



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

Ethical Considerations in Working with Communities

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Agenda

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



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*



Infrastructure for Community Engaged Research

Julie Bosak, DrPH, CNM

Cheri Bryer, CRSW

Overview of didactic section

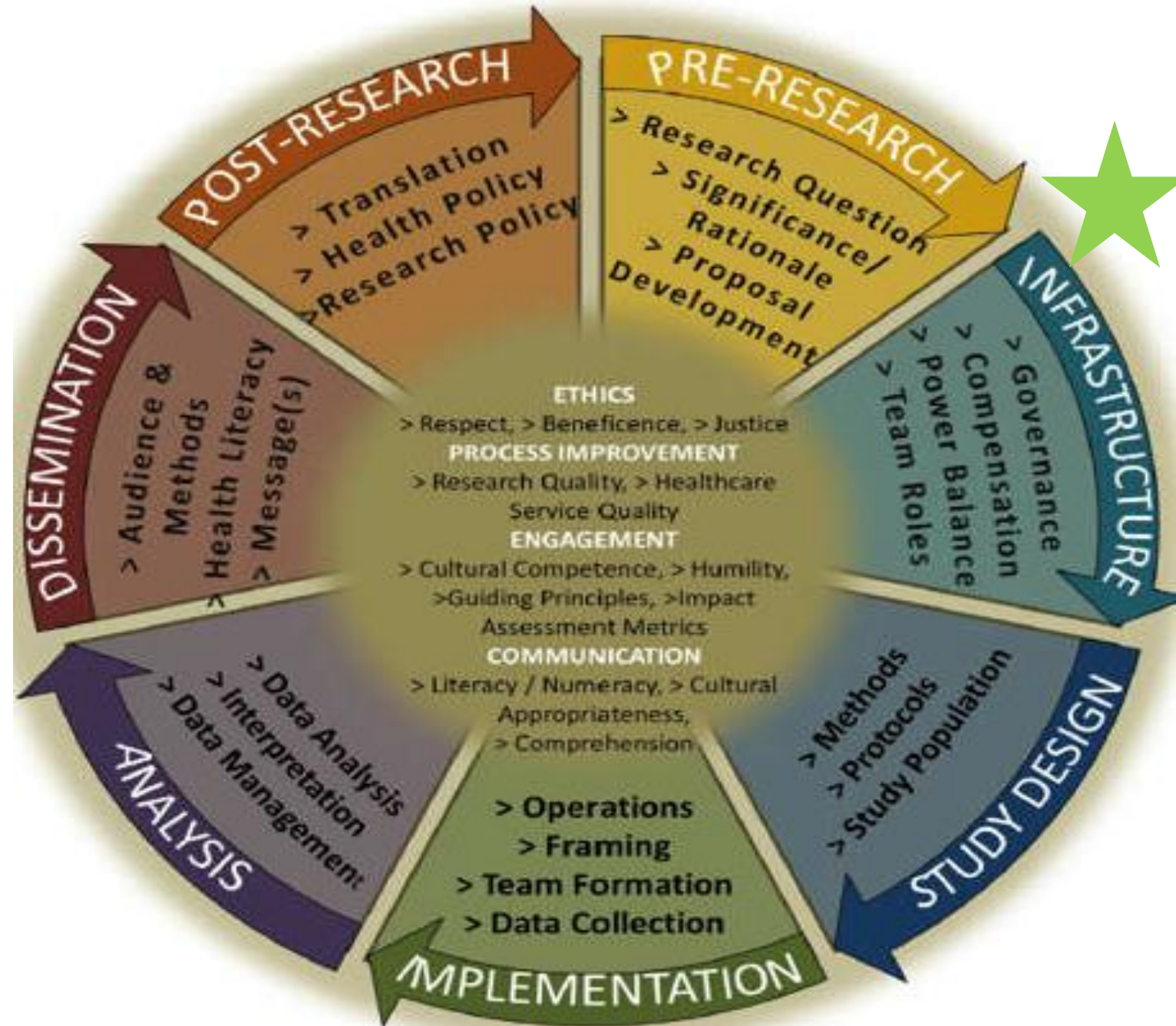
- What are the dimensions to consider within the infrastructure domain for working with community members?
- How does a Community Advisory Board represent and influence these dimensions?

Infrastructure Domain

Stage for decision on aspects of study and planning logistics

Dimensions of Infrastructure

- Governance
- Power Balance
- Team Roles
- Compensation



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?



The diagram consists of two horizontal arrows pointing to the right. The top arrow is light blue and contains the text 'Continuum of Engagement'. Below this arrow, five stages of engagement are listed: 'Outreach', 'Consult', 'Involve', 'Collaborate', and 'Shared Leadership'. The bottom arrow is also light blue and contains the text 'Advisory Board'. This arrow starts at the 'Involve' stage and extends to the right, ending at the 'Shared Leadership' stage. The background of the bottom arrow is a light gray rectangle.

Continuum of Engagement

Outreach

Consult

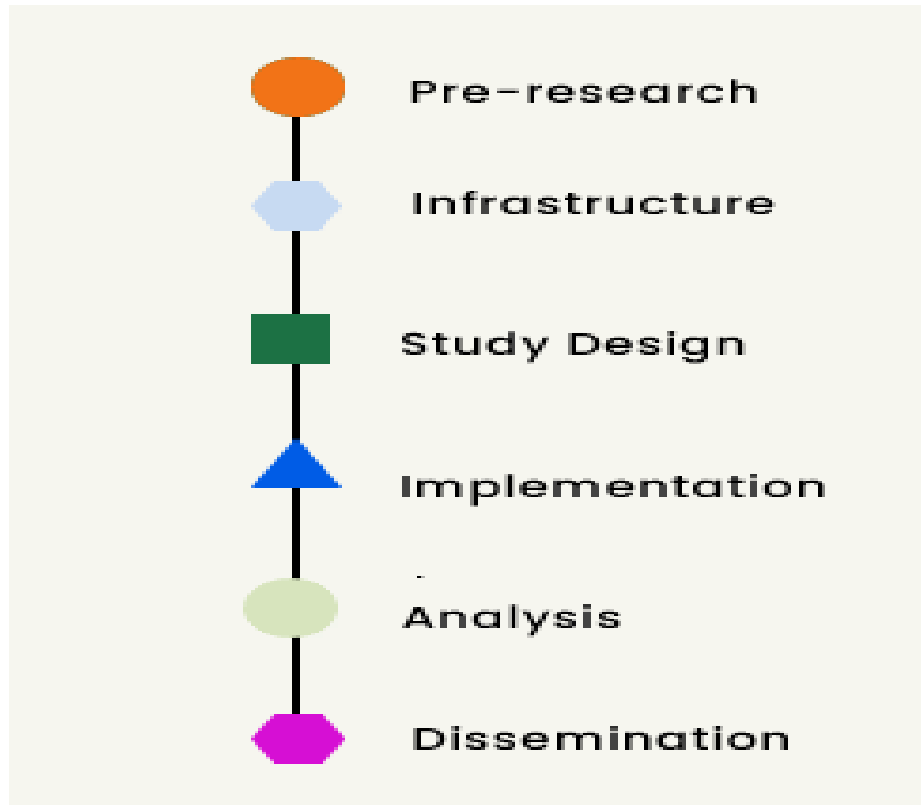
Involve

Collaborate

**Shared
Leadership**

Advisory Board

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

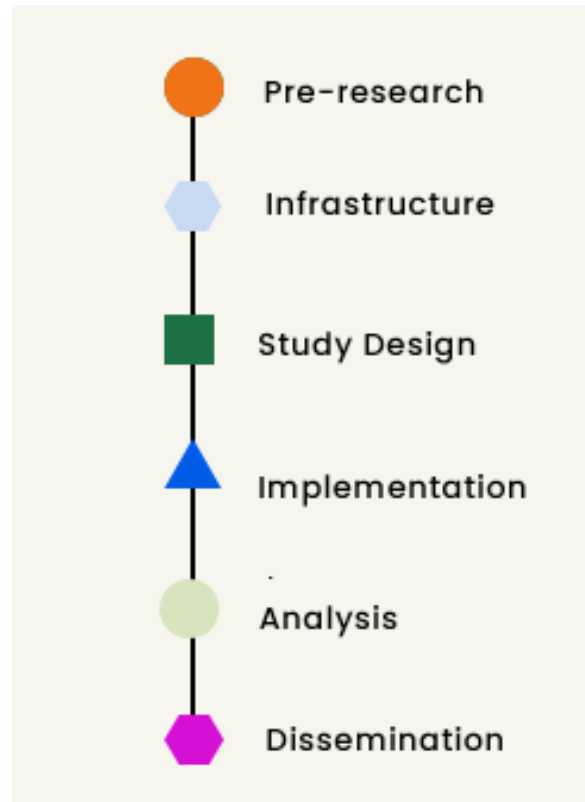
Shared
Leadership



Advisory Board

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

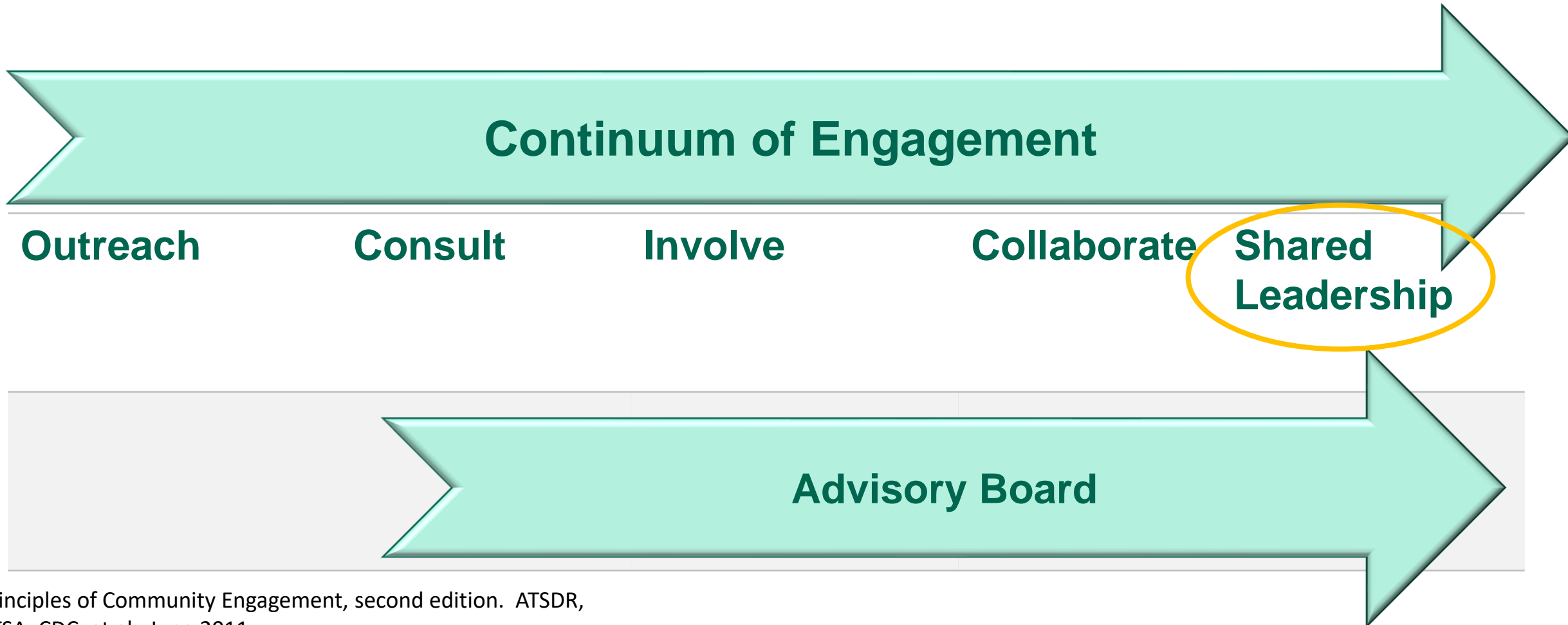
- Feeling exploited or seeing that with others
 - Inadequate **compensation** for your time
 - Compelled to tell your story because of the compensation and power balance
- It is re-traumatizing every time and ensure you offer extra support, protected space

Common challenges with the consulting role

– **Power Balance (imbalance)**

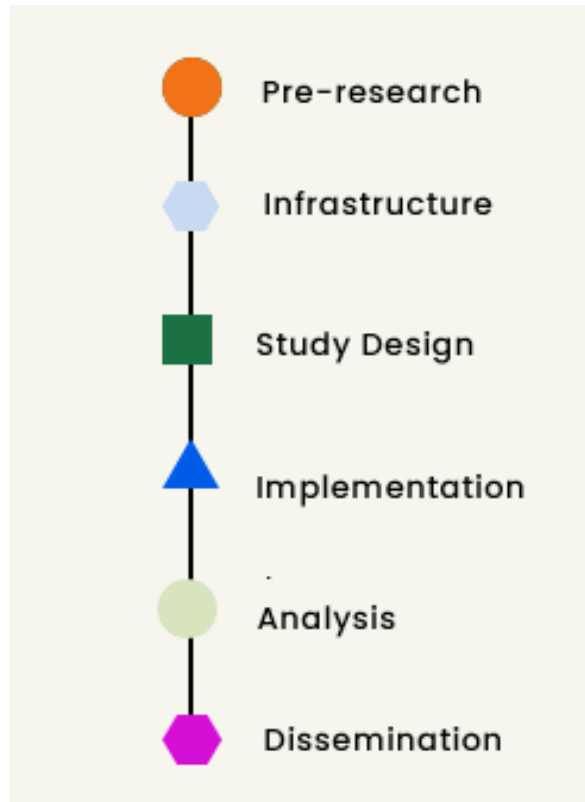
- Ensuring that full study team respects and honors the patient and/or community voice
 - Not simply just meeting the criteria of the study or checking a box
 - If there isn't a baseline respect you can feel "used" to only recruit
- The importance of the interpersonal respect and reactions in every interaction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

How does a CAB differ along the continuum of engagement?



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

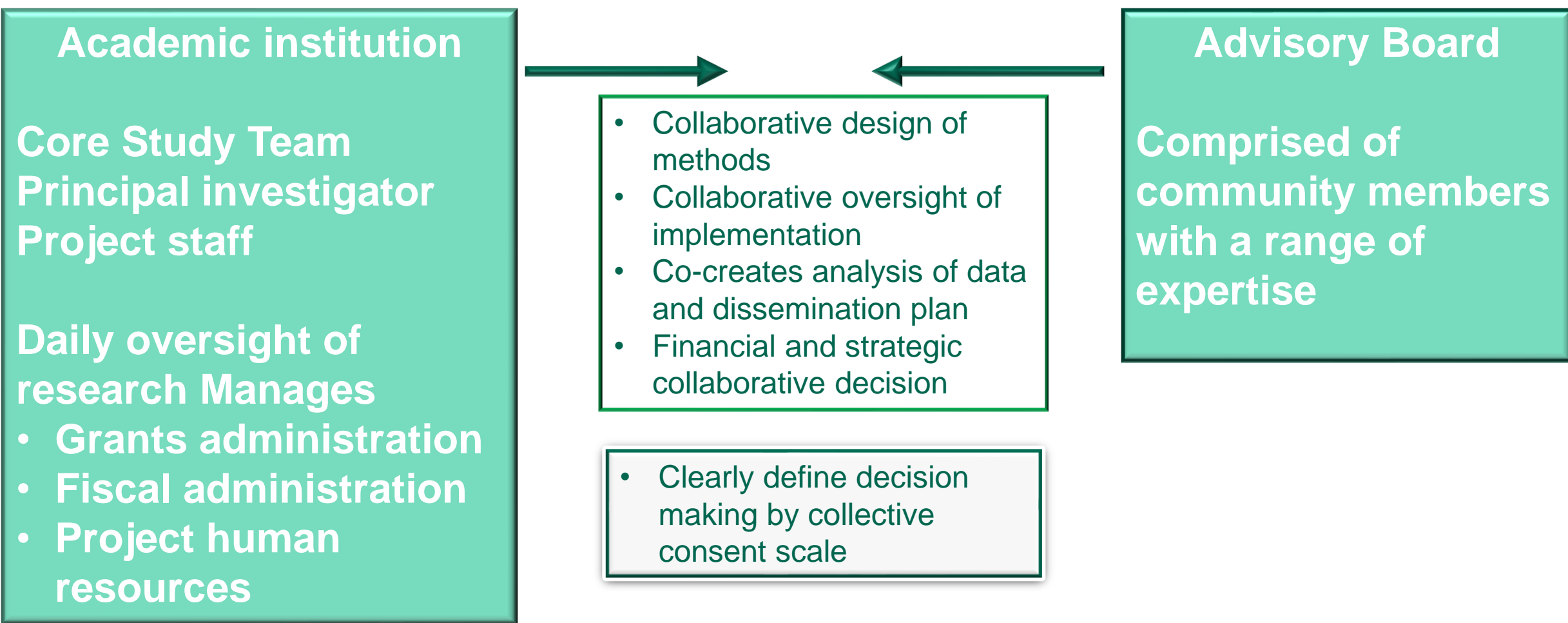
Core Study Team
Principal investigator
Project staff

Daily oversight of research Managers

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

Advisory Board

Comprised of community members with a range of expertise

- 
- 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

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

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

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

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



Dartmouth
Health

Perinatal Initiatives
POPULATION HEALTH

Thank you.

Any Questions?

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

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



PI: Paul J Barr PhD MScPH;

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Lead Scientist: Dr. Renata Yen

Patient Partner Representative: Sheri Piper

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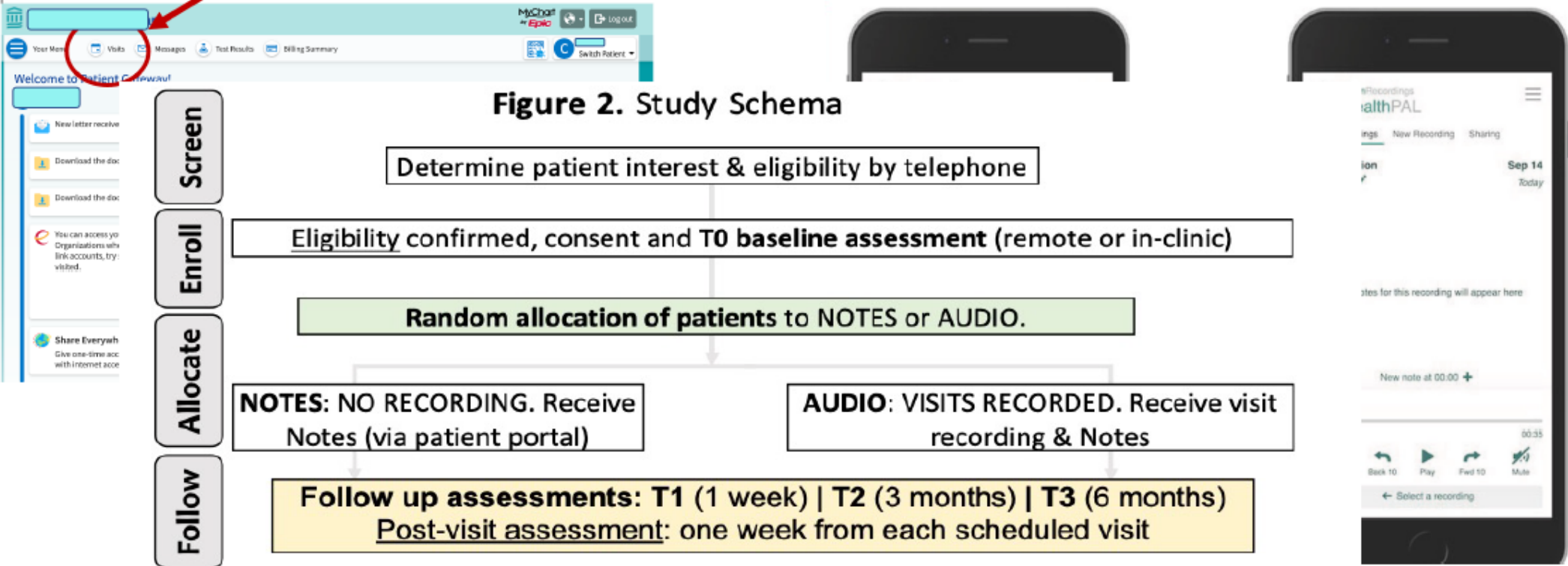
- Fill their medication
- Self-administer complex medicine regimens
- Arrange their appointments
- Pay their bills
- Inform their family of what happened in their clinic visit
- Use medical devices
- Train loved ones to assist, or use use medical devices
- Monitor their symptoms
- Report this all back to the clinician

All while older adults live with their medical conditions

OpenRecordings

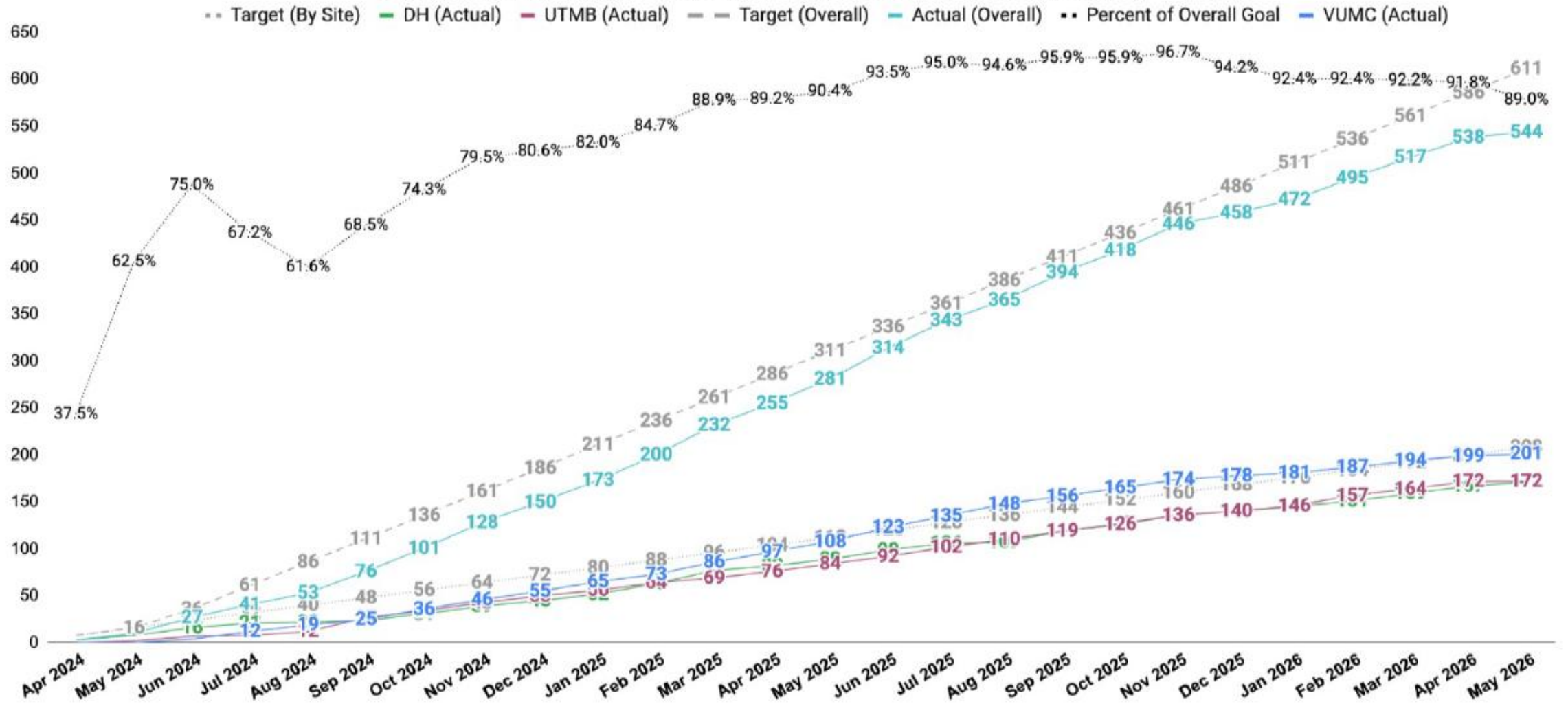


Up to 80% of visit information is forgotten



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

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Research Article

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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

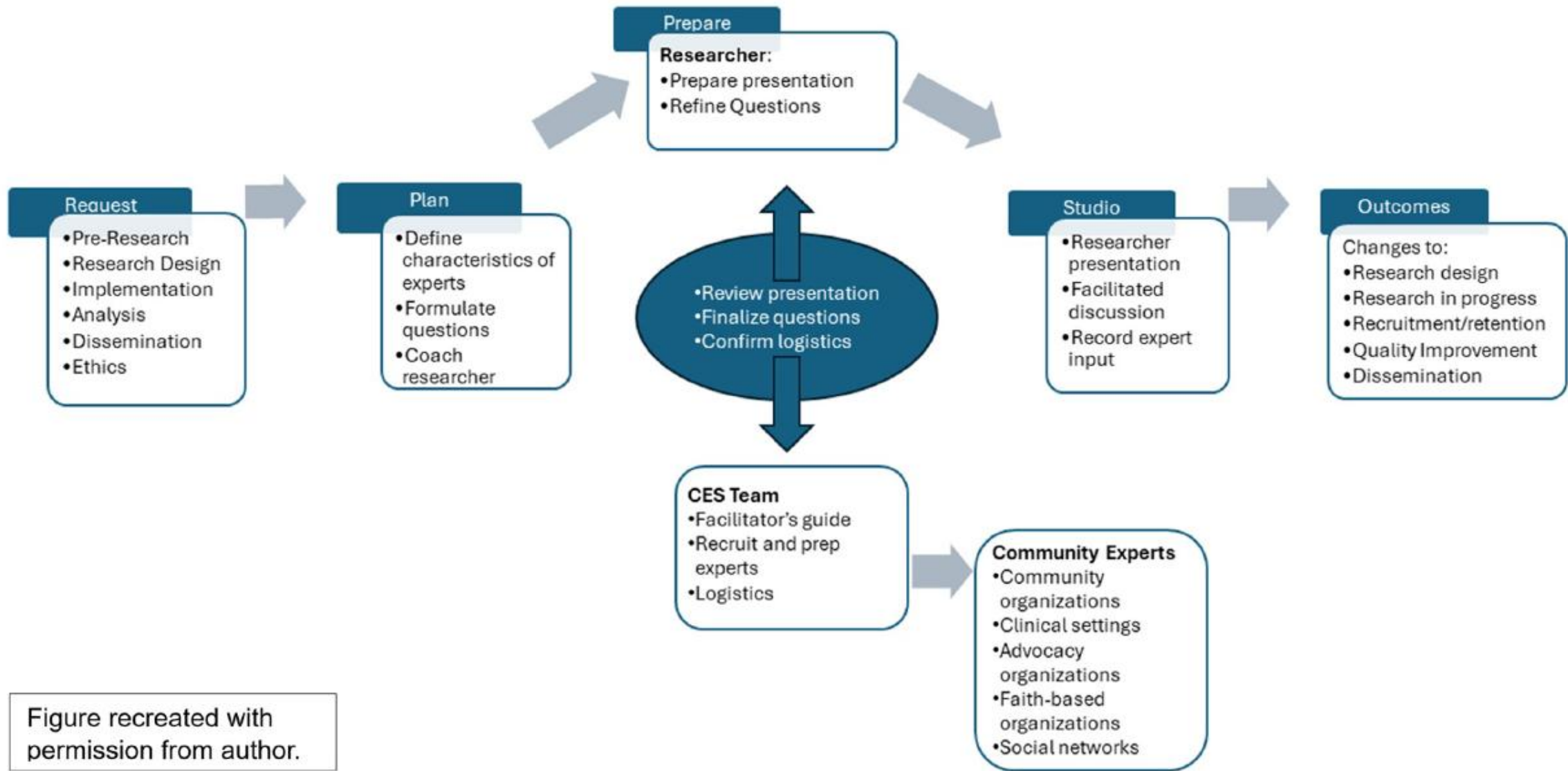
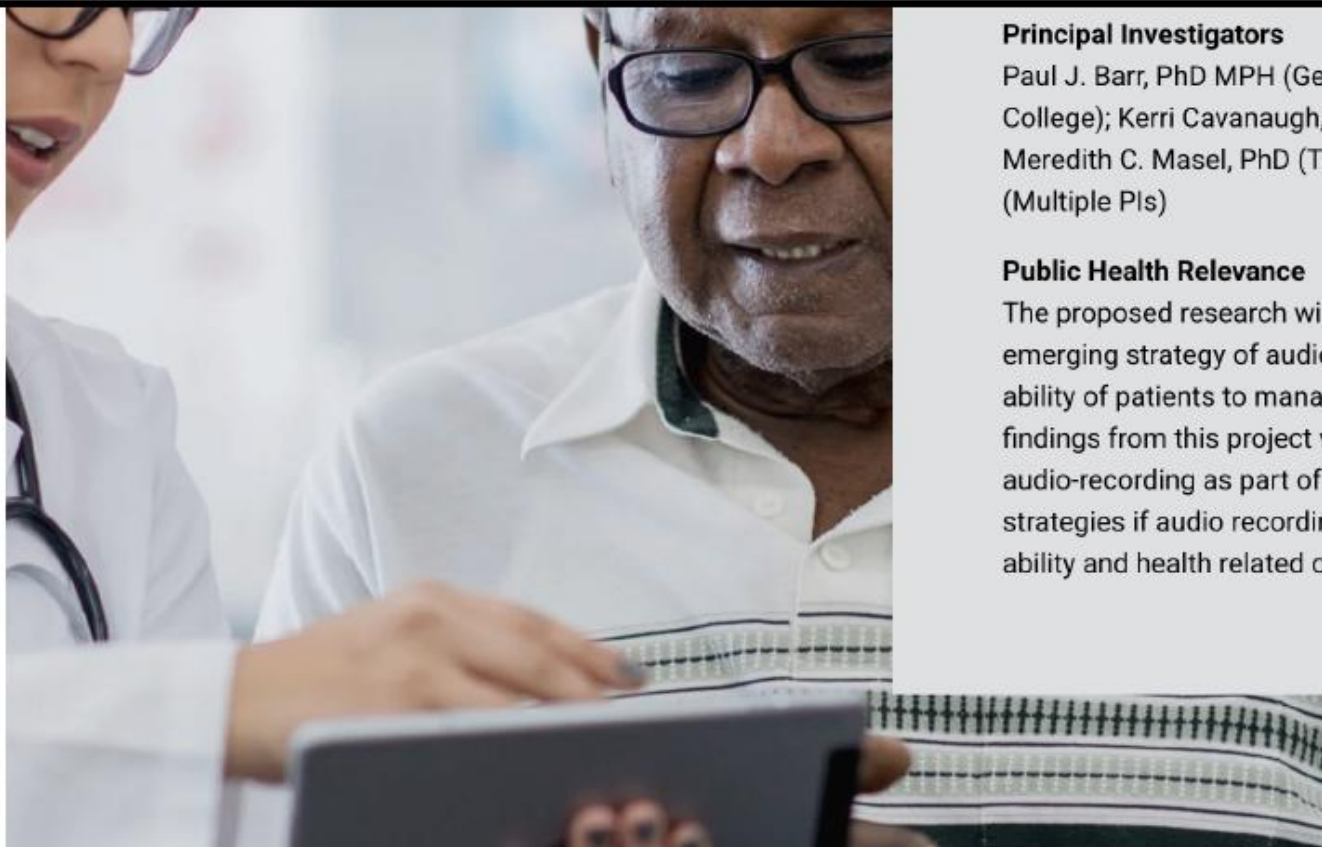


Figure recreated with permission from author.

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

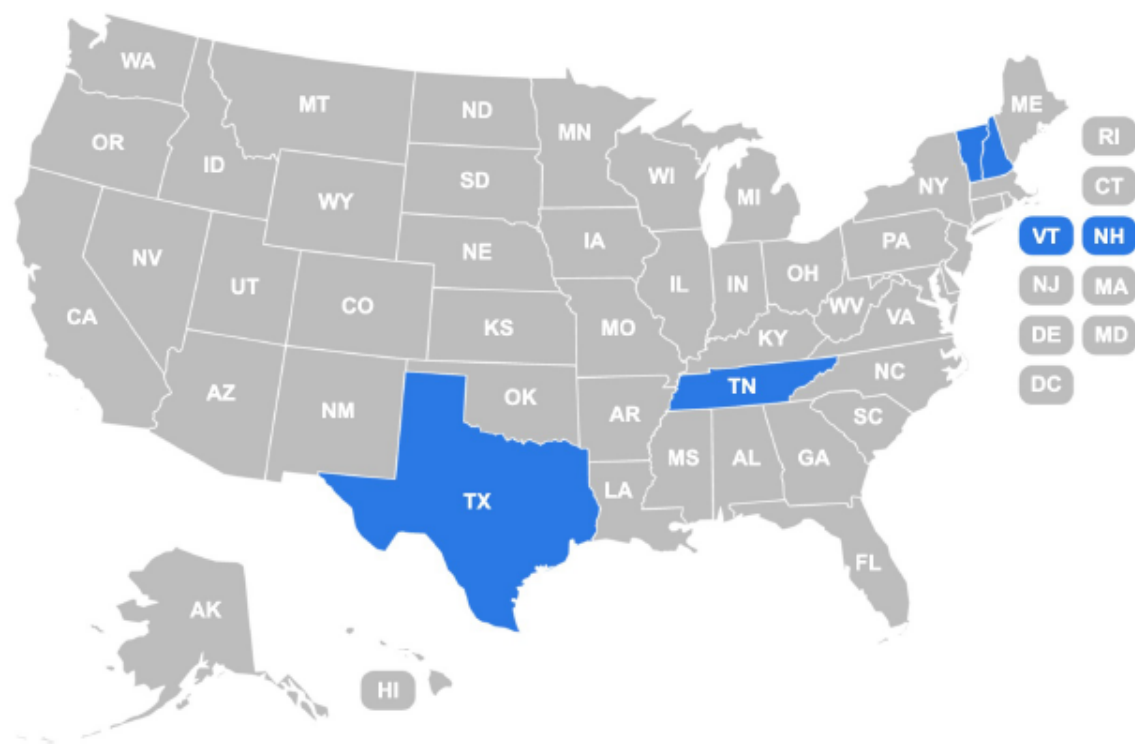
Project Period: 09/15/2019 - 5/31/2021

Other Project Staff

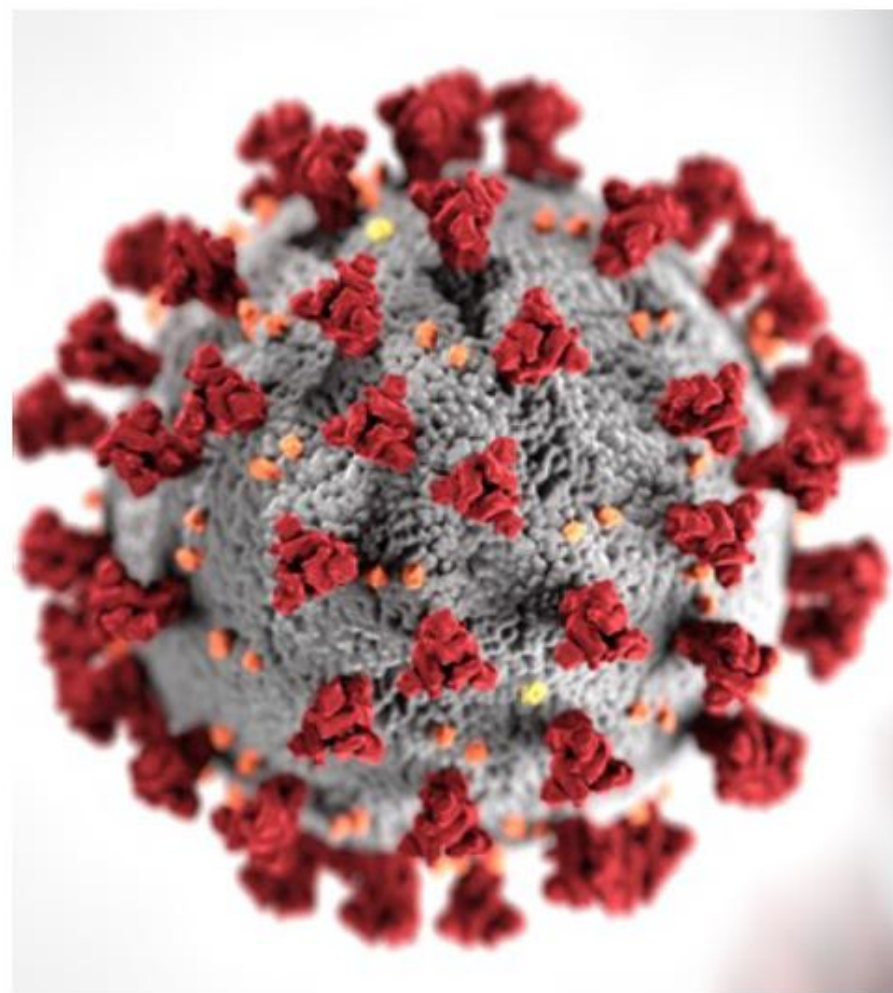
Dartmouth College: Martha Bruce, PhD; James O'Malley, PhD; Elizabeth Carpenter-Song, PhD; William Haslett, PhD; Michelle Dannenberg, MPH; Susan Tarczewski, CCRP; Reed Bratches, MPH, MALS; Jesse Schoonmaker, MD, MPH; Marielle Mugford, BS, CCRP; **Vanderbilt University Medical Center:** Sunil Kripalani, 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.



A B S T R A C T

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

Guest Editor
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: 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

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	<u>Dartmouth</u> : Mr. Arend, Mr. Kottkamp, Ms. Piper; <u>UTMB</u> : Mr. and Mrs. Gore, Mr. Oritz; <u>VUMC</u> : Dr. Reese
Clinician Partners	<u>Dartmouth</u> : Dr. Hong; <u>UTMB</u> : Dr. Gutierrez; <u>VUMC</u> : 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)



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.



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.



Engagement Rubric for Applicants

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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 CURES 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

- 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 cognitive 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

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

Practice Part 1: Recruitment Letter

Dear Mr./Ms. (Patient name),

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 [Insert 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.

The project involves:

- Completing surveys before your next visit to the clinic, 1 week after the clinic visit, 3 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 stored 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 \$50 for taking part in the project. *Up to could be \$1 - \$50 - 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 now at the time. [Your Coordinator Name] will give you a telephone call from a [Dartmouth, VUMC, UTMC] phone number in about two weeks to tell you more and test out if you want to take part in the project.

If you have no interest in taking part, you can email [your coordinator email] or call [your coordinator telephone]. *I did not respond, I would just wish. Thank 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, consider the statement.*

Thank you for trusting me with your care. *Too long overall! — use bullet points to shorten.*

[Division name] ** People are usually more concerned w/IT*

- 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

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

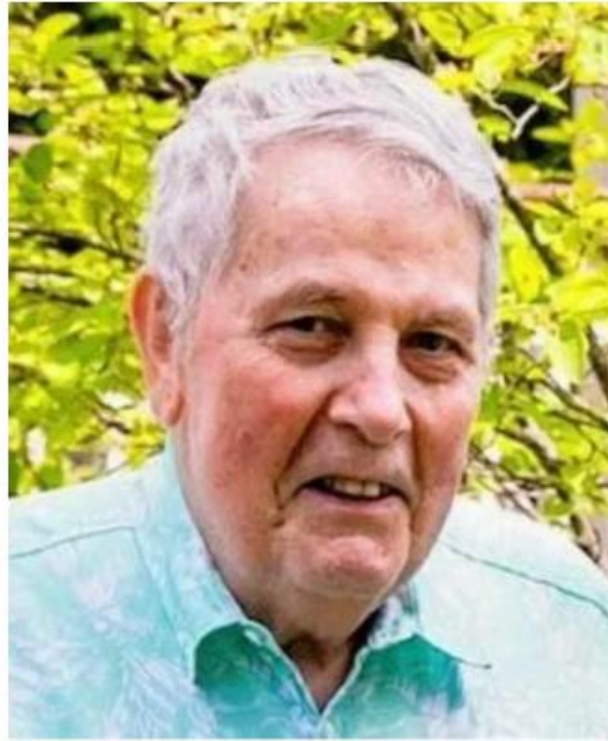


True engagement

OBITUARIES

Roger B. Arend

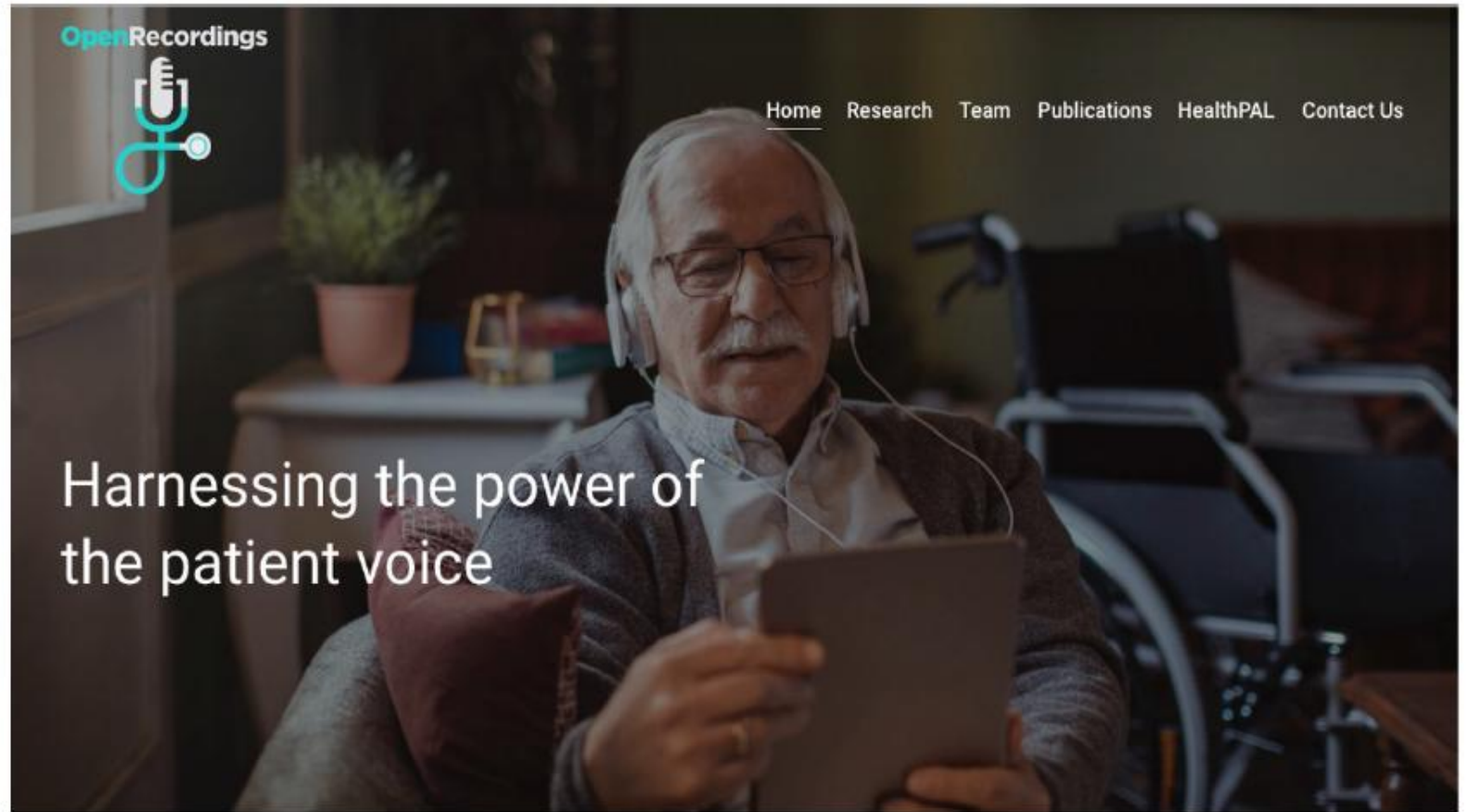
April 14, 2026



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.