

# Introduction to Community Engagement Studios: Strategies & Lessons Learned for Eliciting Community Input for Research



**Dara Sorkin, PhD**

Professor, Depts. of Medicine and Public Health  
Community Engagement Unit Director

UCI Institute for Clinical and  
Translational Science



**Robynn Zender, MS**

Community Health Research Manager

UCI Institute for Clinical and  
Translational Science



**Adrijana Gombosev, MS**

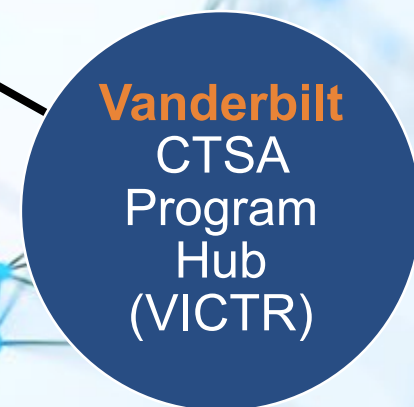
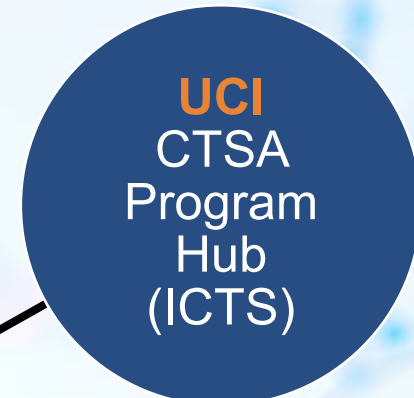
Project Development Manager

UCI Institute for Clinical and  
Translational Science

# Role of NCATS

## National Center for Advancing Translational Sciences (NCATS)

- One of the 27 Institutes and Centers at NIH
- Clinical and Translational Science Award (CTSA) = Program Hub
- >50 medical research institutions across the nation receive CTSA Program funding
- Goal of CTSA Program Hubs = “**More treatments for all people, more quickly**” – Dr. Joni Ritter, Director, NCATS



Ref: <https://ncats.nih.gov/ctsa/about/hubs>

# Community Engagement (CE) Studio History

## Vanderbilt Institute for Clinical and Translational Research (VICTR)

- VICTR Community Engagement team developed Community Engagement Studios (CE Studios)
- VICTR CE team came to UCI ICTS in 2017 to train 22 attendees from 13 CTSA hubs across the US
- VICTR has several publications on CE Studios
  - [PubMed Publications](#)
- PCORI virtual 2-day training in 2021



**Yvonne A Joosten**  
Executive Director, Office for  
Community Engagement, VICTR



**Tiffany L Israel**  
Translational Research  
Coordinator, VICTR



**Consuelo H. Wilkins, MD, MSCI**  
Associate Director, VICTR

# Why We Value CE Studios Here at UCI

## Changed as a result of the CE studio:

- Recruitment/retention strategies
- Research question
- Research design
- Level of community/patient engagement in research activities
- Modified the consent process
- Data collection
- Included more patient-centered questions

## Researcher's view of how CE Studio Experts contributed to their research project:

- Increased their understanding of the community
- Provided ideas on recruiting research participants
- Provided feedback on the feasibility of the project
- Increased their sensitivity to the community
- Provided ideas on how to use results of the project to benefit the community



# Some CE Studios at UCI and Their Impact

Project Title/Topic	CES Impact
Increasing medication adherence through group medical visits	<ul style="list-style-type: none"><li>➤ Modified the definition of a key study outcome variable</li><li>➤ Tailored the intervention and recruitment plan</li><li>➤ "The CES was critical to the success of our project and very competently executed. Simultaneous interpretation improves accessibility of the discussion."</li></ul>
Natural History Study of Inclusion Body Myositis	<ul style="list-style-type: none"><li>➤ Received grant</li><li>➤ "It gave us new perspective in terms of what questions we would want to ask. We included materials on pain and sleep. It was very well received by grant reviewers who specially called out the fact that we did CES in the pink sheet."</li></ul>
Project REACH (Revamping Exercise Assessments in Child Health): Cystic Fibrosis	<p>Things implemented from the studio:</p> <ul style="list-style-type: none"><li>➤ provide study data on child's results to parents</li><li>➤ providing a 1-page fact sheet using bullets for parents to consider during recruitment</li><li>➤ coordinate medical with research visits for participants traveling from a distance</li><li>➤ timing visits so they don't interfere with school</li><li>➤ introduce the study as a wholesome approach to CF treatment</li></ul>

# So let's get started....

# Community Engagement Studios Explained

## What is a CE Studio?

Provides a framework for stakeholders to give immediate feedback to researchers on specific areas of concern before a research project is implemented, or to assist a struggling project.

## Why do a CE Studio?

The CE Studio provides a structured forum to gain valuable patient or community insight.

## Isn't this just a focus group?

No, the main difference is that participants are not part of research but rather inform research.

# Benefits of a CE Studio

- Improve: Quality, relevance, and feasibility of research
  - Recruitment and retention
  - Grant proposals
  - Researchers understanding of, and sensitivity to, the community
- Enhance public participation in research
- Simplify community engagement for researchers
- Transform how community and academic researchers work together



# CE Studio in Context

## Community Engagement Studio vs Focus Group vs Community Advisory Board\*

- Studio vs. FG vs. CAB
- Neutral (3rd party) facilitator
- Flexible discussion guide
- No IRB required

	Community Engagement Studio	Focus Group	Community Advisory Board
<b>Purpose</b>	Project-specific feedback/ guidance to inform research at any stage	Qualitative data collection	On-going guidance, oversight for research project or center
<b>Approach</b>	Bi-directional: researcher presents, community members provide input	Uni-directional: researcher directs, community answers pre-determined questions	Bi-directional: presentations, progress reporting and updates; discussion
<b>Community Role</b>	Consultant. Share expertise based on "lived experience"	Research "subjects"; consented for study. Inclusion/exclusion criteria	Provide oversight, advice
<b>Facilitator</b>	Neutral; trained community member; balances power	Member of research team	Researcher and/or community member
<b>Preparation</b>	Orientation; may pre-review research documents	Usually none	May review documents ahead of time.
<b>Framework</b>	Flexible facilitator guide	IRB-approved script	Agenda
<b>Commitment</b>	Community members could participate in multiple studios	One-time only	On-going; could be for the life of a project

\*Source: Community Engagement (CE) Studio Virtual Training Summit Post-Summit Deliverables, PCORI training, April 29-30, 2021

<https://www.pcori.org/research-results/2020/community-engagement-studio-summit-increasing-diversity-stakeholders-engaged-research>


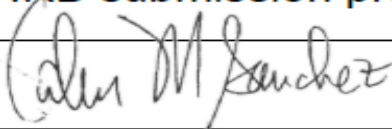


# Resources Required for CE Studio Program

	Resources dedicated to our CE Studio program
<b>Personnel requirements</b>	<ul style="list-style-type: none"><li>▪ 2 mid-level administrators (master's level) @ 4-8 hours/week<ul style="list-style-type: none"><li>- 4-5 CE Studios per year</li></ul></li><li>▪ With additional entry level support (college degree) @ 8-10 hours/week<ul style="list-style-type: none"><li>- 8 CE Studios per year</li></ul></li></ul>
<b>Time required requirements</b>	<p>30-48 hours per studio, depending on variables:</p> <ul style="list-style-type: none"><li>▪ recruitment efforts required</li><li>▪ in-person vs. virtual</li><li>▪ organizing childcare or simultaneous translation</li><li>▪ identifying appropriate location for meeting with appropriate resources</li><li>▪ identifying an appropriate facilitator</li></ul>

# CE Studio IRB

➤ No IRB required → IRB exempt

3. D  T u n q C b		
	Lead Researcher's Signature	Date <u>5-7-2020</u>
	Faculty Sponsor's Signature (if applicable)	Date _____
<b>SECTION 8: UCI DETERMINATION OF HUMAN SUBJECTS RESEARCH</b> <b>FOR HRP STAFF AND IRB ONLY</b> – researchers do not complete this section.		
<input checked="" type="checkbox"/> The proposed activity as described <b>DOES NOT</b> constitute human subjects research. IRB review is not required. This determination only applies to the activities described in this request. If there are any changes that may alter this determination the investigator may request another written determination.		
<input type="checkbox"/> The proposed activity as described <b>constitutes human subjects research</b> . Submission of an IRB Application <b>IS REQUIRED</b> . IRB Approval must be obtained before the research can begin. Please complete and submit an IRB Application with the appropriate protocol narrative. <b>All forms are available on the Applications &amp; Forms web page under IRB forms</b> . If you have questions or needs additional guidance on the IRB submission process, please contact HRP staff for guidance at <a href="mailto:irb@research.uci.edu">irb@research.uci.edu</a> .		
		Date <u>5-8-20</u>
	HRP Staff or IRB Chair	Date

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project

# Pros and Cons: In-person CE Studios

## Pros

- Allows for deeper connection and discussions
- Opportunity for water-cooler conversations
- Better buy-in for Studio
- Dinner!!
- Completion of all evaluation and feedback surveys immediately
- Provide gift cards immediately
- Easier facilitation
- Allows for simultaneous translation

## Cons

- More difficult for experts to fit into their calendar (travel, childcare, other obligations)
- Longer meeting (2-hour), requires travel to and from site
- More expensive to host (dinner, may require childcare, reimbursement of travel/parking costs, rental of meeting location, cleaning fees, live translator fees)
- Harder to get rural experts to participate
- More complicated logistics for CE Studio team

# Pros and Cons: Virtual CE Studios

## Pros

- Easier to schedule
- Less expensive
- Broadens recruitment area
- Great for when in person is not possible
- Great for rare disease studios
- Easier for those with physical disabilities

## Cons

- More difficult to have smooth and natural conversation
- Do not have control over experts turning on cameras
- Hard to weed out false experts
- Facilitator has less control over the virtual room
- Smaller group of experts
- Requires follow up to compensate experts and get evaluations completed
- May be harder for some populations who do not have resources or competencies

# The Anatomy of a CE Studio

What we will cover today.

Advertising CE Studios

Initial meeting with research team

Identifying facilitator

Recruiting community experts

Before the Studio

During the Studio

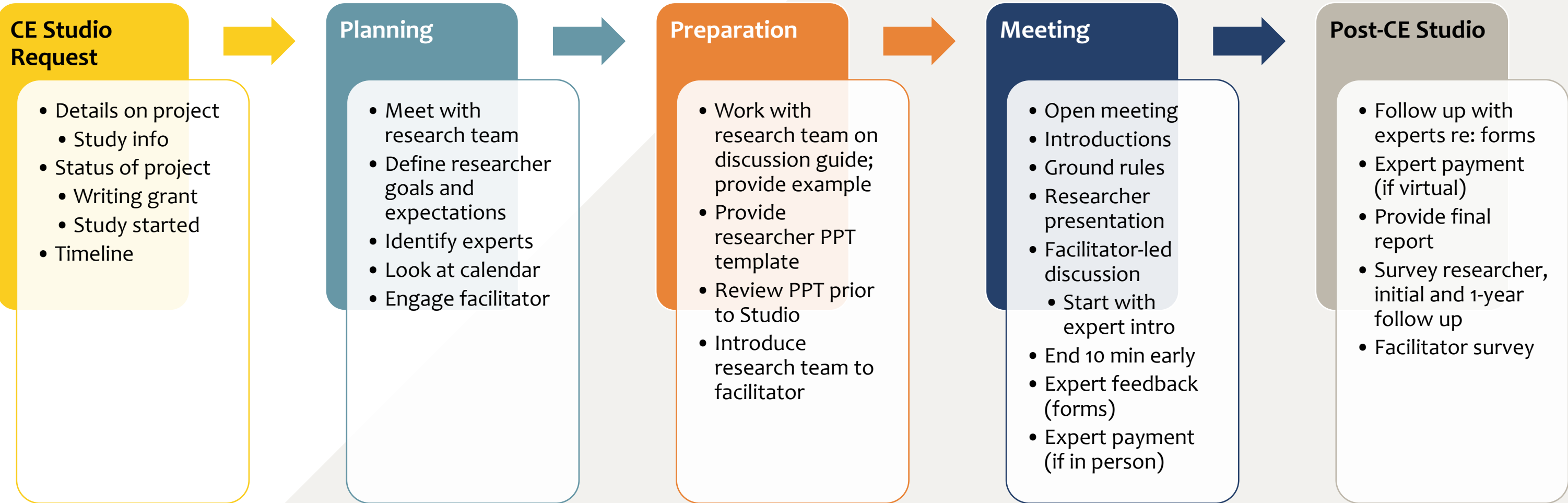
After the Studio

Resources



# CE Studio Steps

From CE Studio request to report.



Adapted from Vanderbilt graphic

# Advertising

How researchers can find out about CE Studios.

Call for Applications

Institution-wide announcement

Application link on CTSA hub website

Word of mouth

## Community Engagement Studio Award

### Call for Applications

#### Purpose

To provide investigators with a 1-time service that elicits input from community members to inform research development and execution for a specific project. This award does not confer actual dollars to the awardee, but rather provides a service valued at \$2,500.



### CE Studio Request

To submit your application, please complete the fields below.

#### Abstract

Please provide a 250-word abstract noting the study aims and the problem the research will address

\* must provide value

Expand

What purpose would the CE Studio serve for you? (check all that apply):

\* must provide value

- Grant proposal or protocol development
- Study design
- Recruitment and/or retention
- Materials review (e.g. recruitment materials, study documents or protocols)
- Dissemination of study results

## Community Engagement Studio



Community input can increase the quality and relevance of research, improve recruitment and retention for clinical trials, and inform community engagement sections for grant proposals, but enhancing public participation is one of the central challenges facing clinical research activities today. Engaging community members, patients, caregivers, community health providers, advocates and policy makers in research is complex. Many researchers are not equipped to identify, recruit, convene, and engage these stakeholders, or prepare them for participation in research in an advisory capacity. The CE Studio provides a framework for stakeholders to give immediate feedback to researchers on specific areas of concern before a research project is implemented, or to assist a struggling project.

# Meet with Research Team

- Initial meeting with the research team
  - Introduce CES and team
  - Review research project expectations
  - Identify who the experts should be
  - Limit the number of meetings with the research team
- CE Studio checklist



## UCI ICTS Community Engagement Studio Preparation Checklist

### CES PREPARATION

- Schedule planning meeting with researcher, and CE Studio team (facilitator, community navigator and faculty member). Identify main themes for discussion guide.
- Identify community members for the expert panel that fit researcher's request.
- Provide orientation to community experts who have not previously participated in a CE Studio.
- Determine availability of all parties starting with the community experts. CE Studios are often held in the evenings and/or on the weekends to accommodate work schedules and other commitments.
- Secure a location that is convenient to the stakeholders who will be in attendance.
- Follow up with the researcher/research team to review the presentation for clear and concise language and images that will be easy for non-researchers to understand. Make recommendations for improvement if needed. Request the final version prior to the CE Studio.
- Confirm time and location with community experts and if necessary, mail or email any materials that need to be reviewed in advance
- Copy complete set of forms needed. Include any materials that will be reviewed by Experts, brochures, posters, etc.
- Arrange for food and drink to be on location.
- Buy gift cards for Experts (\$50 Amazon/Target) and Facilitator (\$200 Visa).
- Confirm AV set up at location (projector, laptop, HDMI cables, adaptors, WiFi).

### THE MEETING

- Welcome and Dinner
- When the group is seated, the navigator or facilitator welcomes everyone and asks them to introduce themselves.
- Community Navigator sets the context by giving a brief overview of the purpose of the meeting and gives instructions on the forms provided to each participant (comment



# Items to Provide to Research Team

After the first meeting.

- Slides template
- Discussion Guide example
- Budget template

## Cost of Organizing CE Studios

	# of Hours	# of Staff Needed	Total Hours
<b>Staffing Costs (\$80/hr)</b>			
Location ID + confirmation*	5	1	5
Experts ID + recruitment	10	1	10
Actual meeting (CES)	2	3	6
Investigator preparation	3	1	3
Facilitator ID + preparation	4	2	8
Translator schedule/preparation*	1	1	1
Meeting preparation--scripts, flyers, gift cards	3	2	6
Compensation tracking	2	1	2
Post-meeting reporting	2	2	4
<b>Total Hrs</b>			<b>45</b>

<b>Total Hrs</b>			<b>44-48</b>
<b>Total \$\$</b>			<b>\$3,080 - \$3,360</b>

<b>Meeting Costs</b>			
Food*			\$270
Gift cards (\$50/expert, \$200/facilitator)			\$800
Facility fee*			\$300
Child care*			\$100
On-site translation*			\$150
Materials translation*			\$150
<b>Total \$\$</b>			<b>\$800 - \$1,770</b>
<b>Grand Total</b>			<b>\$4,000 - \$5,130</b>

\*optional, depending on need for translation, child care, or in-person vs. virtual

# Facilitators

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Facilitator role

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Good facilitation practices

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Facilitator experience

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Facilitator training

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Compensating facilitators

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Where to find good facilitators

## Facilitator role in Community Engagement Studios

In general, the role of the facilitator is to:

- Set a friendly and comfortable tone.
- Create an open environment in which people feel comfortable to express their perspectives.
- Greet each member and develop rapport; encourage cross communication with the

# Community Experts

- What is a community expert?
- What makes a great community expert?
- Recruiting community experts
  - Flyers
  - Recruitment scripts (phone, email)
  - Framing the language
  - Obtain availability for multiple dates/times
- Number of experts per studio
  - In-person studio: 10-12 (over-recruit: 15 total)
  - Virtual studio: 6-8 (over-recruit: 10 total)

## Where we recruit from:

- Community organizations
- Local or national organizations
- Researchers
- Schools
- Previous CE Studio participants
- Consent-to-contact (C2C) registry
- Our own CE Studio registry
- CTSA-based CAB

# Before CE Studio Meeting Activities

Getting everyone ready for the CE Studio.



Facilitator and research team meet prior to studio



Vet potential community experts 1:1, train on using Zoom/directions for in-person



Have Experts complete Bio page prior to CE Studio; confirm availability as date gets closer—send reminders about the meeting



Provide list of experts to facilitator to help facilitator keep track of participants names and comments during the meeting

# The Actual CE Studio

## Logistics of Virtual CE Studio.



Zoom with a waiting room



Message experts in waiting room



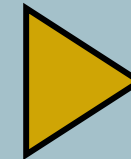
Make all coordinators hosts



Start on time



Don't forget to record for note-taking purposes



Coordinator introduces meeting



Cameras off for coordinators



Researcher gives presentation

# The Actual CE Studio

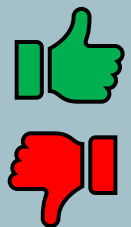
Logistics of Virtual CE Studio.



Facilitator takes over discussion



End meeting 10 minutes early to complete evaluations



Ensure evaluations are complete before sending gift cards via email



Survey links to research team and facilitator



10-minute debrief with team

# The Actual CE Studio

Logistics of In-Person CE Studio.



Ensure room has projector



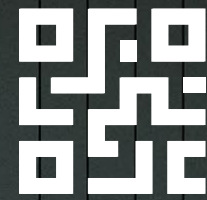
Provide dinner



Accessibility for all attending  
(e.g., elevator)



Research team stays in room (not  
part of discussion, but there for  
study-related questions)



Complete evaluation surveys (QR  
code and printed)



End discussion 10 minutes before  
end time to allow Experts to  
complete 2 surveys and receive  
compensation before they leave

# Post-CE Studio

What happens after the CE Studio.



CE Studio team follows up with Experts, facilitator, and researcher to ensure they complete surveys and receive compensation



CE Studio team completes PowerPoint report within 2-3 weeks for research team



CE Studio team invoices research team for actual expenditures



1-Year Follow Up Surveys with research teams to determine impact of CE Studio



# CE Studio Final Report

## What goes into the report?

1. PDF of PowerPoint
2. Summary of experts present → de-identified
3. Headers focusing on key topics/concepts
4. Highlight certain questions/issues that were raised by experts
5. Quotes from experts that resonated
6. Recommendations from experts
7. Verbatim language from comment forms
8. Overall takeaways

# Lessons Learned

## What we learned at the UCI ICTS.

1. One studio per research project
2. CE Studios are not research
3. Minimum 3 weeks to organize CE Studio
4. Recruitment done by CE Studio staff
5. Minimum of 10 experts required to schedule a virtual studio; and 15 for in-person
6. Cost for CE Studio is typically around \$5,000



### Community Engagement Studios Information and Policies

The Community Engagement Studio (CE Studio) is a one-time meeting for researchers interested in getting feedback and guidance about their research from patients, providers, or others in the community. Reactions to various aspects include the study design, strategies, disseminating information. CE Studios are facilitated in an environment where community members can share their ideas.

The Vanderbilt Institute for Research Core develops researchers work directly with the community. It is culturally sensitive and the Vanderbilt team has trained Translational Science Award institutions, including navigating

The CE Studio provides immediate feedback to researchers as their research is implemented, or to assist a researcher's population (e.g., organizations, etc.) serve as experts. Community input recruitment and retention for grant proposals, but especially facing clinical research at

The CE Studio can be a valuable experience for researchers at any stage in the research process. Faculty, post-docs, fellows, and graduate students who are interested in receiving feedback from their population of interest on the relevance and feasibility of their research ideas have reported positive impacts on their projects and proposals. The CE Studio provides a structured forum to gain valuable patient or community insight and has the potential to transform the way community and academic researchers work together.

We try to limit the amount of effort needed from the PI to have a studio. On average the PI's time commitment is ~5 hours/studio.

#### Process

1. Request CE Studio: <https://ci-redcap.hs.uci.edu/surveys/?s=PEH9XLL8F4>
2. ICTS staff will reach out to schedule a meeting with the PI and study team
3. PI to complete presentation PowerPoint following the provided template. This presentation will be reviewed by the ICTS staff to offer any suggestions for making it more understandable for a community audience, and often to suggest the addition of graphics and images in lieu of wordy explanations.
4. Study team works with ICTS staff to create a discussion guide, which the facilitator will use during the CE Studio discussion
5. ICTS staff works on setting up a location (if not virtual), identifying a facilitator, and recruiting experts to be part of the studio
6. After the completion of the studio, ICTS staff create a final report to be shared with the PI and study team (~2-3 weeks post studio) laying out key points that were discussed and providing takeaways from the studio.

#### Regulations for the CE Studios

1. We offer one CE Studio per project (needed in another language).
2. Since CE Studios are not conducted during the studio is not inform an existing or potential community member approval and use focus groups for the purview of the CE Studio model by your own team. The ICTS team focus groups underway, but cannot
3. The minimum turn-around time to schedule a CE Studio is three (3) weeks, with more time needed depending on the population of experts, location, or other variables.
4. Recruitment for each studio is done by ICTS staff, however the PI is welcome and encouraged to provide us with a list of names for us to contact.
5. A minimum of 8 experts are required to schedule a studio so that at least 5 participants are available for the discussion when that time arrives.
6. Please contact us to request a cost estimate specific to your project. On average the studios run ~\$5,000/studio, this includes payments for experts, facilitator, and hours spent by ICTS staff.

# PCORI-funded CE Studio Training Summit

Vanderbilt University CTSA-led training, partnered with the University of Utah, University of Michigan Ann-Arbor, and Meharry Medical College.

- For more information and training, please visit the PCORI-funded CE Studio training [webpage](#)
- ~8 hours of recorded training (click on below images for recordings)

[Virtual Training Summit PDF](#)



Day 1 | Community Engagement (CE) Studio Virtual Training Summit



Day 2 | Community Engagement (CE) Studio Virtual Training Summit

# Open Q&A

[Link to presentation resources](#)



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*Thank  
You*

## Contacts

- Adrijana Gombosev: [agombose@hs.uci.edu](mailto:agombose@hs.uci.edu)
- Robynn Zender: [rzender@hs.uci.edu](mailto:rzender@hs.uci.edu)