1TR001086-04) and Patient-Centered Outcomes Research Institute (PCORI) (Award 5108699-011)

Relationship-Centered

- Research team members were routinely present in the organization
 - Trusted presence
 - Opportunity to build relationships with service users and staff
 - Increased awareness of the project
 - Facilitated introductions and recruitment
- Investment of time and being a reliable presence are foundational to building trust
 - Time intensive process, but integral to good study design

Multiple Ways to be Involved

- Partners varied in their capacity and interest to engage in the project
- Our team responded by designing activities with different levels of intensity and commitment
 - Advisory Board
 - Interviews
 - Community Forum Discussions
 - Digital stories



Multiple Opportunities to Collaborate on Analysis and Dissemination

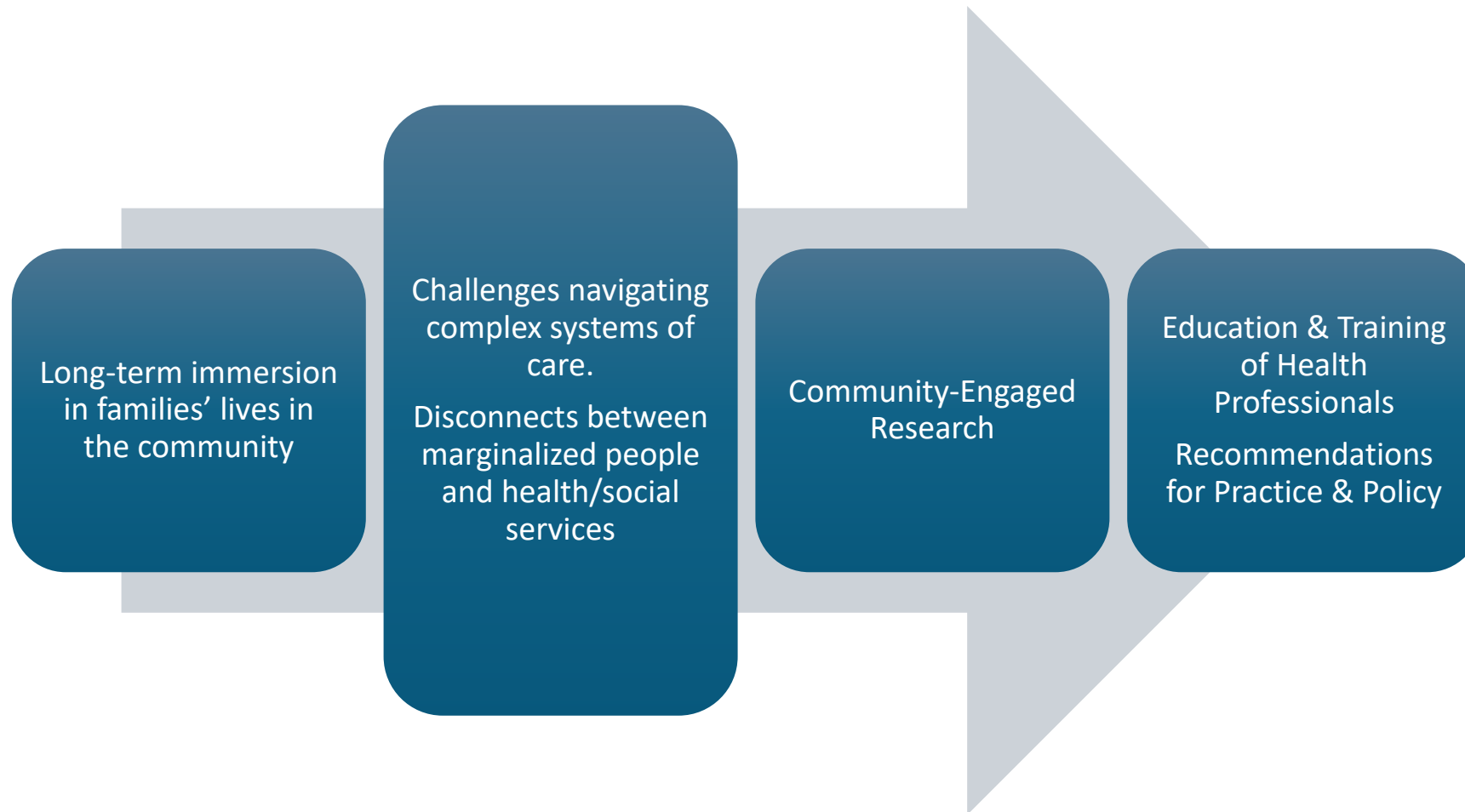
- Interpreting information from interviews and community forums
- Co-producing digital stories
- Co-organizing the community event
- Co-presenting at our community event



Themes and Recommendations

- Challenges and opportunities in identifying as a person with mental illness
 - Double burden of stigma of mental illness and poverty
 - Strong assertions of the knowledge of individuals with lived experience
- Barriers: challenges navigating “the system”; rural isolation
- Vital importance of trust and comfort with health and service providers
- Need for education about existing resources
- Suggestions of care coordinators, advocates within criminal justice

Translating Knowledge into Practice



Ongoing Dissemination of Digital Stories

- Stories integrated into medical education at Geisel
- Sessions on culture of biomedicine and structural competence
 - Identifying missed opportunities to support marginalized populations
 - Reflection on the roles and responsibilities of health care professionals and health systems in addressing social drivers of health



Translating Knowledge into Change

