



**Advance
Rhode Island**
Clinical & Translational Research

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Integrating Community Engagement Studio Sessions into Your Research

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My Background

Social epidemiologist

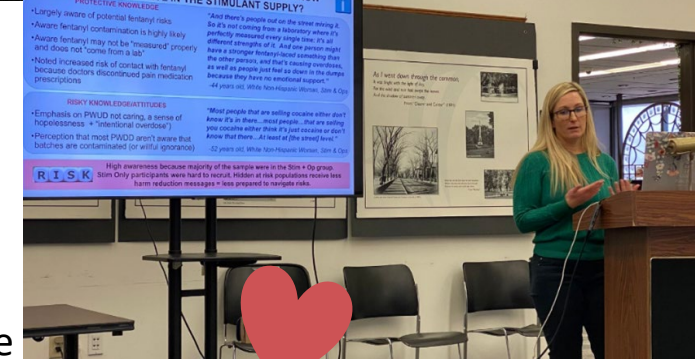
Conducts community-engaged, mixed-methods research that examines the:

- Individual, interpersonal, and structural drivers of health inequities, with a focus on the impact of stigma on the health of people who use drugs, sexual and gender minority populations, and people living with HIV
- Develops and tests multilevel interventions to prevent and treat overdose, substance use disorders, HIV, and poor mental health in diverse populations domestically and internationally

As an expert witness → uses community-engaged research findings to advance and uphold civil rights protections for marginalized communities



Scan to learn more about me



<https://vivo.brown.edu/display/jhughto>

Supports Rhode Island Clinical & Translational Research

Institutional Development Award for Clinical and Translational Research from the
National Institute of General Medical Sciences



Providence VA
Medical Center

MISSION

We support **Rhode Island investigators** through **funding, research resources + services,** and **professional development** offerings. Ultimately, we hope that these efforts **fuel discoveries** and **collaborations** that are **responsive** to the **health priorities** of our state's diverse communities



Our academic, hospital, and community partners make our work possible.

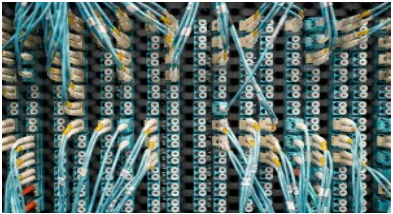
Service Offerings



Professional Development Core equips early-career researchers with the resources and training they need to build competitive research programs that improve the health of Rhode Island populations.



Pilot Projects Program funds investigators from institutions across the state to develop interdisciplinary collaborations and conduct research that spans the translational spectrum.



Biomedical Informatics Core works to transform Rhode Island's research capacity for big data health research infrastructure by enabling access to electronic health data through secure, inter-institutional infrastructure.



Biostatistics, Epidemiology, and Research Design Core provides quantitative, qualitative, and research design support to empower investigators to design, interpret, and publish impactful research.



Community Engagement & Outreach Core helps to facilitate research endeavors that are relevant, accessible, and impactful to communities across Rhode Island.

Investigators* affiliated with Brown University or the University of Rhode Island and our Community Advisory and Action Board or Practice-Based Research Network members are eligible to receive services

STUDIOS DEFINED:

What are Community Engagement Studios?

Facilitate a culturally appropriate, respectful conversation between community experts and a research team planning, carrying out, and/or disseminating information about a relevant investigation

Each Studio is ~90 minutes and may be conducted in-person (preferred) or virtually

Provide a cost-effective and time-efficient method to engage stakeholders to:

- Gain valuable feedback on a research concept or study design elements before spending valuable time and resources
- Prioritize research topics and approaches endorsed by the community
- Increase relevance of research to patients and communities
- Strengthen recruitment and retention efforts
- Increase dissemination reach and uptake of research results



STUDIOS DEFINED:

What are Community Engagement Studios?

A moderated group discussion between an Investigator and Community Experts to explore in-depth opinions and reactions on a particular topic

- **NOT research** → Institutional Review Board (IRB) approval is not required

Community experts possess first-hand knowledge of or lived experience with a particular condition or a community of interest

- Experts are consultants, not research subjects, and are compensated at a rate based on the local average value of volunteer time (e.g., \$50 an hour)



STUDIOS DEFINED: What are Community Engagement Studios?

Studios were originally developed by [Meharry-Vanderbilt Community Engaged Research Core](#) of the Vanderbilt Institute for Clinical and Translational Research



Advance RI-CTR Community Engagement & Outreach (CEO) Core Co-leads, Drs. Jackie White Hughto and Alison Tovar, adapted the Vanderbilt model to be investigator-led and lower-cost

This presentation describes the Advance RI-CTR CEO Core Studio model



STUDIOS DEFINED:

Why Are Studios Not Considered Research?

- Designed to inform the development, conduct, or dissemination of research
- Community experts are not research subjects → they are advisors or consultants
- *Typically* not audio recorded and never transcribed to minimize privacy concerns
- Use a notetaker as well as the notes written by the experts

In some cases, Studios can be audio recorded if the Investigator does not have someone who can serve as a notetaker, the topic is not sensitive, and all experts consent. The recording cannot be transcribed and can only be used for summarizing findings. It must be deleted after the findings are summarized. Please check with your institution's IRB to confirm whether a recording is allowable for your Studio topic and expert panel.

Direct quotes from community experts can never be used in grants, publications, or any other materials.

STUDIOS DEFINED:

At what stage should you conduct a Studio?

Can be **beneficial at ANY point in the research process** to gain a better understanding of community priorities or cultural norms, conceptualize a program or intervention, or get community feedback on research processes, surveys, or tools.

Investigators may conduct a Studio at any stage of their research:

- Planning (preferred): Idea generation; proposal, study design, intervention development or refinement, etc.
- Implementation: feedback on recruitment approaches and challenges; insights into the causes of retention issues, etc.
- Dissemination: member checking of results; insights on best ways to disseminate findings; feedback on adaptations/next steps for future research, etc.

Planning a Studio: Key Studio Components

Staffing:

- Coordination*
- Recruitment*
- Lead facilitator = the investigator*
- Co-facilitator
- Notetaker
 - Audio recording may be possible – check with IRB

Community Experts

- Aim to recruit at least 12 people to get 8 who attend
- Can run Studio with less than 8 people
- “Eligibility criteria” typically less rigid than study enrollment criteria
- Experts should not have a prior relationship with the investigator (e.g., current patient)

Resources

- Space to host studio*

Goal: Make the process as easy as possible to increase experts’ comfort and ability to participate

In-Person

- Community location preferred
- Requisite tech, seating, privacy, etc.
- Easy to find
- Provide day-of support

Virtual

- Experts are not centrally located (e.g., statewide or multi-state recruitment)
- Middle of workday and/or travel time not feasible
- Payments (cash preferred)*
- Food/meal (preferred)
- Parking vouchers

Planning a Studio

Studios typically cost ~\$1,500, but can range from \$600-2,000

Expert Compensation ~ \$600-1200*

- 8-12 experts X \$50/hr X 2 hours (budget for max hours; budget 2 hours, including mealtime, if in-person)
- *Cost-Saving Approach*: Enroll fewer experts; host virtually; limit all Studio activities to 90 minutes

Meals = \$0-300

- Up to 15 people (experts + staff) X \$20
- *Cost Saving Approach*: Host virtually; hold at time of day when a meal is not required; provide snacks; purchase food at grocery store instead of catering

Parking = \$0-450

- Up to 15 people (experts + staff) X \$30 for 2 hours
- *Cost-Saving Approach*: find a location with free parking or increase hourly compensation to account for parking or public transportation costs

Space = \$0-1,000

- Up to \$1,000 to host at a *community* location accessible to experts
- *Cost-Saving Approach*: Host at a free location at the Investigator's institution, host virtually

*Required element

Planning a Studio

~6-8 weeks are typically needed to plan a Studio

Investigators who are independently planning their Studio and have strong community relationships may need as little as two weeks.

Coordination:

- Determine location (in-person or virtual)
- Set date
- Determine staffing and roles
- Determine payment method
- Work with institution to determine and implement payment processes
- Check with IRB if interested in recording
- Create expert contact and consent form
- Create comment form (optional)
- Create evaluation survey (optional)

Recruitment:

- Determine the characteristics of the expert panel
- Devise recruitment approach
- Develop recruitment flyer (if applicable)
- Recruit and schedule experts
- Send a reminder call, text, email to experts the day before (and day of)
 - Ensure experts have necessary details, time, location, parking, etc.

Planning a Studio

- Investigators can create a structured comment form like this
- Alternatively, a notepad or paper should be provided to the experts; they should be encouraged to take notes during the presentation and discussion
- Notes and/or comment sheets should be collected at the end of the session

Planning a Studio: Facilitation Preparation

- The facilitator's job is to create a comfortable environment that allows for open and frank discussion and to guide the conversation.
- Facilitators should not interject their opinions or biases into the conversation.
- Ideally, the facilitator has prior experience working with groups of individuals representing a wide range of socioeconomic backgrounds and varied learning and communication styles.
- Consider bringing on a trained member of the team, a colleague, or external community members to co-facilitate (if resources allow).
- Investigators with limited experience should take advantage of available community-engaged research, Studio, and focus group facilitation trainings and/or consultation services to prepare them to create a comfortable and inclusive environment and guide the Studio discussion with experts.



Planning a Studio: Facilitation Preparation

- **Clarify** the focus of the Studio – *what do you hope to learn from the Studio?**
- **Develop** a brief presentation to orient experts to study (in layman’s terms)*
 - Print (if in person) or send (if virtual) presentation to experts so they can follow along and refer back to slides during the discussion
- **Formulate** the questions that will be posed to the experts*
 - Identify 2-3 big-picture questions to ask the experts
 - Consider creating a flexible “facilitator’s guide” with sub-questions and probes that the Investigator can reference during the Studio
- **Create** ground rules for participation (e.g., maintain respect and confidentiality for other experts, “step-up and step-back,” ask experts to identify other rules)*
 - Ground rules can be discussed at the beginning or end of the presentation before the discussion

Implementing a Studio

Pre-Facilitation:

- Arrive early to receive food and set up space (in person only)
- Greet experts as they arrive*
- Build rapport over meal (in person only)
- Experts complete contact and payment form*

What to bring:

- ✓ Sign-in sheet*
- ✓ Contact consent and payment form*
- ✓ Compensation (if cash or physical gift card)
- ✓ Comment forms or notepads*
- ✓ Expert and researcher evaluation forms
- ✓ Flip charts, markers
- ✓ Investigator presentation on jump drive or laptop*
- ✓ Laptop computer, projector, clicker if needed
- ✓ Copies of presentation and any other materials for expert review/discussion*

Facilitation:

- Facilitator welcome and introductions*
- Set ground rules*
- Facilitator presentation*
- Expert feedback and facilitated discussion*
- Wrap-up and review of next steps*

Post-Facilitation:

- Evaluation survey (optional)
- Payments* and parking (if applicable)

Follow-Up Activities:

- Write-up notes*
- Debrief with team
- Follow up with experts to share how their input shaped the research*

Translation & Dissemination of Studio Findings

Describing Studio findings in a grant or manuscript:

- Use notes to summarize findings and how the findings have/will be used to improve the research
- Typically, researchers describe the Studio process and the input they received
- Since the community experts are not research participants, researchers cannot:
 - Provide identifiable details of who participated or analyze their input by any demographics
 - Provide direct quotes from experts

We received detailed input from community experts to prepare us to implement a clinic-based intervention. A group of patients from the clinic where the intervention will be implemented was convened using a structured process called a Community Engagement Studio. Studios use best practices for community engagement to overcome barriers to engaging groups of stakeholders and facilitate meaningful input from community experts. From the Studio, we learned that patients thought the registration process was too long and that the experience with the interdisciplinary team was very important in determining whether they would return to the clinic. We used the input from the Studio to streamline our registration process and provide more opportunities for patients to engage with our interdisciplinary team. Overall, the input we received from patients was extremely helpful in understanding facilitators and barriers to utilizing clinic services. This information will help us to improve operations, which will aid in the recruitment and retention of patients for our planned clinic-based study.

Integrating a Studio into a Grant Proposal

Studios should be described in the section of the grant that pertains to the stage of research at which the Studios were or will be employed:

Completed Studios: Findings can be described in the formative research section



Proposed Studios: Intervention Development or Adaptation:

Typically, Studios are not listed as an overall Aim since they are not research. Instead, they are generally described as a sub-aim or part of the process of an aim (example):

Aim 1: Intervention Development. Aim 1a. Develop a preliminary intervention protocol informed by gender minority stress theory, the gender affirmation framework, and evidence-based cognitive behavioral clinical strategies. Aim 1b. Conduct Studio sessions with two expert panels comprised of community clinicians and transgender women to identify culturally relevant content and community-informed clinical strategies for incorporation into the intervention; iteratively refine the intervention protocol according to expert feedback.

Integrating a Studio into a Grant Proposal

Proposed Studios Continued....

Recruitment: If used to prepare for or refine recruitment approaches, the Studio process could be described in the recruitment section of the approach for a specific Aim

Dissemination: If used to aid in dissemination, the Studio process could be described at the end of the grant

Additional details about the Studio methodology can and should be included in the Human Subjects form (if the form is required)

Placement is up to the researcher

Be sure to **call attention to the Studio** process → it **adds value** to any grant application.



**New Grants
Funded in
2024**

Key Considerations:

Studios

VS.

Focus Groups

- **No IRB approval needed**
- **Shorter planning timeline**
- **Flexible → not restricted to IRB-approved questions or protocol**
- **No transcription or analysis costs**
- **Can readily integrate findings into grant proposal, manuscript**

- **Can only disseminate process and big-picture findings, but not identifiable data**
- **Cannot report detailed demographics of panel**
- **Cannot transcribe findings or use direct quotes in research**

- **IRB approval required**
- **Longer timeline required for IRB approval**
- **Need to adhere to protocol and facilitation guide**
- **Added costs for transcription and staffing to code and analyze data**

- **Documentation of rich data in the form of audio recordings and transcripts**
- **Can supplement with survey and report on detailed demographics of panel**
- **Expert quotes can be used and integrated into grants, manuscripts, and other formats**

Advance RI-CTR Coordinated Studios

Advance RI-CTR is only able to fund, coordinate, and co-facilitate a limited number of Studios per grant year (August to July)

- Eligibility: RI-based investigators with faculty appointments at Brown or URI, members of our Community Action and Advisory Board (CAAB), and members of our Community Engaged Practice-Based Research Network (CEPBRN) are eligible to apply for a coordinated Studio
- Eligible researchers who are currently or were recently funded by Advance RI-CTR, those who received a letter of support from Advance RI-CTR to conduct a Studio using external funding, and members of our CAAB and CEPBRN are prioritized for the funded/coordinated Studio sessions
- [Eligible investigators](#) and CAAB and CEPBRN members can request a consultation with the Community Engagement and Outreach Core to receive guidance or support on how to conduct a Studio
- [Eligible investigators](#) and affiliates can request a consultation with the [Biostatistics, Epidemiology, and Research Design Core](#) to receive guidance on how to facilitate a Studio or focus group (guide development, facilitation training)
- Anyone can visit the [Advance RI-CTR website](#) to access our recorded trainings and resources
- Sign up for our [newsletter](#) to learn about upcoming trainings and resources

Studio Resources

Learn more about the original Vanderbilt Studio model and access useful resources:

Joosten YA, Israel TL, Williams NA, Boone LR, Schlundt DG, Mouton CP, Dittus RS, Bernard GR, Wilkins CH. Community Engagement Studios: A Structured Approach to Obtaining Meaningful Input From Stakeholders to Inform Research. Acad Med. 2015 Dec;90(12):1646-50. doi: [10.1097/ACM.0000000000000794](https://doi.org/10.1097/ACM.0000000000000794).

Israel T, Farrow H, Joosten Y, Vaughn Y. Community Engagement Studio Toolkit 2.0. Meharry-Vanderbilt Community Engaged Research Core Vanderbilt Institute for Clinical and Translational Research Sponsor Award No: 3-UL1-RR025747-02S1, UL1 RR024975 and UL1-TR000445. https://www.meharry-vanderbilt.org/sites/vumc.org.meharry-vanderbilt/files/public_files/CESToolkit%202.0.pdf

Examples of published Studio findings:

Quinn ED, Cotter K, Kurin K, Brown K. Conducting a Community Engagement Studio to adapt enhanced milieu teaching. Am J Speech Lang Pathol. 2022 May 10;31(3):1095-1113. doi: [10.1044/2021_AJSLP-21-00100](https://doi.org/10.1044/2021_AJSLP-21-00100)

Nielson C, Huang Y, Kull CA, Park AH. Utilizing Community Engagement Studios to inform patient experience in a multicenter randomized control trial. Int J Pediatr Otorhinolaryngol. 2020 Jun;133:110007. doi: [10.1016/j.ijporl.2020.110007](https://doi.org/10.1016/j.ijporl.2020.110007)

Stock MR, Ceide ME, Lounsbury DW, Zwerling J. Utilizing community engagement studios to inform clinical trial design at a Center of Excellence for Alzheimer's Disease. J Clin Transl Sci. 2022 Apr 11;6(1):e73. doi: [10.1017/cts.2022.388](https://doi.org/10.1017/cts.2022.388).

ANY
QUESTIONS?



Feedback
Survey

https://brown.co1.qualtrics.com/jfe/form/SV_bDyAq2KEI8zNBoq

Keep In Touch!

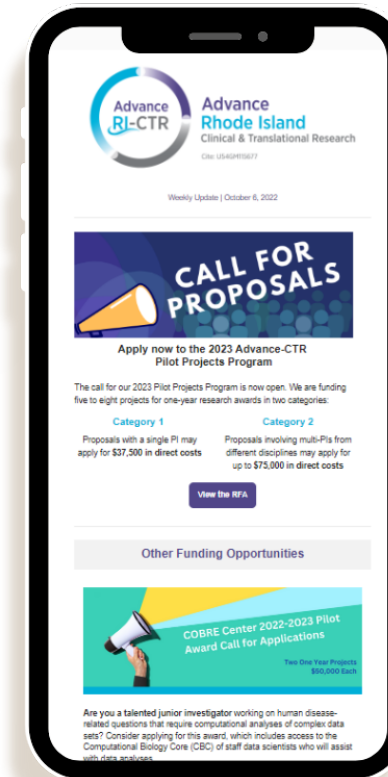
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Thank you!

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SUPPLEMENTARY TABLE