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Project
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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 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**
4/2/2026	Ethical Considerations in Working with Communities
4/16/2026	Infrastructure for Working with Community Members
5/7/2026	Pre-research Engagement
5/21/2026	Research Implementation
6/4/2026	Analysis/Dissemination
6/18/2026	Spotlight on Methods

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Ethical Considerations in Working with Communities

Alice Ely,
Executive Director
Public Health Council of the Upper Valley

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

PRE-RESEARCH
> Research Question
> Significance/ Rationale
> Proposal Development

INFRASTRUCTURE
> Governance
> Compensation
> Power Balance
> Team Roles

STUDY DESIGN
> Methods
> Protocols
> Study Population

IMPLEMENTATION
> Operations
> Framing
> Team Formation
> Data Collection

ANALYSIS
> Data Analysis
> Interpretation
> Data Management

DISSEMINATION
> Audience & Methods
> Health Literacy
> Message(s)

POST-RESEARCH
> Translation
> Health Policy
>Research Policy

ETHICS
> Respect, > Beneficence, > Justice

PROCESS IMPROVEMENT
> Research Quality, > Healthcare Service Quality

ENGAGEMENT
> Cultural Competence, > Humility, >Guiding Principles, >Impact Assessment Metrics

COMMUNICATION
> Literacy / Numeracy, > Cultural Appropriateness, > Comprehension

Agenda

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

ETHICS

> Respect, > Beneficence, > Justice

PROCESS IMPROVEMENT

> Research Quality, > Healthcare Service Quality

ENGAGEMENT

> Cultural Competence, > Humility, >Guiding Principles, >Impact Assessment Metrics

COMMUNICATION

> Literacy / Numeracy, > Cultural Appropriateness, > Comprehension

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

Ethical Considerations in Working with Communities

- How do we know what may be harmful?
- How do we know what may be beneficial?
- How do we know what would be a fair distribution of burdens and benefits?
- How do we we know who is vulnerable?

Key Principles of Community Engagement

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

Community Engagement Skills

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

Community Engagement Tips for Everyone

- Be clear about motivation and expectation
  - – Explicitly articulate motivation
  - – Explicitly articulate goals
  - – Discuss limitations, parameters, requirements
  - – Identify investments
    - Time
    - People
    - Space
  - – Talk timelines
  - – Identify outputs/products

Community Engagement Tips for Everyone

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

Community Engagement Tips for Researchers

- 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

Thank you

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Session 2, Infrastructure for Working with Community Members, April 16, 2026

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Infrastructure for Community Engaged Research

Julie Bosak, DrPH, CNM

Cheri Bryer, CRSW

Overview of didactic section

- What are the dimensions to consider within the infrastructure domain for working with community members?
- How does a Community Advisory Board represent and influence these dimensions?

Infrastructure Domain

Stage for decision on aspects of study and planning logistics

Dimensions of Infrastructure

- Governance
- Power Balance
- Team Roles
- Compensation

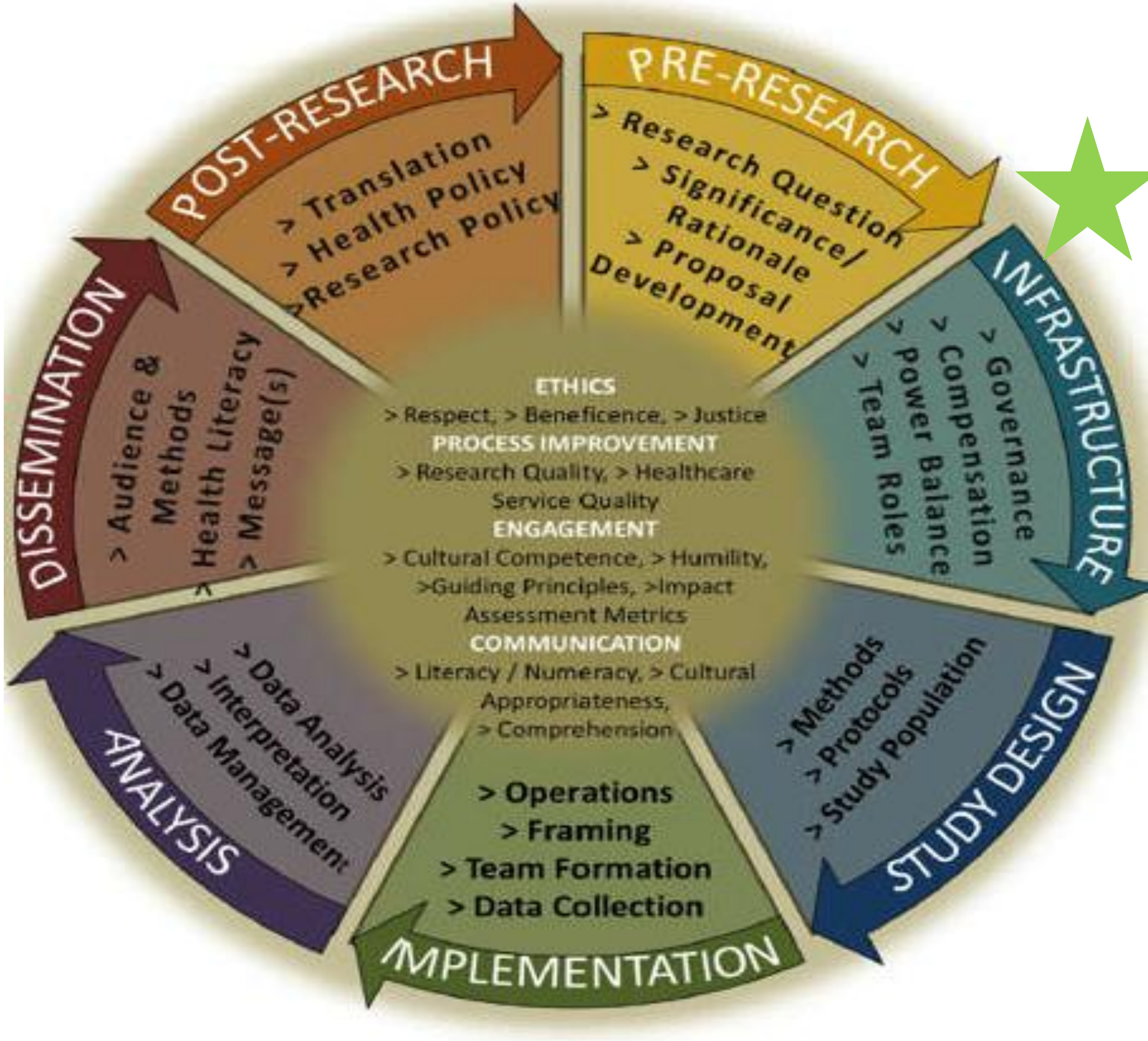


Fig 1 from Stallings S et al., Health Expectations 2019

Governance

- Defines rules, roles and procedures that ensure adequate oversight and describe decision making

Power Balance

- Identifying areas of imbalance and strategies to diminish it

Team Roles

- Identify different roles within the study team

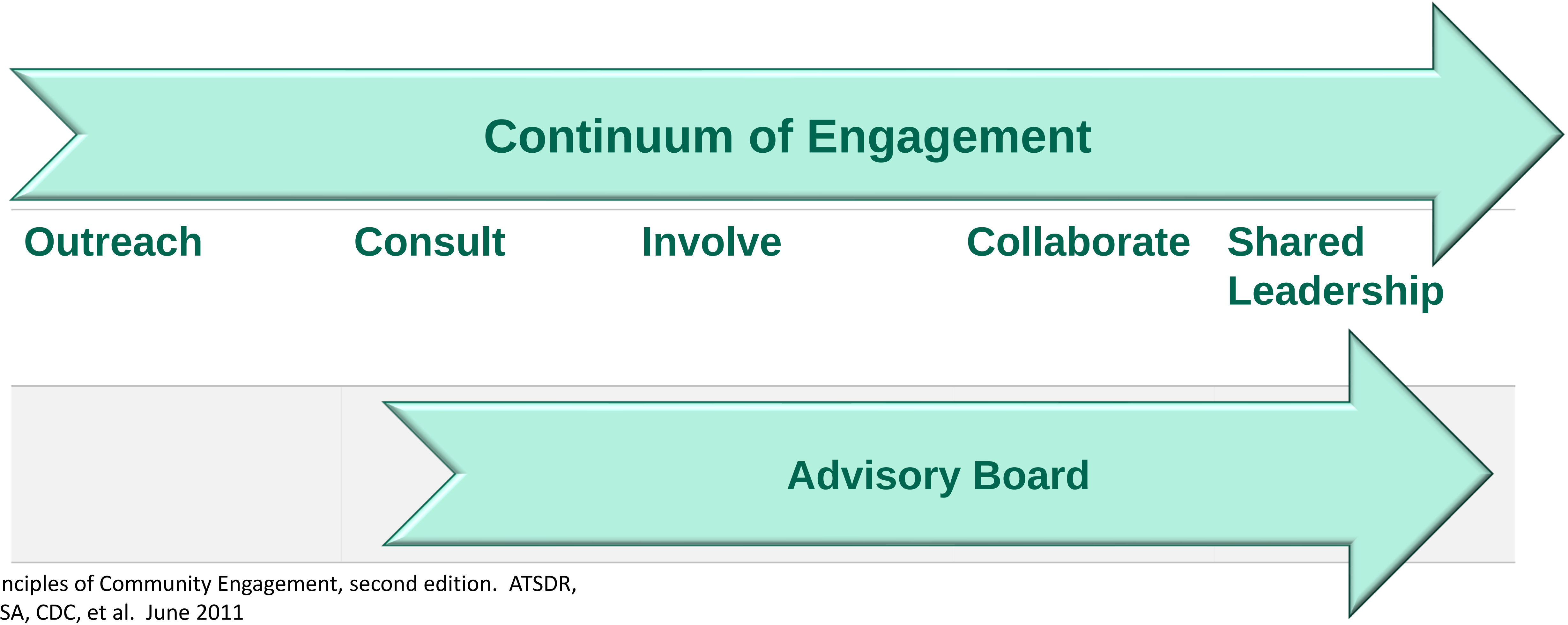
Compensation

- Decide on how research participants will be compensated

Consumer Advisory Boards (CABs)

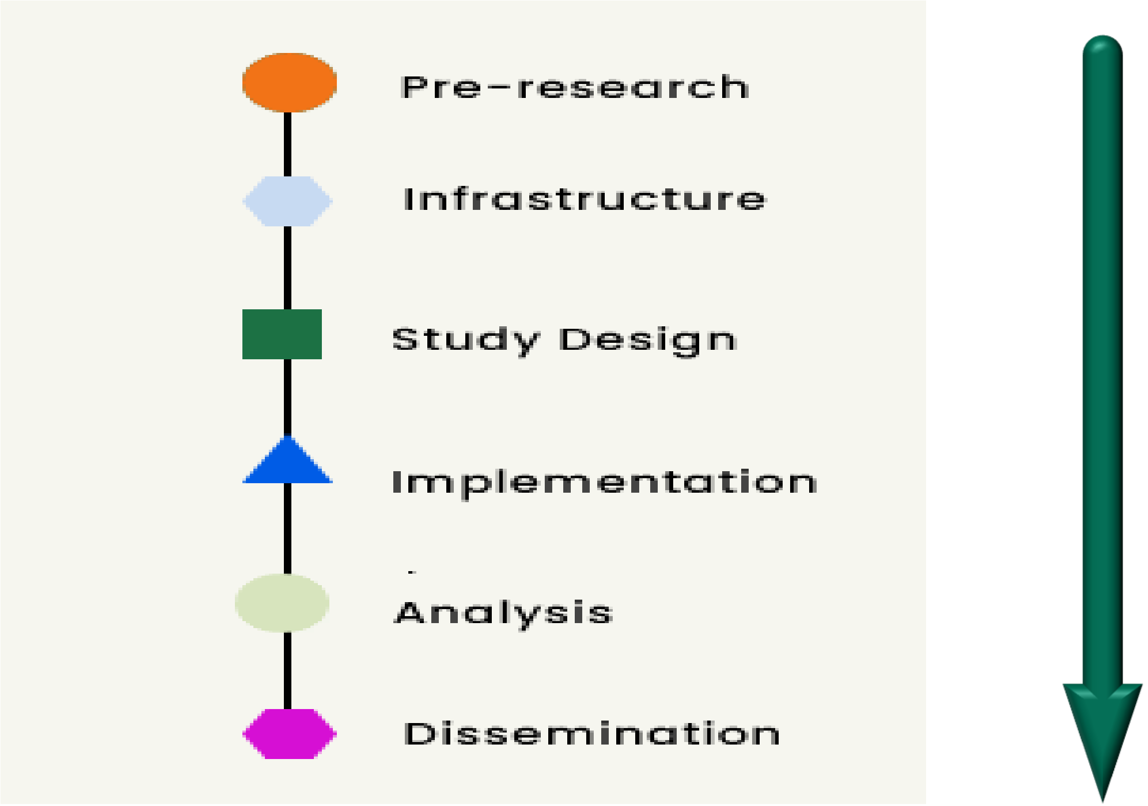
- A CAB is a group of individuals that represent your target research population- often individuals from community organizations that serve your population and/or individuals from the population.
  - “bridge the gap between the community and researchers to increase the relevance of the research” (Lawrence & Stewart, 2016)
- Two main structural decisions about your research methods
  - What level of engagement (how much influence) will the CAB possess
  - At what point in the research process are they formed

How does a CAB differ along the continuum of engagement?



Principles of Community Engagement, second edition. ATSDR, CTSA, CDC, et al. June 2011

What stage of the research will the CAB be formed?



Considerations for level of engagement and phase of involvement for your CAB

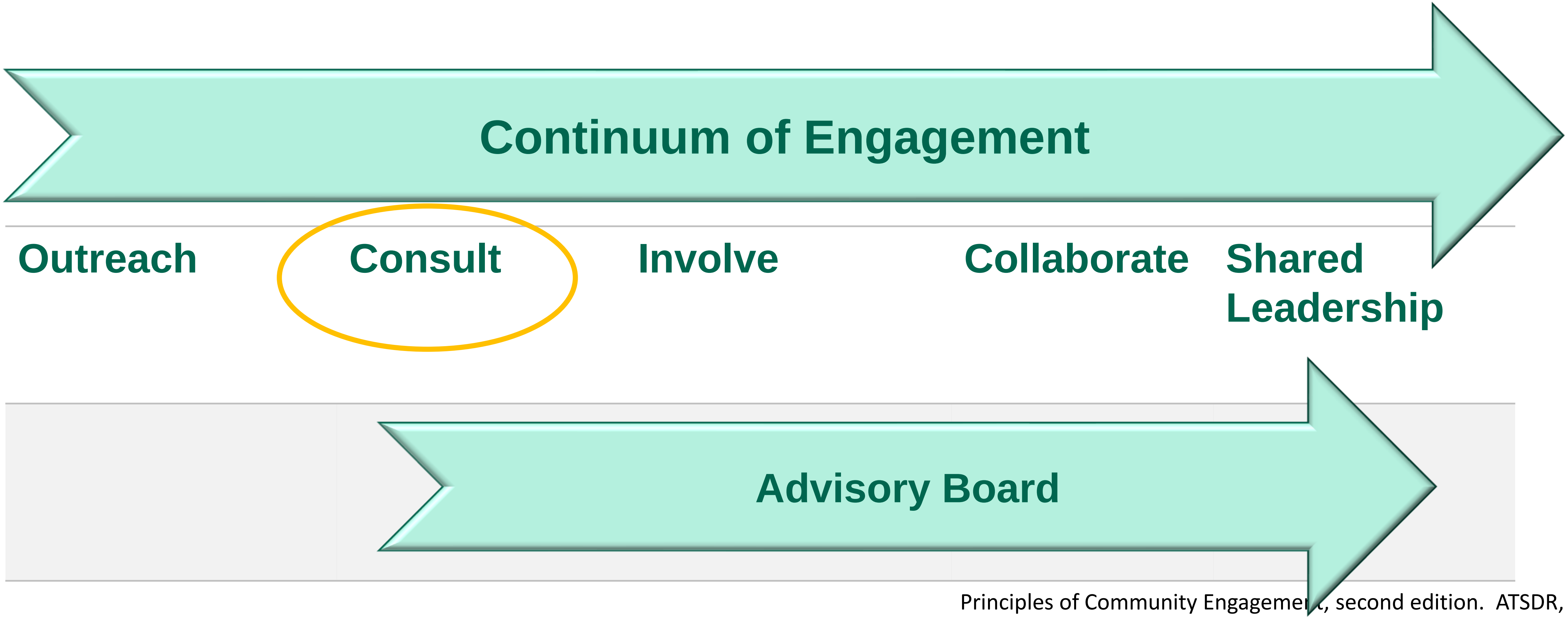
- ❖What type of research are you doing?
  - ❖Clinical trial versus translational community based implementation

- ❖What is the “readiness” status of you and your team
  - ❖Do you have relationships and history within the community
  - ❖Do you have at least one champion with a pre-existing trusting relationships?
  - ❖Is this a new research area or geography so you are starting from scratch?
  - ❖What is your bandwidth and budget for supporting a CAB?

Governance

- What are the structures and processes that define the CAB and its influence over the larger study.
- Important to be as clear as possible up front
  - – A well defined governance structure protects community interests
  - – Ideally you create some version of a charter and group norms
  - – How are decisions being made?
    - Consensus?
    - Who has the final decision power?
  - – Is it different dependent upon the content of the decision?
    - Financial versus choice of language or recruitment strategies

How does a CAB differ along the continuum of engagement?



Continuum of Engagement

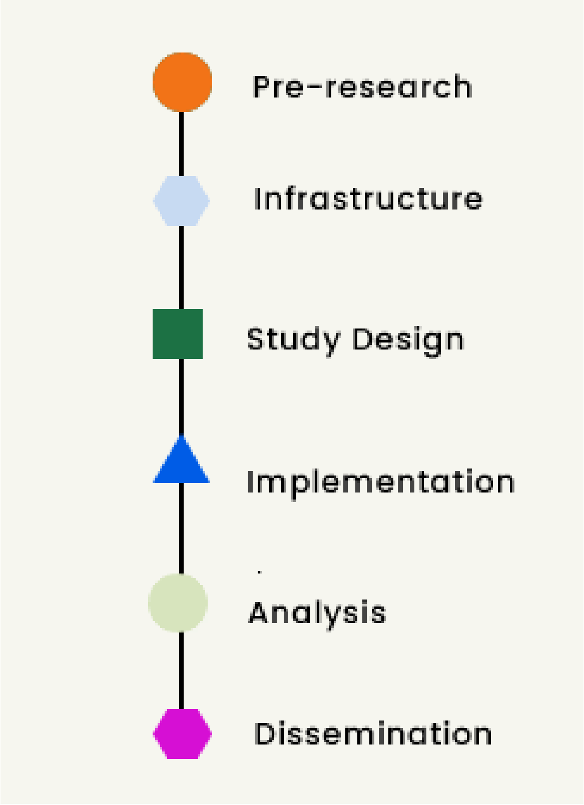
Outreach | **Consult** | **Involve** | **Collaborate** | **Shared Leadership**

Advisory Board

Principles of Community Engagement, second edition. ATSDR, CTSA, CDC, et al. June 2011

Consulting role

CAB members provide input and perspective on different aspects of the research



Research question and area of focus, budget

Support ideas for recruitment and utilize my social network

Provide input on findings and how to present them in a way that makes sense to “regular people”

CAB as an consulting role

- Examples of a Consulting role
  - CAB for a study on methadone and integrated OB and Mental health care- aim of study to increased understanding of co-located versus separate services
  - Typically input on language and framing of a topic to ensure it isn’t stigmatizing, correct style of communication (use of words) that are easily understood by community members
    - Less frequent meetings, providing input, responding to current work

Benefits of a having a CAB

- For the study team- ideally learn the value of having the lived expertise at the table
  - Feels initially like some researchers are unsure/uncomfortable with what an individual with lived expertise might offer, but often open up and realize that everybody can learn from each other.
- Personal development for a community members
  - Builds confidence in knowing my perspective is important
  - Knowledge and relationships can create professional opportunities
  - Opportunity to have on an impact and help others

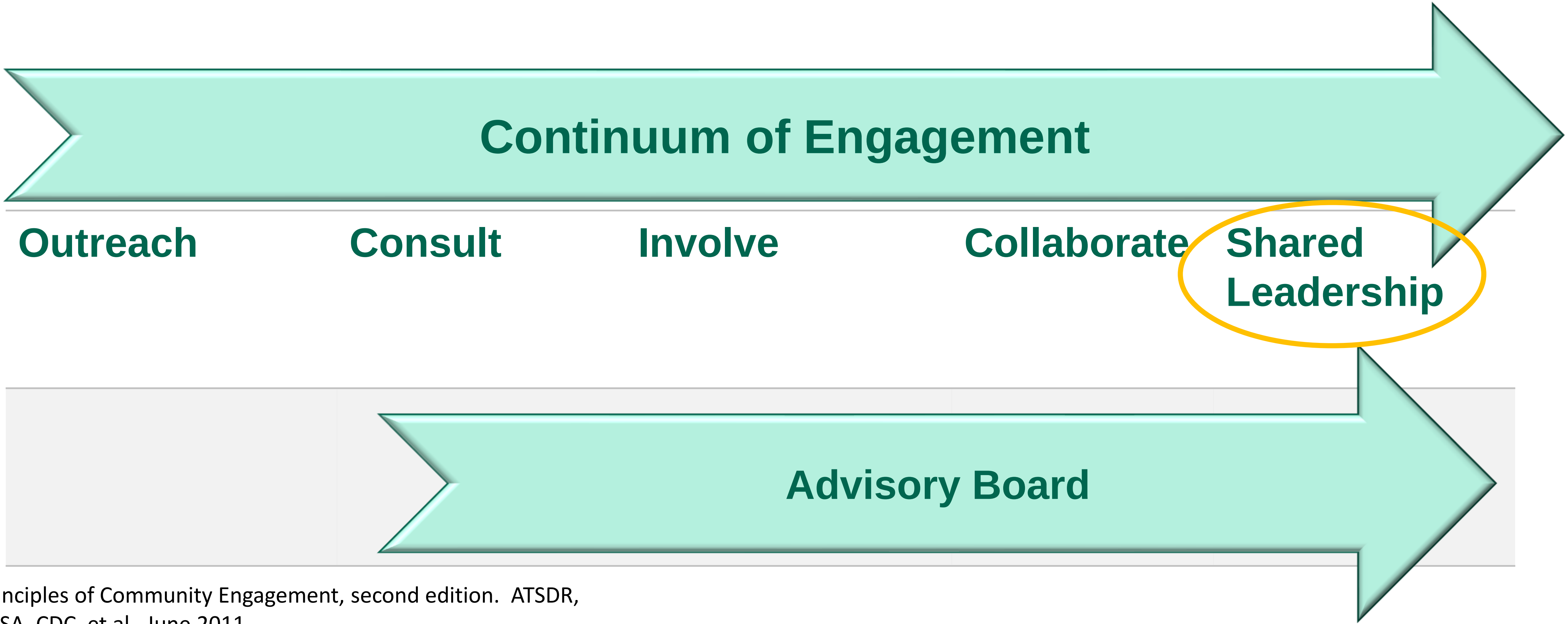
Common challenges with the consulting role

- Feeling exploited or seeing that with others
  - Inadequate **compensation** for your time
  - Compelled to tell your story because of the compensation and power balance
    - It is re-traumatizing every time and ensure you offer extra support, protected space

Common challenges with the consulting role

- **Power Balance (imbalance)**
  - Ensuring that full study team respects and honors the patient and/or community voice
  - Not simply just meeting the criteria of the study or checking a box
  - If their isn’t a baseline respect you can feel “used” to only recruit
- The importance of the interpersonal respect and reactions in every interaction
  - “I don’t want to hear from you, I want the provider’s input”

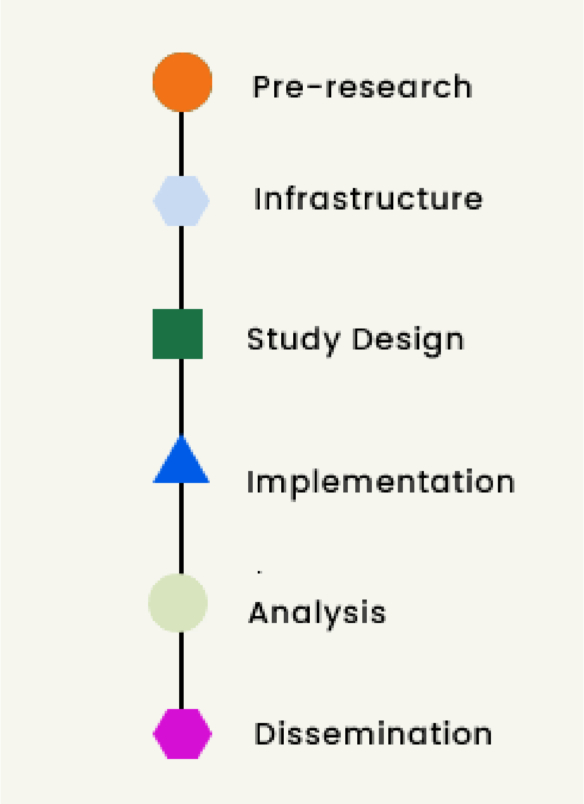
How does a CAB differ along the continuum of engagement?



Principles of Community Engagement, second edition. ATSDR, CTSA, CDC, et al. June 2011

Shared governance

CAB members as part of the decision making along the continuum



Research question and area of focus, budget

Collaboratively create approach and possibly lead recruitment

Co-create findings based on initial analysis

CAB shared leadership governance structure

Academic institution

Core Study Team
Principal investigator
Project staff

Daily oversight of research Manages

- **Grants administration**
- **Fiscal administration**
- **Project human resources**

- Collaborative design of methods
- Collaborative oversight of implementation
- Co-creates analysis of data and dissemination plan
- Financial and strategic collaborative decision

- Clearly define decision making by collective consent scale

Advisory Board

Comprised of community members with a range of expertise

Decision-making Process: **Strive for Consensus**: Levels of Agreement

1. Enthusiastically agree
2. Yes, I agree
3. I have minor reservations and generally agree. I will actively support the decision of the group
4. I have major reservations and would like more dialogue before moving forward
5. I do not support this idea. I do not think it is in our best interest to move forward

- **Discussion rule**: Discuss, try to resolve reservations >3.
- **Decision rule**: If everyone is a 3 or lower, ‘good enough’ & move forward. If not, work to consensus a second time

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Understanding and managing the power imbalance?

  - Recognize that one will **always** exist especially if the academic institution provides the finances and holds the research grant
- **Will look different dependent upon your research community and CAB membership**
  - Community organization staff and/or leadership
  - Do you have a mix of stakeholders including community members, patients and organizational leadership
  - Who is your population?
    - With historically marginalized population such as pregnant women in recovery extra attentiveness needed

Steps to manage the power dynamic and create meaningful participation

Must intentionally work to create a more equitable and collaborative relationship – this takes extra time, energy and effort of the full study team

- ☐ Up front assessment of the dynamic
  - ☐ Where are the inequities, biases, discrimination, racism, rank and privilege amongst your CAB and on your study team
- ☐ 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 or is this just “best practice” so tolerate it

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Power Dynamic

- Choice of facilitator- culturally responsive approach

  – Ideally someone from the community that has already built trust with many of the members

- Study team keeps openness and curiosity with ALL questions and/or dissent
  - Watch tone, body language, follow up

References: Andress, L., Hall, T., Davis, S. *et al.*, 2020. Bosak et al., 2023

Strategies to building trusting relationships

- Creating **TIME** to build relationships
  - Facilitator between meeting check-ins to answer questions, explain content, build confidence
  - Create space in the meetings for small breakouts
- Smaller task focused groups that mix study team and CAB members
- Orient to content -provide detailed, digestible materials to level the knowledge base

How do you get started if you have never created a CAB?

- Ideally this happens prior to a grant application
- Identify champions in your target community and start engaging with them preferably through a “warm hand off”
    - Thoughtful about how you hold space in the community
        - You are not the expert, the community members are the experts
            - Listen more than you talk, be curious
- Be fully transparent about your needs, timeline etc.
    - Better to have the hard honest conversation then avoid it

Forming your CAB

- Will it be remote or in person?
  - Impact of participants availability
    - Remote diminishes barriers as long as all participants have access to technology and internet
    - Harder to build trusting relationships when fully remote
- How large of a geographic area are you covering?
- What is the cadence of meetings?
    - How do you determine time – do you cater to normal work hours or evenings?

Small details that make a difference

- Building trust – be clear and then do what you say
  - Clear expectations on timing, location, amount of time needed
  - Clear on compensation – how it will be provided, when it will be provided.
    - All the steps to the process (W-9) and long the process takes and then be reliable (ex. Gift cards mailed or electronic?)
  - Things that might seem small to us are consequential to participants such as a delay in a $50 honorarium

- How are you addressing barriers to participation on the CAB and in the work
  - Childcare, gas money, compensation, support participation at conferences

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Perinatal Initiatives
POPULATION HEALTH

Thank you.

Any Questions?

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Session 3, Pre-research Engagement,
May 7, 2026

CHRONICLE

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)
Lead Scientist: Dr. Renata Yen
Patient Partner Representative: Sheri Piper
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- Fill their medication
- Self-administer complex medicine regimens
- Arrange their appointments
- Pay their bills
- Inform their family of what happened in their clinic visit
- Use medical devices
- Train loved ones to assist, or use use medical devices
- Monitor their symptoms
- Report this all back to the clinician

All while older adults live with their medical conditions

OpenRecordings

Research reported in this presentation was funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Award (*HA-2021C3-24754*).

Up to 80% of visit information is forgotten

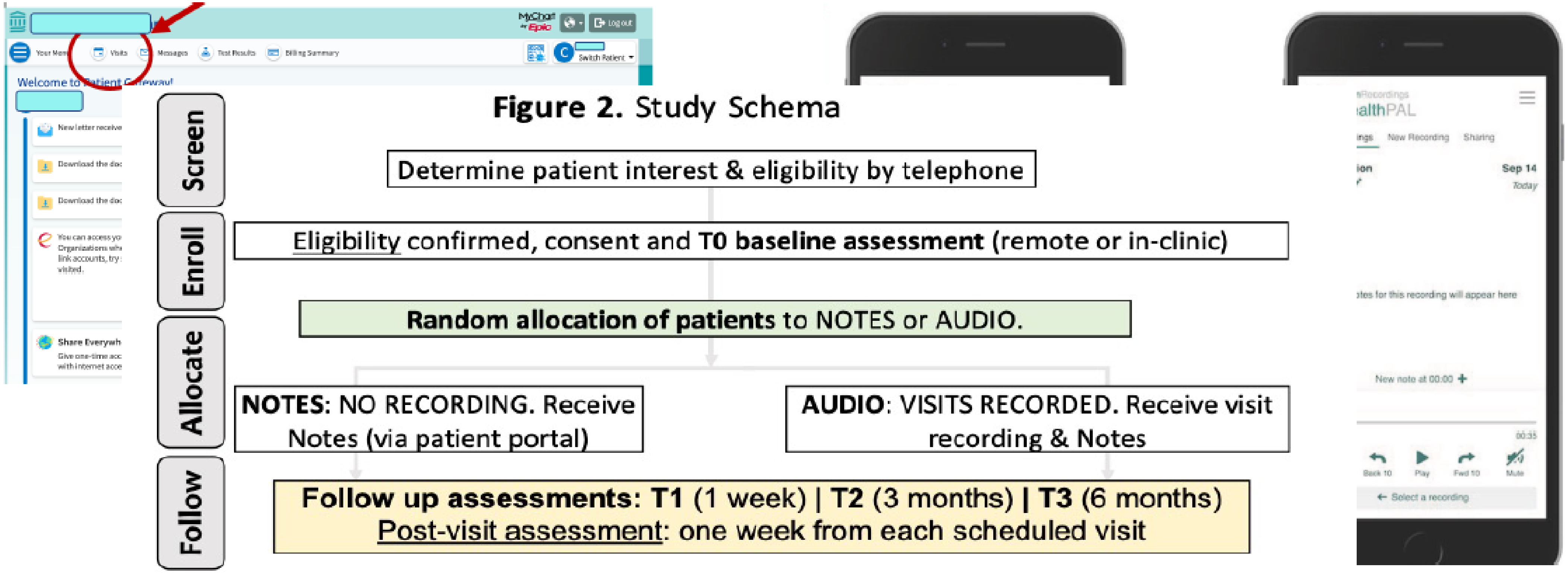


Figure 2. Study Schema

Screen

Determine patient interest & eligibility by telephone

Enroll

Eligibility confirmed, consent and **T0 baseline assessment** (remote or in-clinic)

Allocate

Random allocation of patients to NOTES or AUDIO.

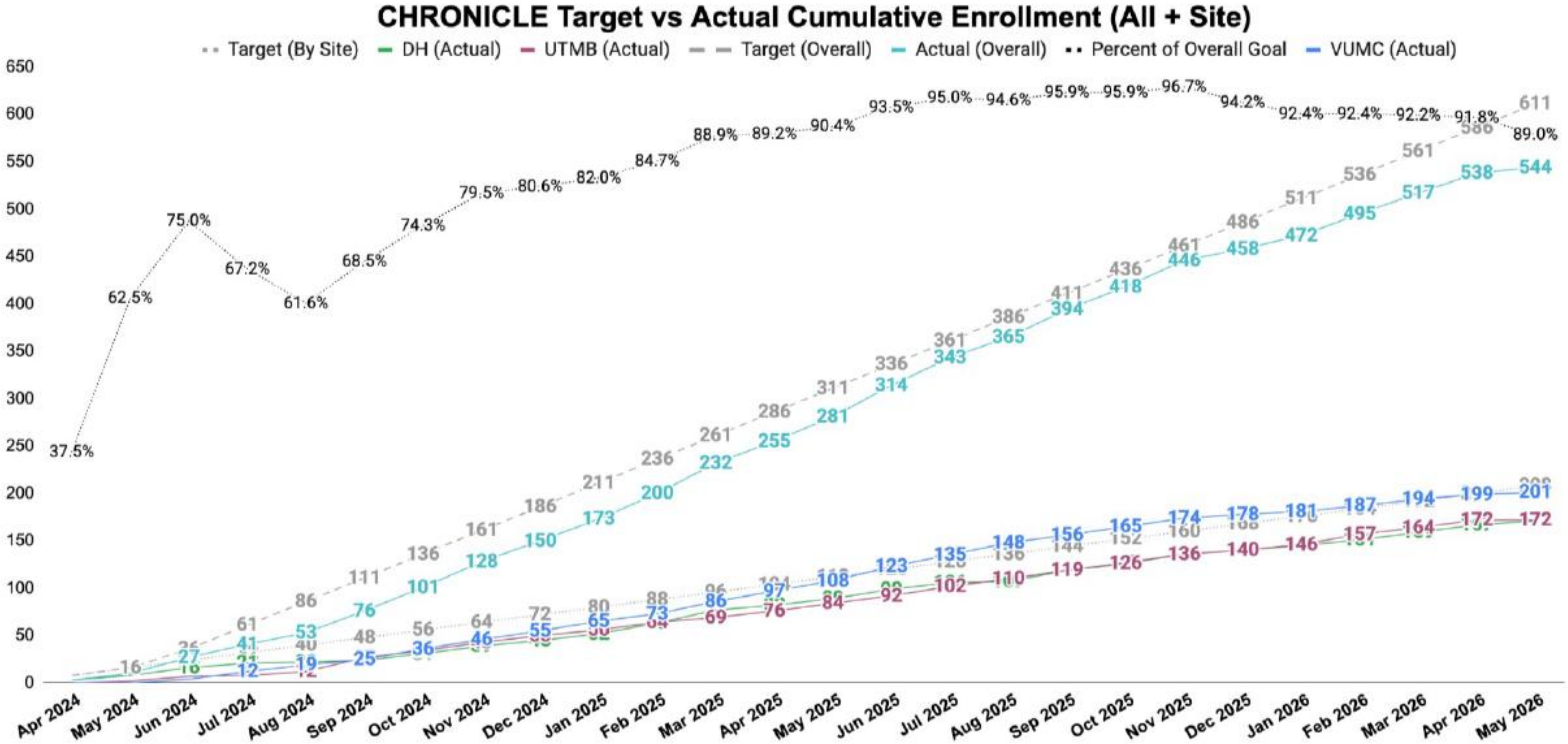
NOTES: NO RECORDING. Receive Notes (via patient portal)

AUDIO: VISITS RECORDED. Receive visit recording & Notes

Follow

Follow up assessments: T1 (1 week) | **T2** (3 months) **| T3** (6 months)
Post-visit assessment: one week from each scheduled visit

400/900 older adults with high blood pressure or diabetes and one more condition
50/300 caregivers (family or friends) of these older adults



CHRONICLE Target vs Actual Cumulative Enrollment (All + Site)

Stakeholder engagement methods

Grant preparations (design, outcomes, ethical)

- Community Engagement Studios (facilitated by local groups)
- Ad hoc meetings with identified stakeholders

Study launch preparations (logistics)

- Patient/caregiver partner training/expectations and ground rules (PCORI fundamentals, TOPPER, in-person and virtual)
- Patient/caregiver partner review of all materials
- Clinician breakfast/lunches in the clinic

Ongoing engagement (logistics, interpretation)

- Quarterly patient/caregiver stakeholder meeting (separate from specific project); Bi-annual all-team meeting
- Research Engagement Survey Tool (Annual survey)
- Problem solving – i.e., change in recruitment wording to boost caregiver recruitment

Stakeholder engagement methods

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Journal of Clinical and Translational Science

www.cambridge.org/cts

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

Meredith C. Masel[1,2,3], Kerri L. Cavanaugh[4,5,6,7], Sharon P. Croisant[8], Krista Bohn[9], James S. Goodwin[2,3,10], Martha L. Bruce[11,12] and Paul J. Barr[12,13,14]

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Research Article

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Revised: 11 September 2024
Accepted: 24 September 2024

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

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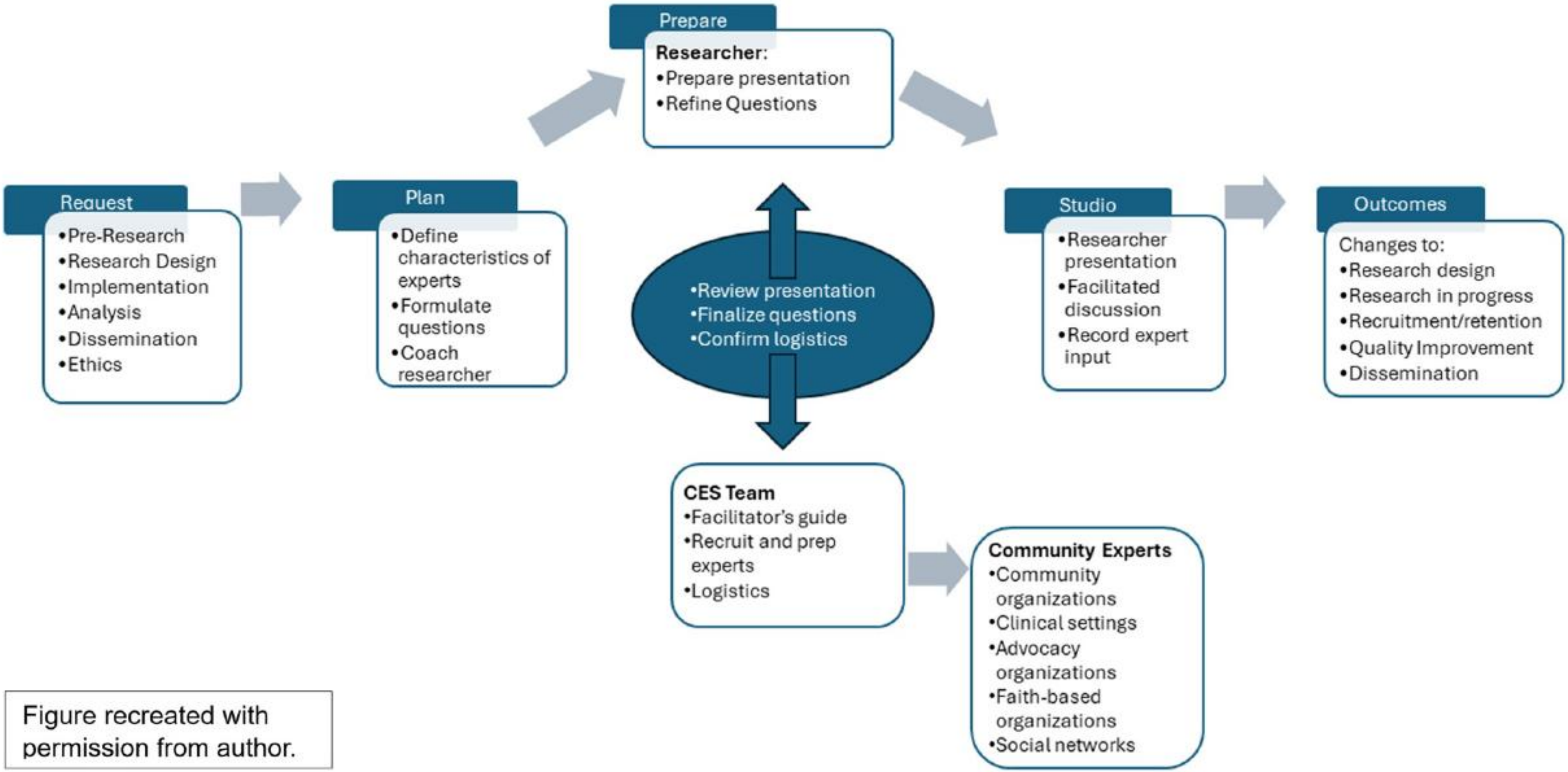
Meredith C. Masel and Kerri L. Cavanaugh are co-first authors.

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



Request
- Pre-Research
- Research Design
- Implementation
- Analysis
- Dissemination
- Ethics

Plan
- Define characteristics of experts
- Formulate questions
- Coach researcher

Prepare

Researcher:
- Prepare presentation
- Refine Questions

- Review presentation
- Finalize questions
- Confirm logistics

CES Team
- Facilitator's guide
- Recruit and prep experts
- Logistics

Community Experts
- Community organizations
- Clinical settings
- Advocacy organizations
- Faith-based organizations
- Social networks

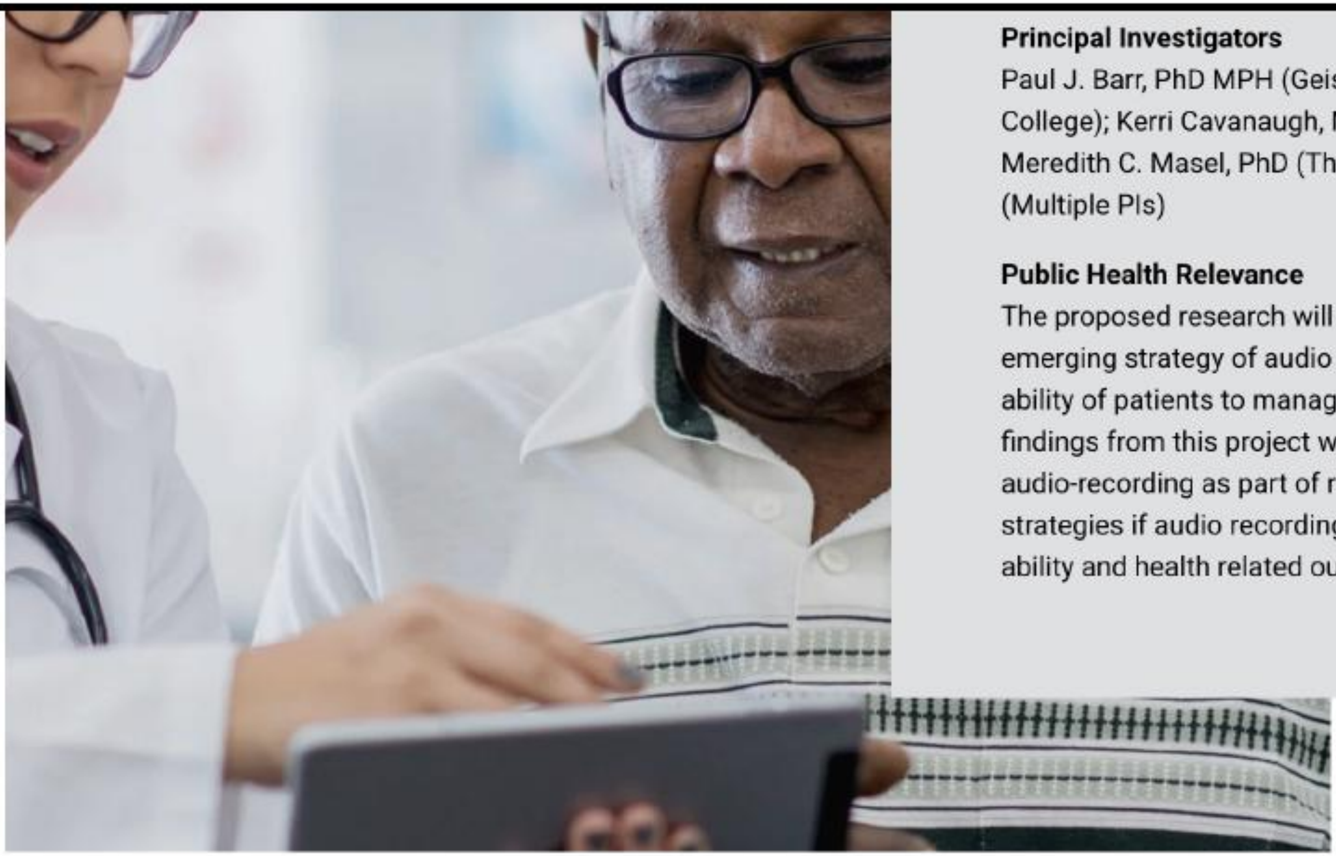
Studio
- Researcher presentation
- Facilitated discussion
- Record expert input

Outcomes

Changes to:
- Research design
- Research in progress
- Recruitment/retention
- Quality Improvement
- Dissemination

Figure recreated with permission from author.

Community Engagement Studio Process
(CES 2.0 Toolkit Page 16)



Principal Investigators

Paul J. Barr, PhD MPH (Geisel School of Medicine at Dartmouth College); Kerri Cavanaugh, MD (Vanderbilt University Medical Center); Meredith C. Masel, PhD (The University of Texas Medical Branch) (Multiple PIs)

Public Health Relevance

The proposed research will determine the effectiveness of the emerging strategy of audio recording and sharing of clinic visits on the ability of patients to manage their healthcare. It is expected that findings from this project will inform future policy related to the use of audio-recording as part of routine care and guide implementation strategies if audio recording is found to improve self-management ability and health related outcomes.

Funding Source

National Institute on Aging (NIA), R56AG061522

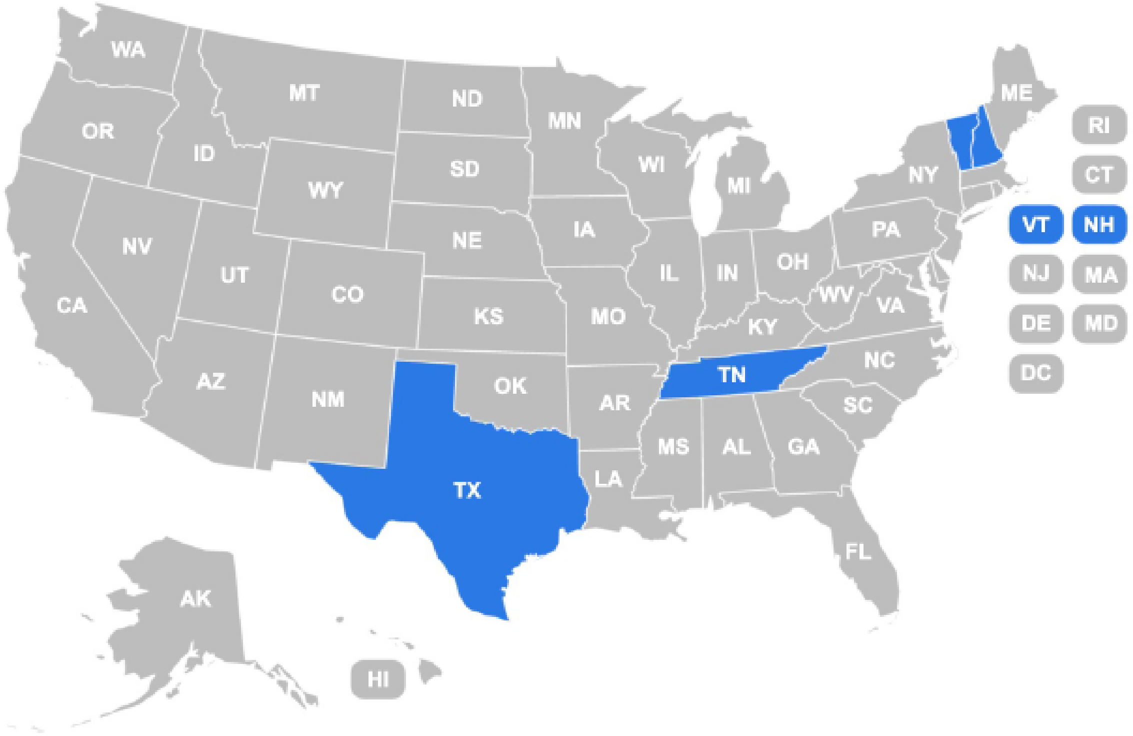
Project Period: 09/15/2019 - 5/31/2021

Other Project Staff

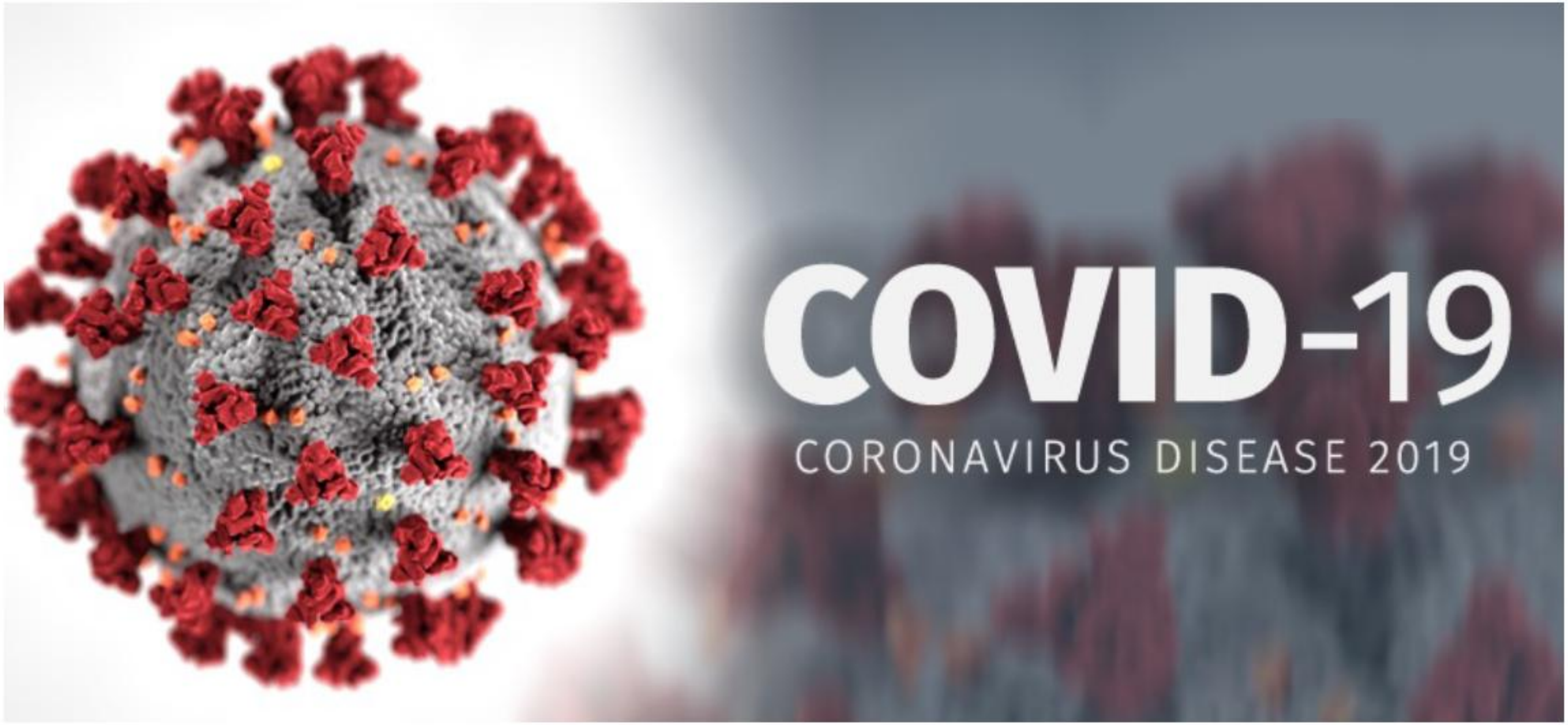
Dartmouth College: Martha Bruce, PhD; James O'Malley, PhD; Elizabeth Carpenter-Song, PhD; William Haslett, PhD; Michelle Dannenberg, MPH; Susan Tarczewski, CCRP; Reed Bratches, MPH, MALS; Jesse Schoonmaker, MD, MPH; Marielle Mugford, BS, CCRP; **Vanderbilt University Medical Center**: Sunil Kripalani, MD, MSc; Sonya Williams; **The University of Texas Medical Branch**: James Goodwin, MD; Isamar Ortiz, BA

Patient Partners: Sheri Piper; Roger Arend

Settings for CE Studio



- Community experts who mirrored our target research population.
  - Older adults with multimorbidity
- Time, day and location determined by community navigator


COVID-19
CORONAVIRUS DISEASE 2019

Format

PI Presentation

The facilitator guided the group through discussions of four main topic areas:

1. *Recommendations for Recruitment and Retention*
2. *Study Protocol*
3. *Study Reminders from the study staff*
4. *Recording Technology, and overall thoughts on the usefulness of audio recording visits*

Community Experts were asked to share their honest opinions, good or bad, as the feedback was critical to ensure the highest likelihood of completing a successful project.

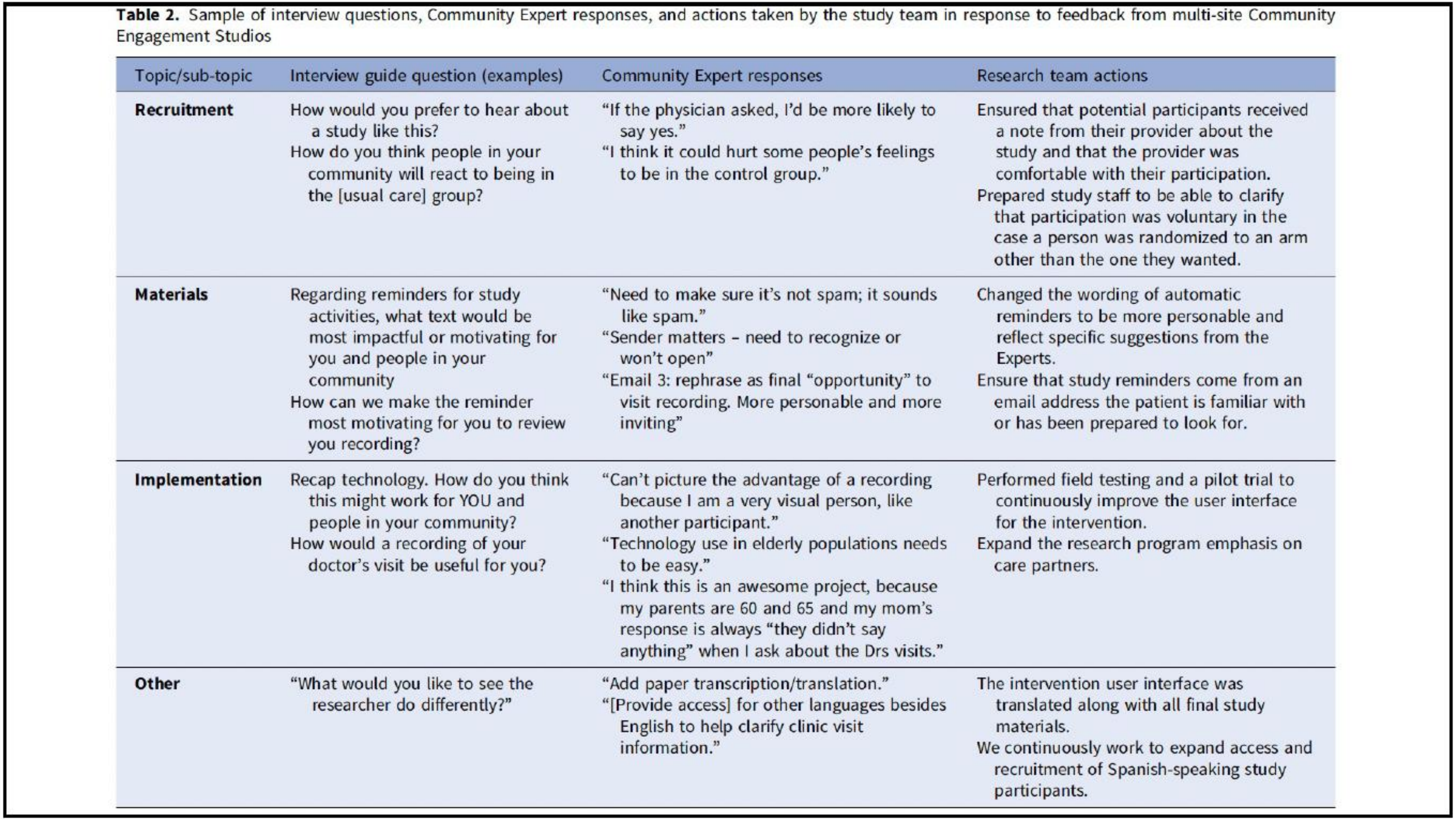
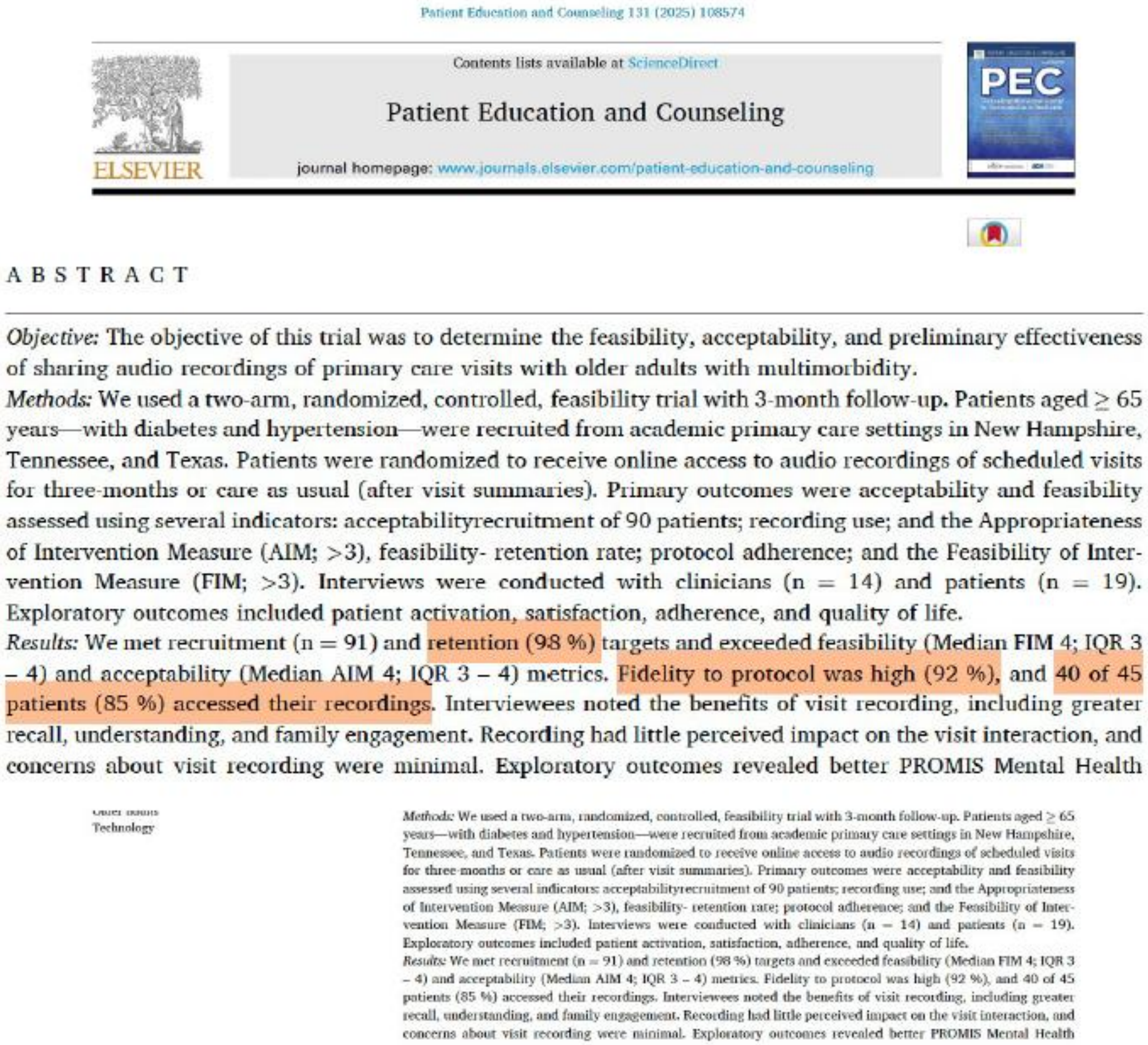


Table 2. Sample of interview questions, Community Expert responses, and actions taken by the study team in response to feedback from multi-site Community Engagement Studios

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.



Patient Education and Counseling 131 (2025) 108574

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Patient Education and Counseling

journal homepage: www.journals.elsevier.com/patient-education-and-counseling

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: acceptabilityrecruitment 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

Technology

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: acceptabilityrecruitment 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.

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CHRONICLE

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)
- **Lead Scientist**: Dr. Renata Yen
- **Patient Partners**: Sheri Piper

Stakeholder groups	Stakeholders
Patient Partners	Dartmouth: Mr. Arend, Mr. Kottkamp, Ms. Piper; UTMB: Mr. and Mrs. Gore, Mr. Oritz; VUMC: Dr. Reese
Clinician Partners	Dartmouth: Dr. Hong; UTMB: Dr. Gutierrez; VUMC: Dr. Goyal
Healthcare decision makers	Dr. Conroy (CEO Dartmouth Hitchcock Health); Dr Raimer (President UTMB); Dr. Sternberg (Chief Medical Officer & Chief Patient Experience Officer, VUMC)
Payor	Dr. Pierce (Cigna)
Advocacy groups	National Council on Aging (Ms. Cameron); National Alliance for Caregiving (Mr. Wittke); OpenNotes (Dr. Blease)
Local Group	Dartmouth Centers for Aging (Ms. Flaherty); Osher Lifelong Learning Institute (Ms. Sierpina)
Policy makers	American Geriatrics Society (Ms. Lundebjerg)

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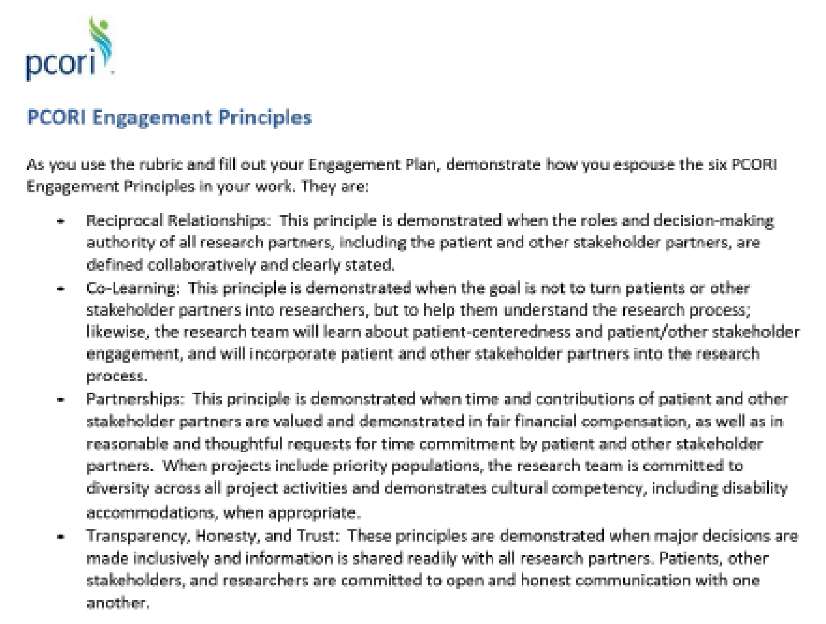
Guidance for Applicants Completing a PCORI Funding Announcement (PFA) Engagement Plan

The Engagement Rubric is divided into three sections; planning, conduct, and dissemination. Each section includes descriptions of the types of activities likely to take place within each phase of research and examples of engagement from PCORI-funded projects. Each numbered section below corresponds to a numbered section in the engagement plan that accompanies each PFA.

1. PLANNING THE STUDY: Describe how patient and stakeholder partners will participate in study planning and design. (As you fill out Section 1 of your Engagement Plan, refer to the information below.)

Potential activities include:

- Developing the research question and relevant outcomes to be studied, to ensure that the project and its results will be useful and important to patient and stakeholder communities.
- Defining the characteristics of study participants, to minimize the risk that certain patients will be included or excluded due to criteria that are not relevant.
- Designing the study to minimize disruption to patient and stakeholder study participants, thereby promote retention of study participants.



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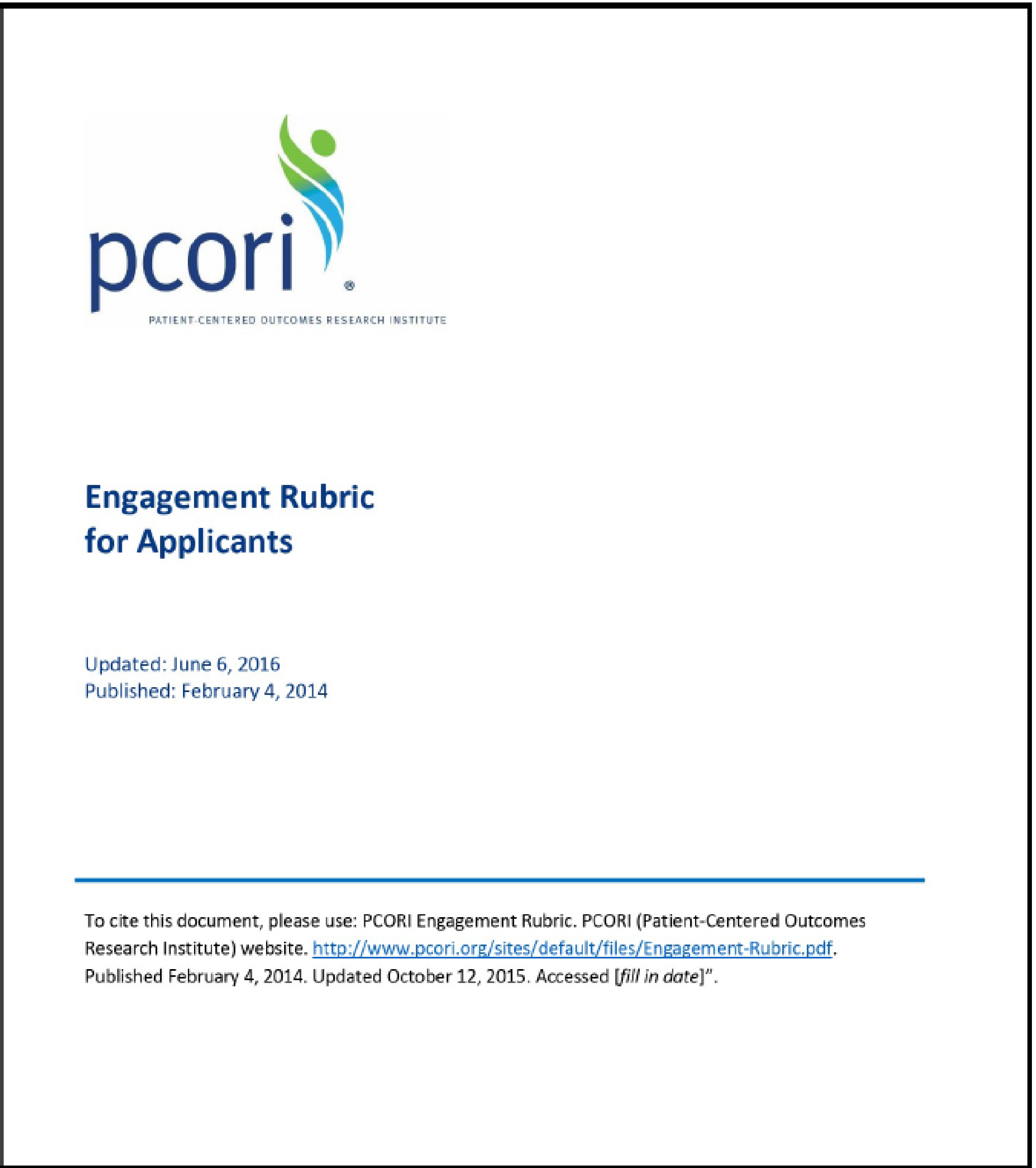
PCORI Engagement Principles

As you use the rubric and fill out your Engagement Plan, demonstrate how you espouse the six PCORI Engagement Principles in your work. They are:

- Reciprocal Relationships: This principle is demonstrated when the roles and decision-making authority of all research partners, including the patient and other stakeholder partners, are defined collaboratively and clearly stated.
- Co-Learning: This principle is demonstrated when the goal is not to turn patients or other stakeholder partners into researchers, but to help them understand the research process; likewise, the research team will learn about patient-centeredness and patient/other stakeholder engagement, and will incorporate patient and other stakeholder partners into the research process.
- Partnerships: This principle is demonstrated when time and contributions of patient and other stakeholder partners are valued and demonstrated in fair financial compensation, as well as in reasonable and thoughtful requests for time commitment by patient and other stakeholder partners. When projects include priority populations, the research team is committed to diversity across all project activities and demonstrates cultural competency, including disability accommodations, when appropriate.
- Transparency, Honesty, and Trust: These principles are demonstrated when major decisions are made inclusively and information is shared readily with all research partners. Patients, other stakeholders, and researchers are committed to open and honest communication with one another.



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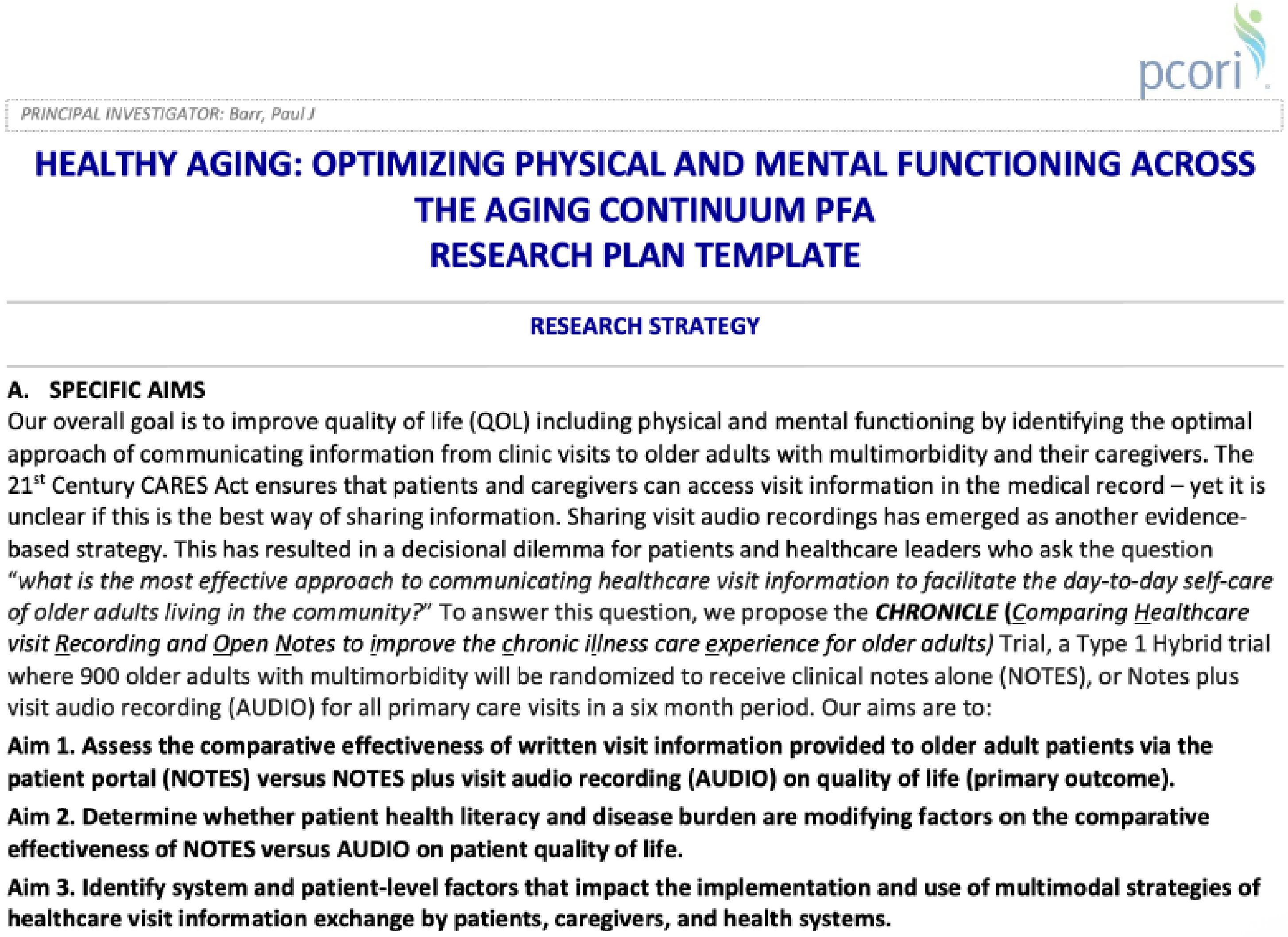
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Engagement Rubric for Applicants

Updated: June 6, 2016
Published: February 4, 2014

To cite this document, please use: PCORI Engagement Rubric. PCORI (Patient-Centered Outcomes Research Institute) website. http://www.pcori.org/sites/default/files/Engagement-Rubric.pdf. Published February 4, 2014. Updated October 12, 2015. Accessed [*fill in date*]".



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PRINCIPAL INVESTIGATOR: Barr, Paul J

HEALTHY AGING: OPTIMIZING PHYSICAL AND MENTAL FUNCTIONING ACROSS THE AGING CONTINUUM PFA
RESEARCH PLAN TEMPLATE

RESEARCH STRATEGY

A. SPECIFIC AIMS

Our overall goal is to improve quality of life (QOL) including physical and mental functioning by identifying the optimal approach of communicating information from clinic visits to older adults with multimorbidity and their caregivers. The 21st Century CARES Act ensures that patients and caregivers can access visit information in the medical record – yet it is unclear if this is the best way of sharing information. Sharing visit audio recordings has emerged as another evidence-based strategy. This has resulted in a decisional dilemma for patients and healthcare leaders who ask the question "*what is the most effective approach to communicating healthcare visit information to facilitate the day-to-day self-care of older adults living in the community?*" To answer this question, we propose the ***CHRONICLE*** **(***Comparing Healthcare visit Recording and Open Notes to improve the chronic illness care experience for older adults)* Trial, a Type 1 Hybrid trial where 900 older adults with multimorbidity will be randomized to receive clinical notes alone (NOTES), or Notes plus visit audio recording (AUDIO) for all primary care visits in a six month period. Our aims are to:

Aim 1. Assess the comparative effectiveness of written visit information provided to older adult patients via the patient portal (NOTES) versus NOTES plus visit audio recording (AUDIO) on quality of life (primary outcome).

Aim 2. Determine whether patient health literacy and disease burden are modifying factors on the comparative effectiveness of NOTES versus AUDIO on patient quality of life.

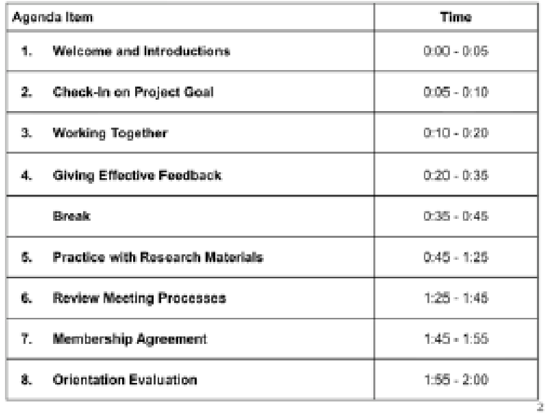
Aim 3. Identify system and patient-level factors that impact the implementation and use of multimodal strategies of healthcare visit information exchange by patients, caregivers, and health systems.

Wisconsin Network
for Research Support

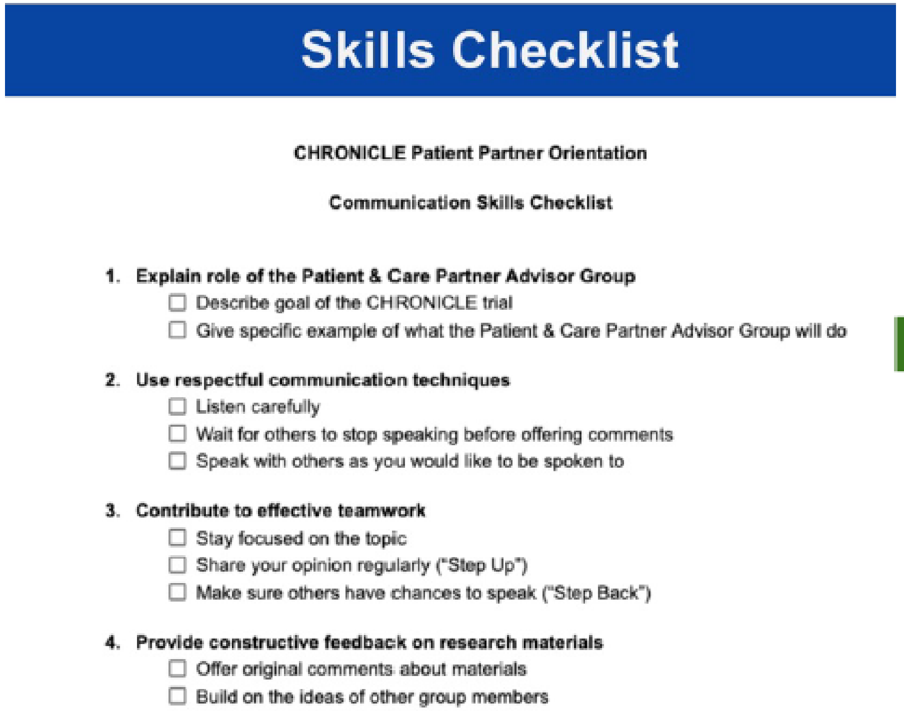
Toolkit on Patient Partner Engagement in Research

Patient partner orientation

Agenda



Agenda Item	Time
1. Welcome and Introductions	0:00 - 0:05
2. Check-In on Project Goal	0:05 - 0:10
3. Working Together	0:10 - 0:20
4. Giving Effective Feedback	0:20 - 0:35
Break	0:35 - 0:45
5. Practice with Research Materials	0:45 - 1:25
6. Review Meeting Processes	1:25 - 1:45
7. Membership Agreement	1:45 - 1:55
8. Orientation Evaluation	1:55 - 2:00

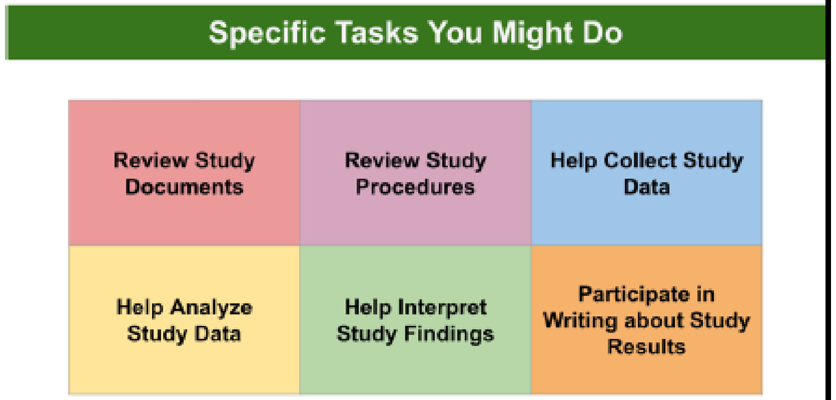


Skills Checklist

CHRONICLE Patient Partner Orientation

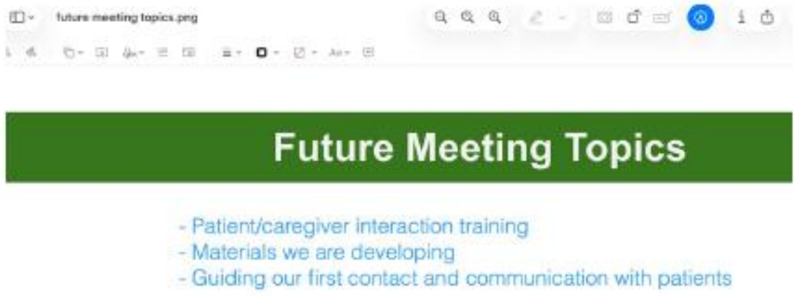
Communication Skills Checklist

1. **Explain role of the Patient & Care Partner Advisor Group**
   - ☐ Describe goal of the CHRONICLE trial
   - ☐ Give specific example of what the Patient & Care Partner Advisor Group will do
2. **Use respectful communication techniques**
   - ☐ Listen carefully
   - ☐ Wait for others to stop speaking before offering comments
   - ☐ Speak with others as you would like to be spoken to
3. **Contribute to effective teamwork**
   - ☐ Stay focused on the topic
   - ☐ Share your opinion regularly ("Step Up")
   - ☐ Make sure others have chances to speak ("Step Back")
4. **Provide constructive feedback on research materials**
   - ☐ Offer original comments about materials
   - ☐ Build on the ideas of other group members



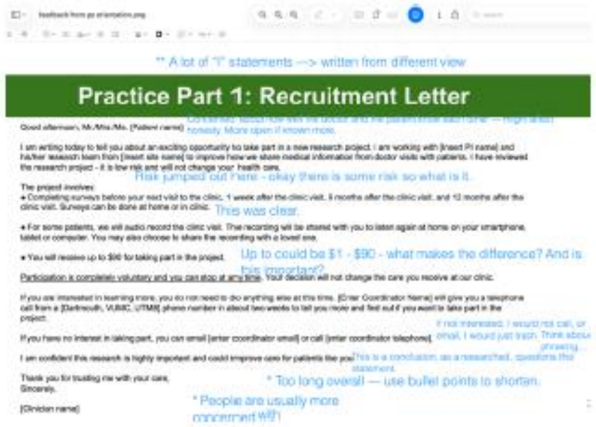
Specific Tasks You Might Do

Review Study Documents	**Review Study Procedures**	**Help Collect Study Data**
Help Analyze Study Data	**Help Interpret Study Findings**	**Participate in Writing about Study Results**



Future Meeting Topics

- Patient/caregiver interaction training
- Materials we are developing
- Guiding our first contact and communication with patients



** A lot of "I" statements —> written from different view

Practice Part 1: Recruitment Letter

Good afternoon, Mr./Mrs./Ms. [Patient name]

Concerned about how will the doctor and the patient know each other — might affect honesty. More open if known more.

I am writing today to tell you about an exciting opportunity to take part in a new research project. I am working with [insert PI name] and his/her research team from [insert site name] to improve how we share medical information from doctor visits with patients. I have reviewed the research project - it is low risk and will not change your health care.

Risk jumped out here - okay there is some risk so what is it.

The project involves:

- Completing surveys before your next visit to the clinic, 1 week after the clinic visit, 6 months after the clinic visit, and 12 months after the clinic visit. Surveys can be done at home or in clinic.

This was clear.

- For some patients, we will audio record the clinic visit. The recording will be shared with you to listen again at home on your smartphone, tablet or computer. You may also choose to share the recording with a loved one.
- You will receive up to $90 for taking part in the project.

Up to could be $1 - $90 - what makes the difference? And is this important?

Participation is completely voluntary and you can stop at any time. Your decision will not change the care you receive at our clinic.

If you are interested in learning more, you do not need to do anything else at this time. [Enter Coordinator Name] will give you a telephone call from a [Dartmouth, VUMC, UTMB] phone number in about two weeks to tell you more and find out if you want to take part in the project.

If you have no interest in taking part, you can email [enter coordinator email] or call [enter coordinator telephone].

If not interested, I would not call, or email, I would just trash. Think about phrasing...

I am confident this research is highly important and could improve care for patients like you.

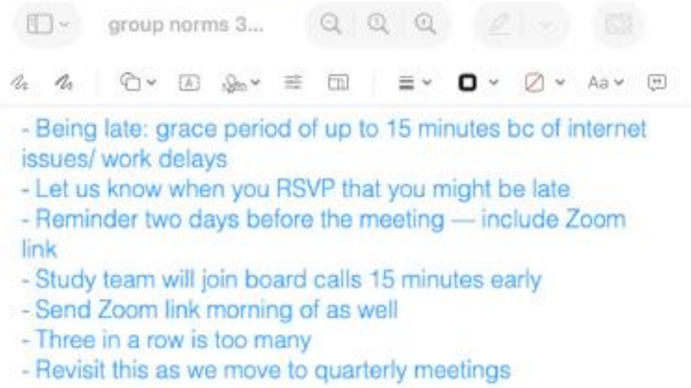
This is a conclusion, as a researcher, questions this statement.

Thank you for trusting me with your care,
Sincerely,

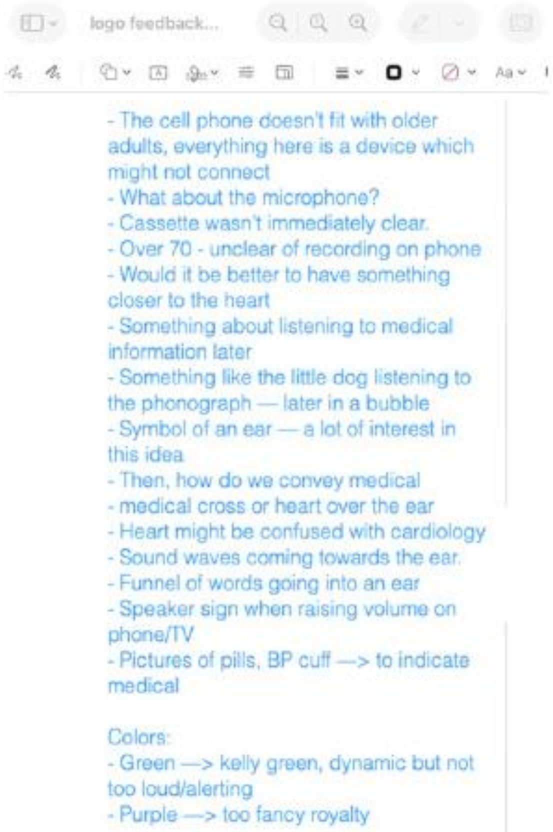
[Clinician name]

* Too long overall — use bullet points to shorten.

* People are usually more concerned with

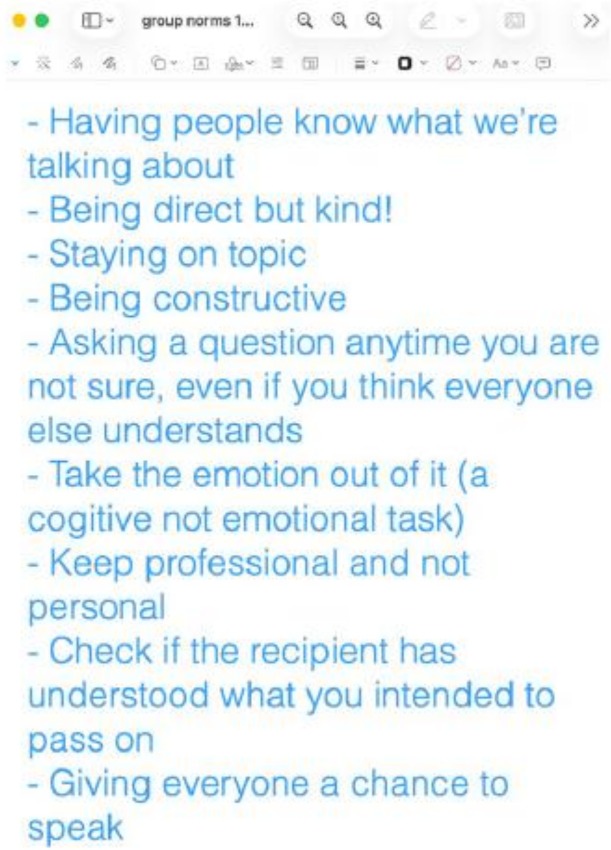


- Being late: grace period of up to 15 minutes bc of internet issues/ work delays
- Let us know when you RSVP that you might be late
- Reminder two days before the meeting — include Zoom link
- Study team will join board calls 15 minutes early
- Send Zoom link morning of as well
- Three in a row is too many
- Revisit this as we move to quarterly meetings



- The cell phone doesn't fit with older adults, everything here is a device which might not connect
- What about the microphone?
- Cassette wasn't immediately clear.
- Over 70 - unclear of recording on phone
- Would it be better to have something closer to the heart
- Something about listening to medical information later
- Something like the little dog listening to the phonograph — later in a bubble
- Symbol of an ear — a lot of interest in this idea
- Then, how do we convey medical
- medical cross or heart over the ear
- Heart might be confused with cardiology
- Sound waves coming towards the ear.
- Funnel of words going into an ear
- Speaker sign when raising volume on phone/TV
- Pictures of pills, BP cuff —> to indicate medical

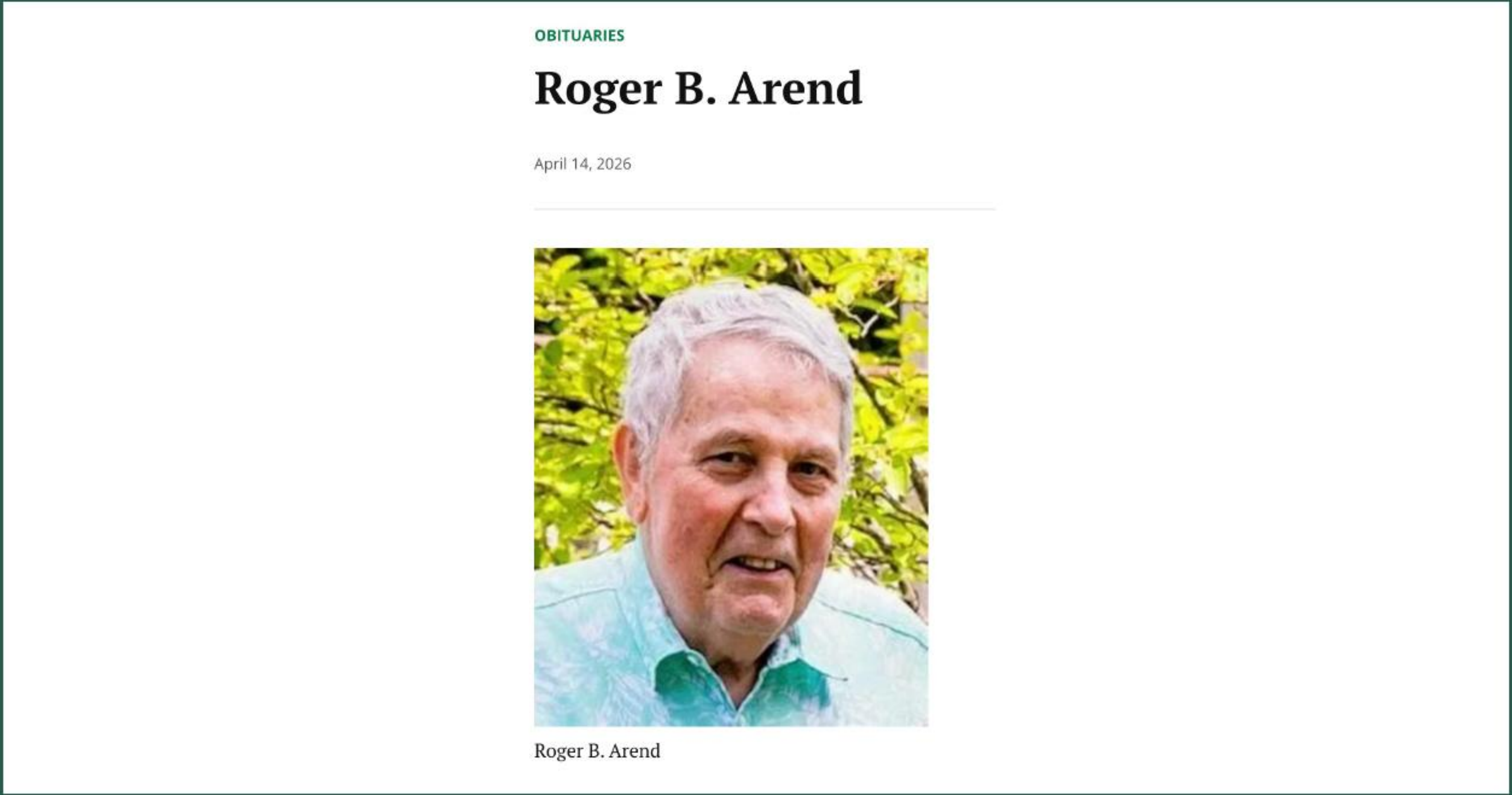
Colors:
- Green —> kelly green, dynamic but not too loud/alerting
- Purple —> too fancy royalty



- Having people know what we're talking about
- Being direct but kind!
- Staying on topic
- Being constructive
- Asking a question anytime you are not sure, even if you think everyone else understands
- Take the emotion out of it (a cogitive not emotional task)
- Keep professional and not personal
- Check if the recipient has understood what you intended to pass on
- Giving everyone a chance to speak

Feedback on everything – collected and clear actions relayed back to patient partners

True engagement



OBITUARIES

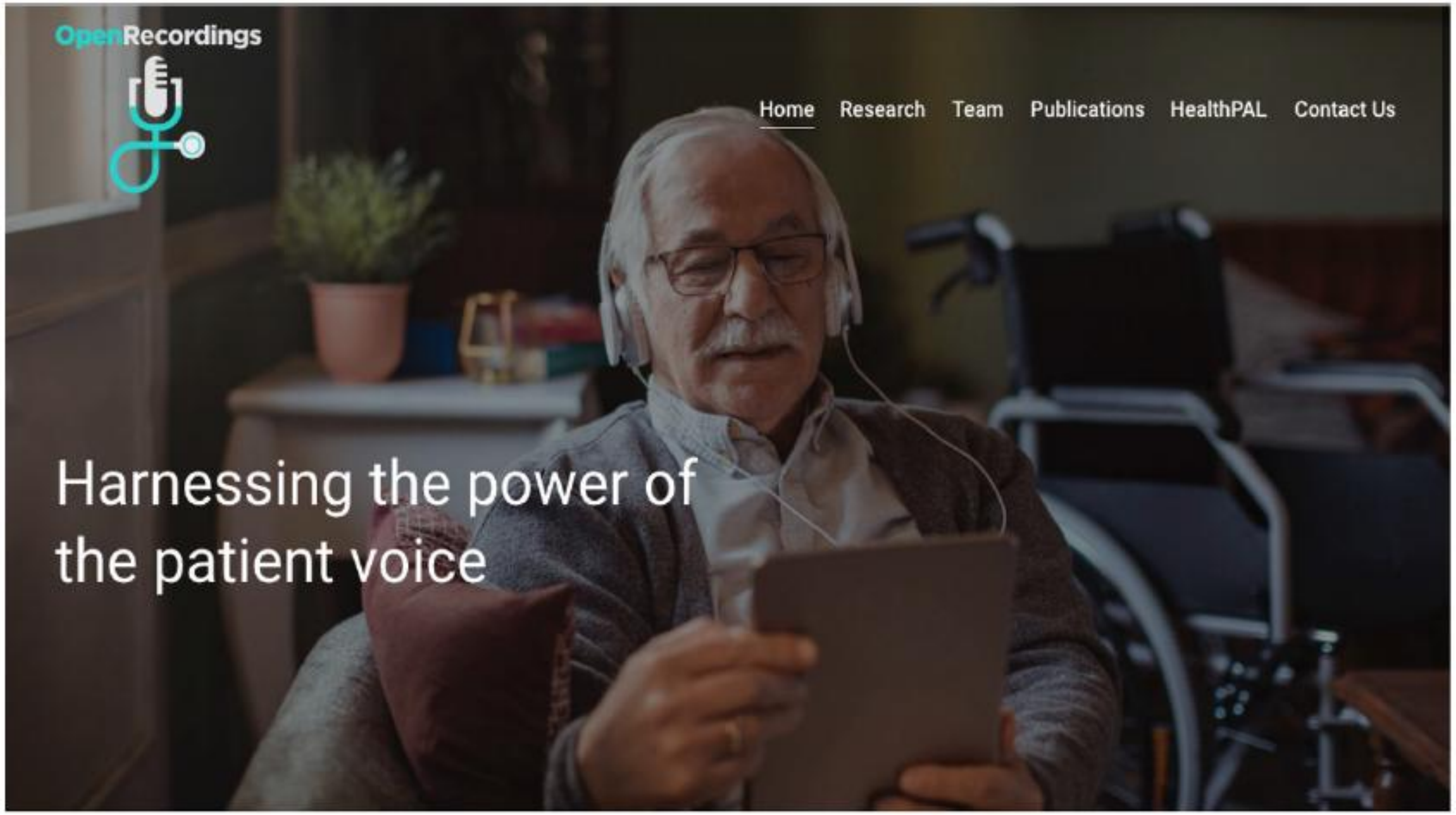
Roger B. Arend

April 14, 2026

Roger B. Arend

Thank you

paul.j.barr@dartmouth.edu



Harnessing the power of the patient voice

We are a multidisciplinary group of researchers, patients, and doctors working together to understand how to improve the communication of clinic visit information. We are particularly interested in the application of audio and video recordings of clinic visits to support this communication.

Dartmouth Health

Project ECHO®

WELCOME to

Get Engaged:

An ECHO to Increase Skills for Community Engaged Research

Session 4, Research implementation
May 21, 2026

Dartmouth Health

Implementing Community Engaged Research: Emotional Journey Mapping

Daisy Goodman DNP, MPH, CNM, CARN-AP

Lisa Lamadriz MPH, RN, IBCLC

Disclosures

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The views, statements and opinions in this presentation are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

We acknowledge with sincere gratitude **the birthing people of NH** who shared their experiences of care so generously with this project

How is Community Engaged Research defined?

"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"

(PCORI, 2018)

Why Does Community Engagement Matter In Reproductive Health Research?

- Medical mistrust is "a dynamic, transactional response, shaped by lived experiences" (Adekunle, 2025)
- Long history of criminality in OB/GYN research
  - François Marie Prevost: cesarean section (1830s)
  - James Marion Sims: fistula repair (1840s)
  - Josef Mengele: sterilization (1940s)
  - Gregory Pincus/John Rock: contraceptive pill development (1950s)
  - Untreated Syphilis Study at Tuskegee (1932-1972)

Adekunle, T. Reproductive coercion, medical mistrust, and Black women's health from the antebellum period to the 21st century. *Int J Equity Health* **24**, 302 (2025). https://doi.org/10.1186/s12939-025-02665-2; Owens, D, Fett, S. Black Maternal and Infant Health: Historical Legacies of Slavery. American Journal of Public Health 109, 1342_1345, https://doi.org/10.2105/AJPH.2019.305243
About The Untreated Syphilis Study at Tuskegee | Syphilis Study | CDC

“Surgeon & philanthropist, founder of the women’s hospital state of New York his brilliant achievement carried the fame of American surgery throughout the world”

REMOVED IN 2018

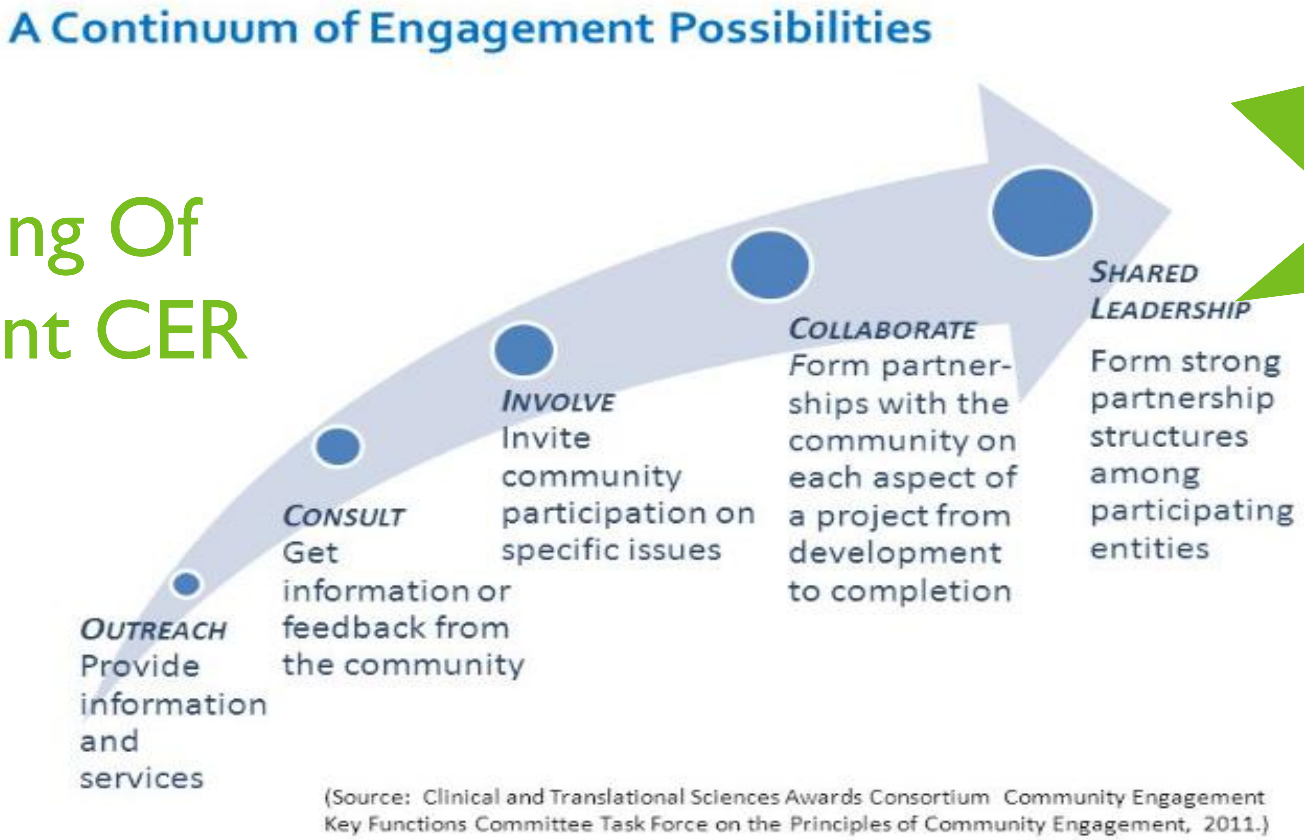
“In recognition of his services in the cause of science and mankind awarded highest honors by his countrymen and decorations from the nations of Belgium and France…”

https://www.theatlantic.com/health/archive/2018/04/j-marion-sims/558248/

Dartmouth Health

“Nothing about us without us”

Our Understanding Of How To Implement CER Is Continually Evolving….



A Continuum of Engagement Possibilities

Outreach
Provide information and services

Consult
Get information or feedback from the community

Involve
Invite community participation on specific issues

Collaborate
Form partnerships with the community on each aspect of a project from development to completion

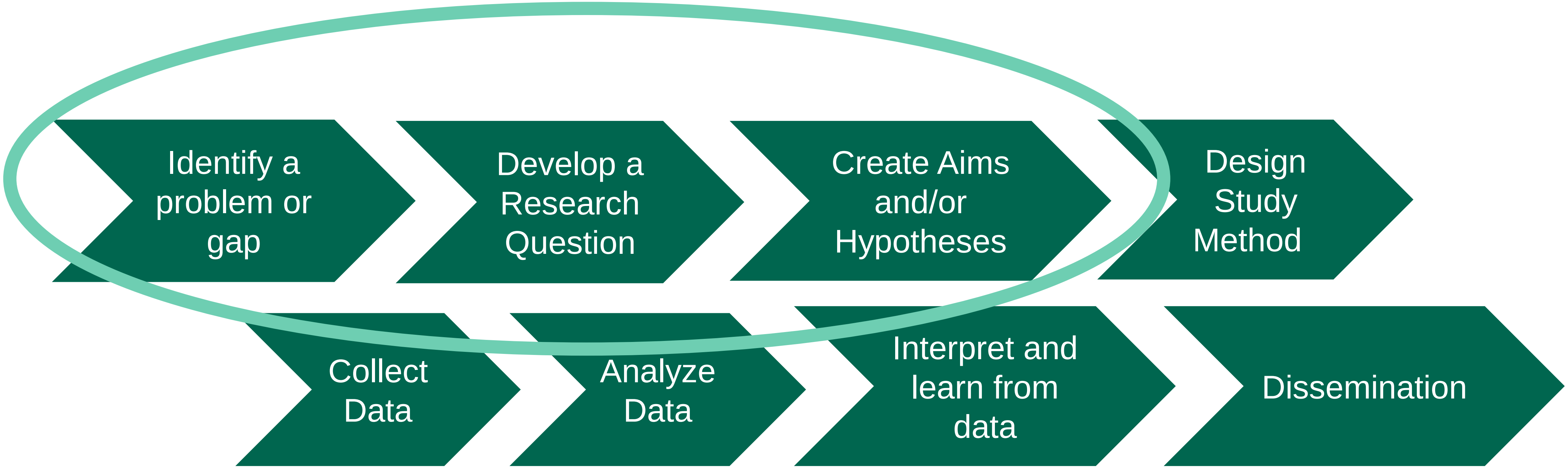
Shared Leadership
Form strong partnership structures among participating entities

(Source: Clinical and Translational Sciences Awards Consortium Community Engagement Key Functions Committee Task Force on the Principles of Community Engagement, 2011.)

Community Members as Co-researchers

https://guides.mclibrary.duke.edu/CENR_researchers; Collins SE. Am Psychol. 2018.

Opportunities To Apply CER Principles Exist At All Stages Of The Research Process



Identify a problem or gap

Develop a Research Question

Create Aims and/or Hypotheses

Design Study Method

Collect Data

Analyze Data

Interpret and learn from data

Dissemination

Going upstream: Using Emotional Journey Mapping to identify problems and gaps

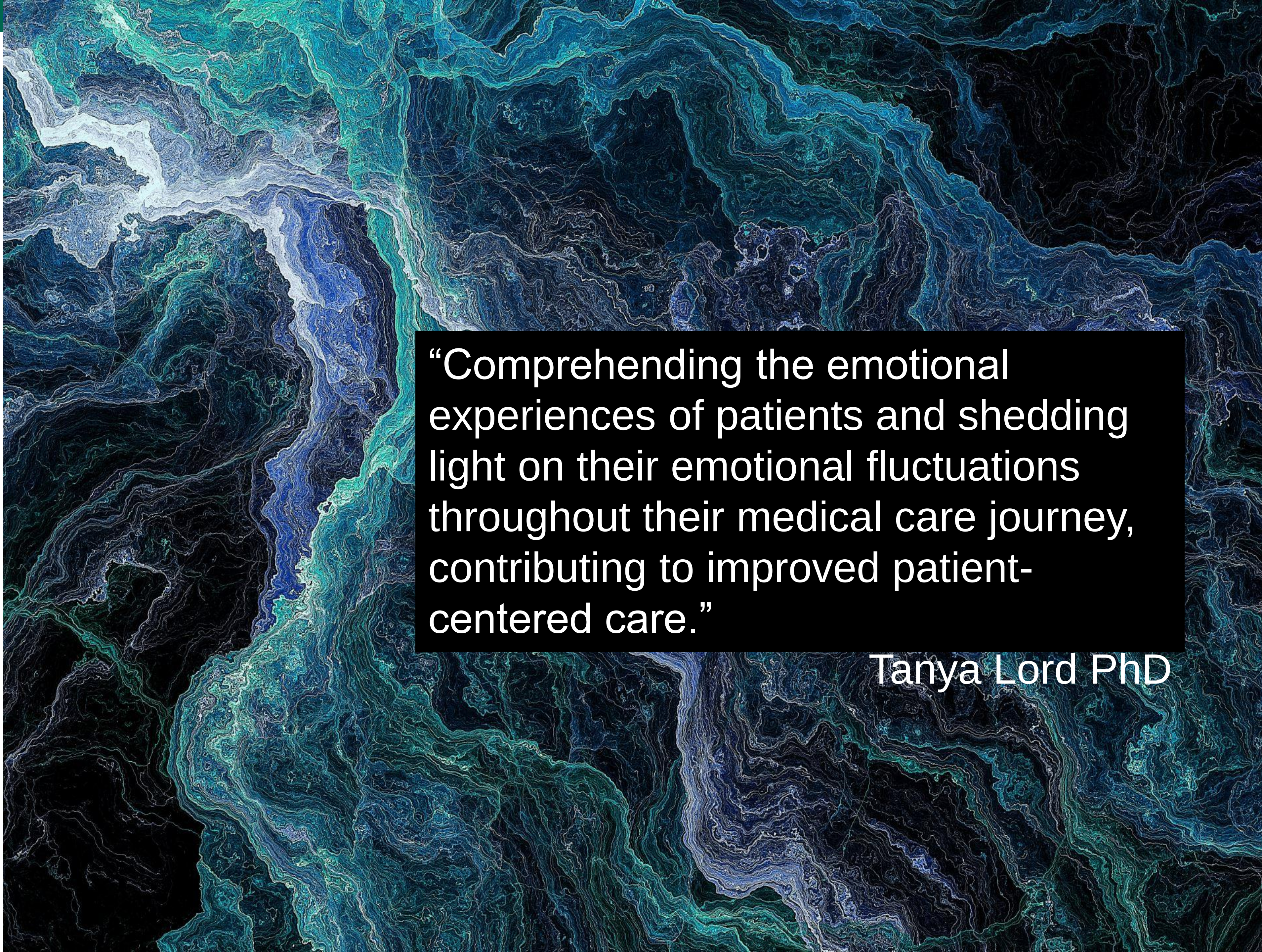
Dartmouth
Health

NH Birthing People Speak Out Through Emotional Journey Mapping (EJM)

What is Emotional Journey Mapping?

> *“I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel”*
>
> Maya Angelou

Emotional Journey Mapping is…



> “Comprehending the emotional experiences of patients and shedding light on their emotional fluctuations throughout their medical care journey, contributing to improved patient-centered care.”

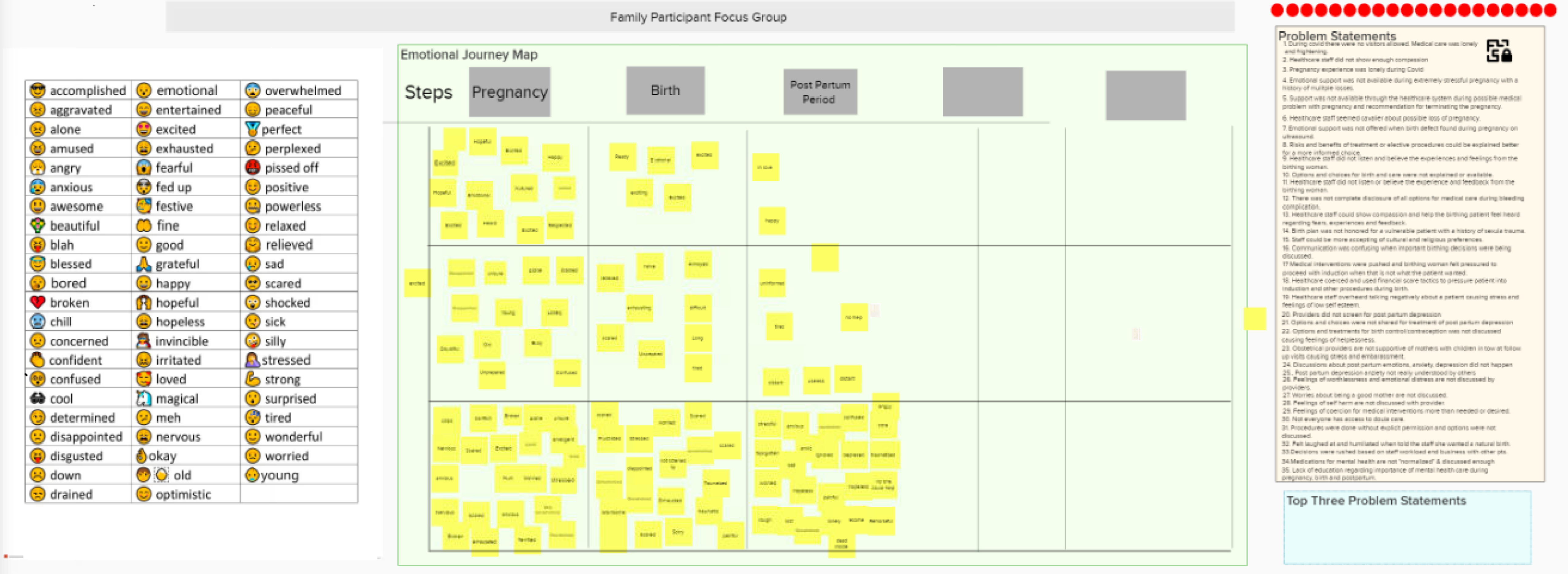
Tanya Lord PhD

Dartmouth
Health

EJM Sessions:
Three Examples And Format

Dartmouth Health

Emotional Journey Mapping Perinatal Experience



Family Participant Focus Group

- accomplished
- aggravated
- alone
- amused
- angry
- anxious
- awesome
- beautiful
- blah
- blessed
- bored
- broken
- chill
- concerned
- confident
- confused
- cool
- determined
- disappointed
- disgusted
- down
- drained
- emotional
- entertained
- excited
- exhausted
- fearful
- fed up
- festive
- fine
- good
- grateful
- happy
- hopeful
- hopeless
- invincible
- irritated
- loved
- magical
- meh
- nervous
- okay
- old
- optimistic
- overwhelmed
- peaceful
- perfect
- perplexed
- pissed off
- positive
- powerless
- relaxed
- relieved
- sad
- scared
- shocked
- sick
- silly
- stressed
- strong
- surprised
- tired
- wonderful
- worried
- young

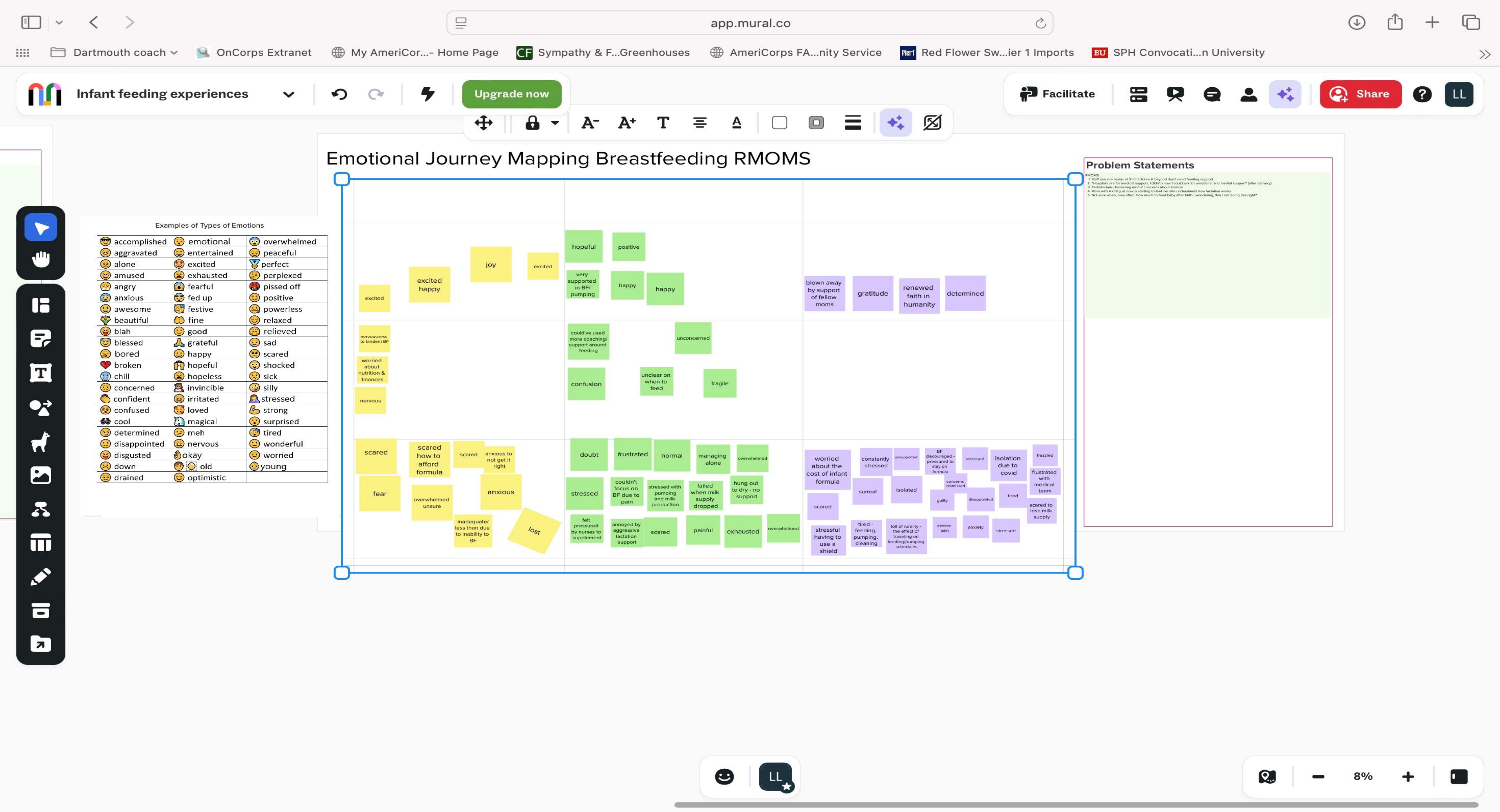
Problem Statements

1. During covid there were no visitors allowed. Medical care was lonely and frightening.
2. Healthcare staff did not show enough compassion
3. Pregnancy experience was lonely during Covid
4. Emotional support was not available during extremely stressful pregnancy with a history of multiple losses.
5. Support was not available through the healthcare system during possible medical problem with pregnancy and recommendation for terminating the pregnancy.
6. Healthcare staff seemed cavalier about possible loss of pregnancy.
7. Emotional support was not offered when birth defect found during pregnancy on ultrasound.
8. Risks and benefits of treatment or elective procedures could be explained better for a more informed choice.
9. Healthcare staff did not listen and believe the experiences and feelings from the birthing woman.
10. Options and choices for birth and care were not explained or available.
11. Healthcare staff did not listen or believe the experience and feedback from the birthing woman.
12. There was not complete disclosure of all options for medical care during bleeding complication.
13. Healthcare staff could show compassion and help the birthing patient feel heard regarding fears, experiences and feedback.
14. Birth plan was not honored for a vulnerable patient with a history of sexula trauma.
15. Staff could be more accepting of cultural and religious preferences.
16. Communication was confusing when important birthing decisions were being discussed.
17 Medical interventions were pushed and birthing woman felt pressured to proceed with induction when that is not what the patient wanted.
18. Healthcare coerced and used financial scare tactics to pressure patient into induction and other procedures during birth.
19. Healthcare staff overheard talking negatively about a patient causing stress and feelings of low self esteem.
20. Providers did not screen for post partum depression
21. Options and choices were not shared for treatment of post partum depression
22. Options and treatments for birth control/contraception was not discussed causing feelings of helplessness.
23. Obstetrical providers are not supportive of mothers with children in tow at follow up visits causing stress and embarassment.
24. Discussions about post partum emotions, anxiety, depression did not happen
25. . Post partum depression anxiety not really understood by others
26. Feelings of worthlessness and emotional distress are not discussed by providers.
27. Worries about being a good mother are not discussed.
28. Feelings of self harm are not discussed with provider.
29. Feelings of coercion for medical interventions more than needed or desired.
30. Not everyone has access to doula care.
31. Procedures were done without explicit permission and options were not discussed.
32. Felt laughed at and humiliated when told the staff she wanted a natural birth.
33.Decisions were rushed based on staff workload and business with other pts.
34.Medications for mental health are not "normalized" & discussed enough
35. Lack of education regarding importance of mental health care during pregnancy, birth and postpartum.

Top Three Problem Statements

Introductions

Discuss feelings, emotions at each point of the perinatal journey



Emotional Journey Mapping Breastfeeding RMOMS

Examples of Types of Emotions

accomplished
aggravated
alone
amused
angry
anxious
awesome
beautiful
blah
blessed
bored
broken
chill
concerned
confident
confused
cool
determined
disappointed
disgusted
down
drained

emotional
entertained
excited
exhausted
fearful
fed up
festive
fine
good
grateful
happy
hopeful
hopeless
invincible
irritated
loved
magical
meh
nervous
okay
old
optimistic

overwhelmed
peaceful
perfect
perplexed
pissed off
positive
powerless
relaxed
relieved
sad
scared
shocked
sick
silly
stressed
strong
surprised
tired
wonderful
worried
young

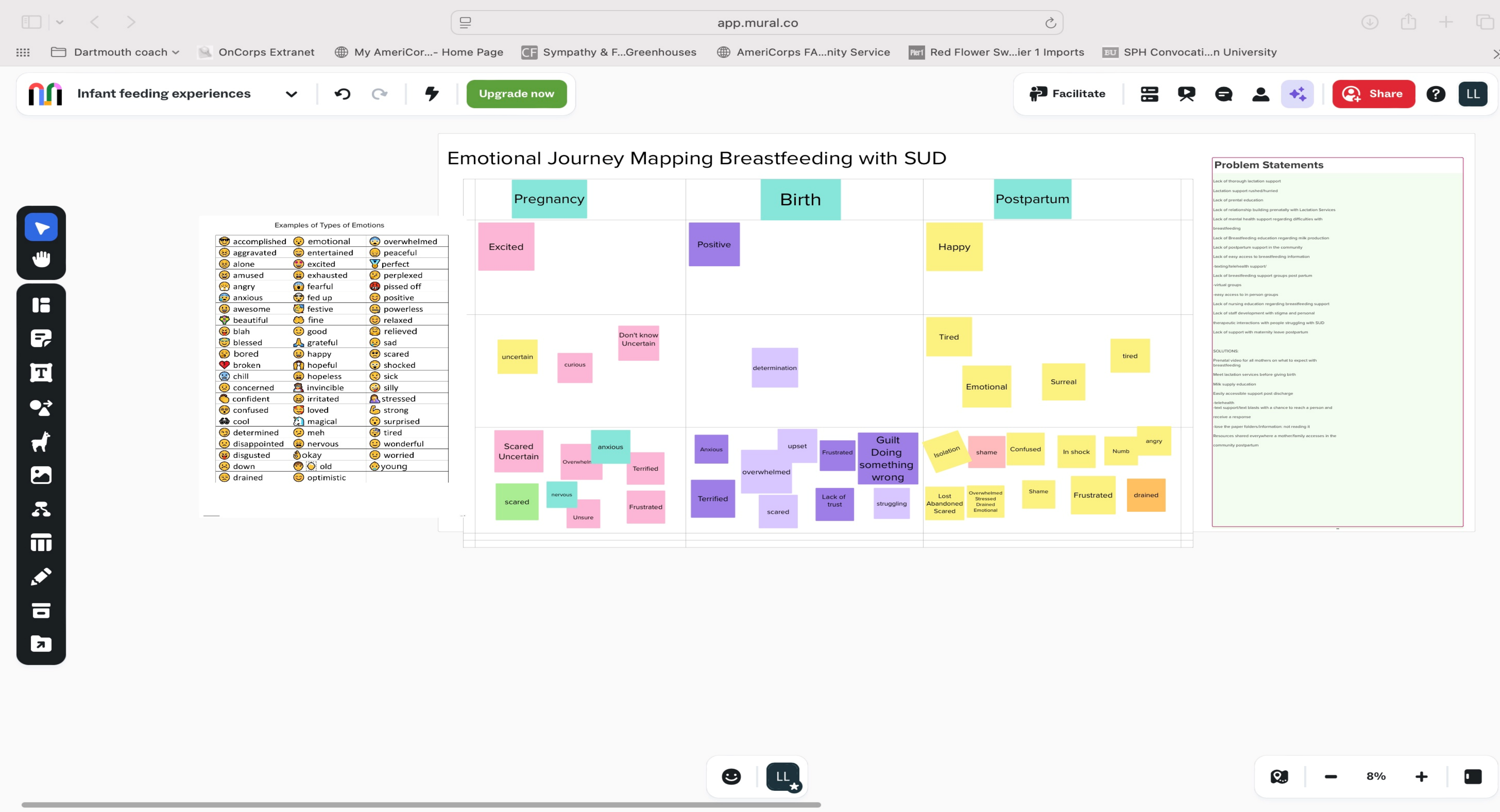
excited
excited happy
joy
excited
nervousness to tandem BF
worried about nutrition & finances
nervous
scared
scared how to afford formula
scared
anxious to not get it right
fear
overwhelmed unsure
anxious
inadequate/ less than due to inability to BF
lost

hopeful
positive
very supported in BF/ pumping
happy
happy
could've used more coaching/ support around feeding
unconcerned
confusion
unclear on when to feed
fragile
doubt
frustrated
normal
managing alone
overwhelmed
stressed
couldn't focus on BF due to pain
stressed with pumping and milk production
failed when milk supply dropped
hung out to dry - no support
felt pressured by nurses to supplement
annoyed by aggressive lactation support
scared
painful
exhausted
overwhelmed

blown away by support of fellow moms
gratitude
renewed faith in humanity
determined
worried about the cost of infant formula
constantly stressed
unsupported
BF discouraged - pressured to stay on formula
stressed
isolation due to covid
frazzled
surreal
isolated
concerns dismissed
guilty
disappointed
tired
frustrated with medical team
scared
scared to lose milk supply
stressful having to use a shield
tired - feeding, pumping, cleaning
toll of rurality - the effect of traveling on feeding/pumping schedules
severe pain
anxiety
stressed

Problem Statements

RMOMS
1. Staff assume moms of 2nd children & beyond don't need feeding support
2. "Hospitals are for medical support, I didn't know I could ask for emotional and mental support" (after delivery)
3. Pediatricians dismissing moms' concerns about formula
4. Mom with 4 kids just now is starting to feel like she understands how lactation works
5. Not sure when, how often, how much to feed baby after birth - wondering, 'Am I not doing this right?'



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sick
silly
stressed
strong
surprised
tired
wonderful
worried
young

Emotional Journey Mapping Breastfeeding with SUD

Pregnancy

Excited

uncertain
curious
Don't know Uncertain

Scared Uncertain
Overwhelm
anxious
Terrified
scared
nervous
Unsure
Frustrated

Birth

Positive

determination

Anxious
upset
overwhelmed
Frustrated
Guilt Doing something wrong
Terrified
scared
Lack of trust
struggling

Postpartum

Happy

Tired
tired
Emotional
Surreal

Isolation
shame
Confused
In shock
Numb
angry
Lost Abandoned Scared
Overwhelmed Stressed Drained Emotional
Shame
Frustrated
drained

Problem Statements

Lack of thorough lactation support

Lactation support rushed/hurried

Lack of prental education

Lack of relationship building prenatally with Lactation Services

Lack of mental health support regarding difficulties with

breastfeeding

Lack of Breastfeeding education regarding milk production

Lack of postpartum support in the community

Lack of easy access to breastfeeding information

-texting/telehealth support/

Lack of breastfeeding support groups post partum

-virtual groups

-easy access to in person groups

Lack of nursing education regarding breastfeeding support

Lack of staff development with stigma and personal

therapeutic interactions with people struggling with SUD

Lack of support with maternity leave postpartum

SOLUTIONS:

Prenatal video for all mothers on what to expect with breastfeeding

Meet lactation services before giving birth

Milk supply education

Easily accessible support post discharge

-telehealth
-text support/text blasts with a chance to reach a person and

receive a response

-lose the paper folders/information: not reading it

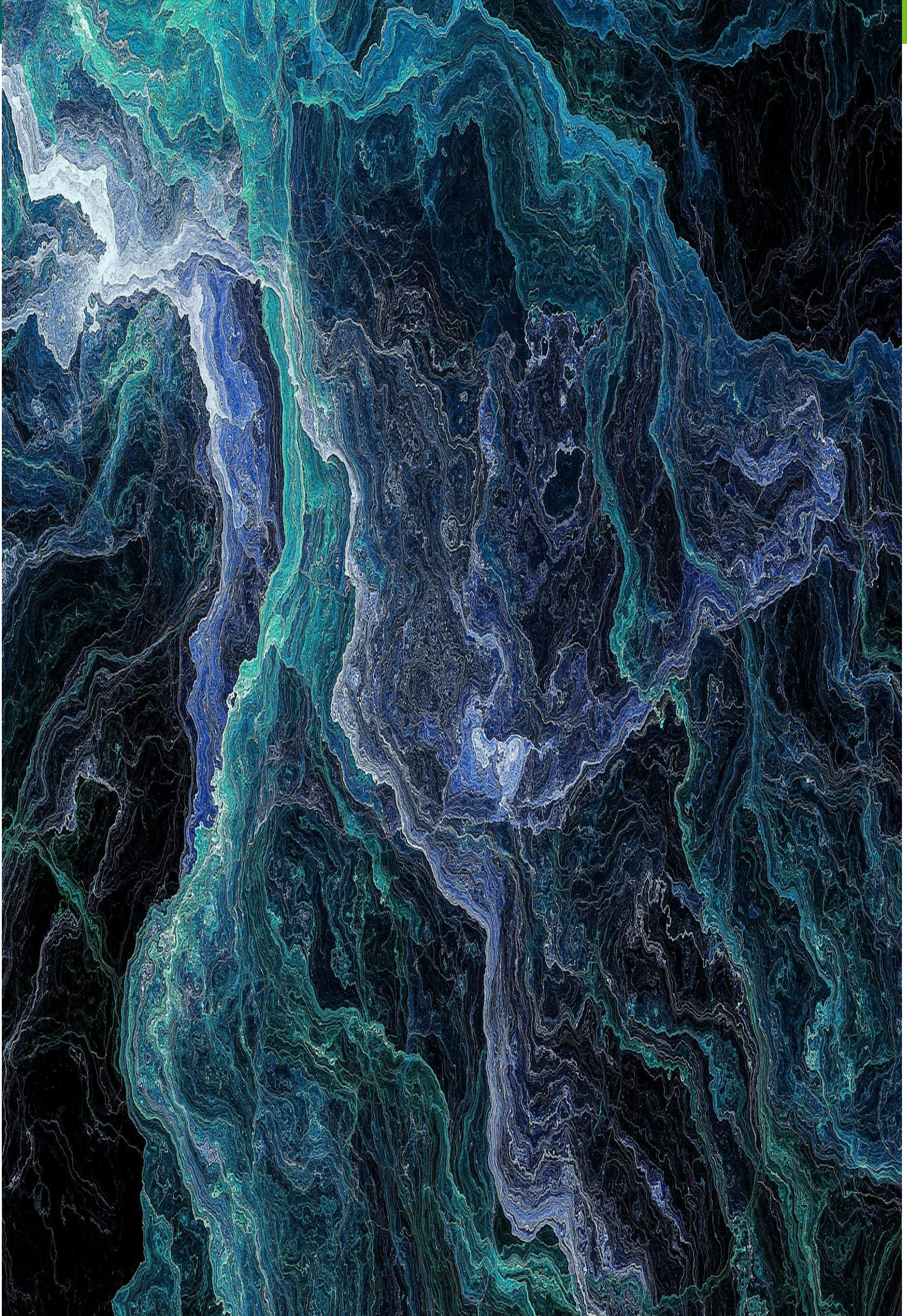
Resources shared everywhere a mother/family accesses in the

community postpartum

- Eager to share stories
- Expressed gratitude for the opportunity to share and listen
- Relayed importance of improving the experience for others
- Mental health and postpartum depression were significant topics that consistently emerged without specific prompts.
- Shared stories of past birth traumas
- Discussed challenging interactions with healthcare staff.
- Relayed importance of having personal and cultural preferences respected during the birth process
- Expressed distress at feeling coerced away from plans
- Shared feelings of sadness and frustration
- Shared that lack of communication and understanding from healthcare providers led to a breakdown in trust
- Shared feeling unable to communicate with providers regarding "unspoken feelings" of guilt, shame, disconnect with previous child or current infant.

Problem Statements: Analysis of Transcripts

- Lack of compassion from healthcare staff to help the birthing patient feel heard regarding fears, experiences and feedback
- Lack of acceptance of cultural and religious preferences from healthcare staff
- Lack of effective communication regarding risks and benefits of treatment or elective procedures to provide informed choice
- Lack of discussions about post partum emotions, anxiety, depression
- Lack of education regarding symptoms of post partum depression and detachment
- Lack of continuity of obstetrical care
- Lack of patient education regarding anticipatory guidance for inpatient care
- Lack of therapeutic discussions to prepare for C-Section
- Lack of support for new motherhood role
- Lack of access to a post partum doula to guide birthing parent with sensitive postpartum needs



Emerging Dialogues

- Provider Compassion and Empathy
- Shared Decision Making
- Mental Health and Emotional Support
- Patient Autonomy
- Patient Empowerment
- Respect and Dignity
- Cultural Awareness and Respect
- Provider Continuity
- Patient Education and Understanding
- Clinical Care
- Postpartum Support
- Breastfeeding Support

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Challenges and Lessons Learned

- Language access- make sure your interpreter is coming!
- W9s
  - Often a barrier to participation
  - Explore best stipend compensation (check, gift card)
- Avoid posting widely on social media unless you insert a "Captcha" button-thousands of bots emerge otherwise
- Consider providing cell phones and/or data when needed
- Childcare to assist with participation

Summary

- Research involving people who experience inequity must be community engaged to avoid replicating oppressive relationships and structures
- Community engaged research is liberatory!
- Emotional Journey Mapping is a methodology which centers patient experience and can be used to identify problems or gaps, generate research questions, and aims and hypotheses
- Community engagement early in the research process can identify future collaborators and co-researchers

"Nothing about us without us"

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Thank you!

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