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

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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
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

<table>
<thead>
<tr>
<th>Project Title/Topic</th>
<th>CES Impact</th>
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</thead>
</table>
| Increasing medication adherence through group medical visits | ➢ Modified the definition of a key study outcome variable  
➢ Tailored the intervention and recruitment plan  
➢ "The CES was critical to the success of our project and very competently executed. Simultaneous interpretation improves accessibility of the discussion.” |
| Natural History Study of Inclusion Body Myositis | ➢ Received grant  
➢ “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.” |
| Project REACH (Revamping Exercise Assessments in Child Health): Cystic Fibrosis | Things implemented from the studio:  
➢ provide study data on child's results to parents  
➢ providing a 1-page fact sheet using bullets for parents to consider during recruitment  
➢ coordinate medical with research visits for participants traveling from a distance  
➢ timing visits so they don't interfere with school  
➢ introduce the study as a wholesome approach to CF treatment |
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

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

| Community Engagement Studio vs Focus Group vs Community Advisory Board* |
|--------------------------------------------------|------------------------|---------------------|
| **Purpose**                                      | Community Engagement Studio          | Focus Group                  | Community Advisory Board |
|                                                  | Project-specific feedback/guidance to inform research at any stage | Qualitative data collection | On-going guidance, oversight for research project or center |
| **Approach**                                     | 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 |
| **Community Role**                               | Consultant. Share expertise based on “lived experience” | Research “subjects”; consented for study. Inclusion/exclusion criteria | Provide oversight, advice |
| **Facilitator**                                  | Neutral; trained community member; balances power | Member of research team | Researcher and/or community member |
| **Preparation**                                  | Orientation; may pre-review research documents | Usually none | May review documents ahead of time. |
| **Framework**                                    | Flexible facilitator guide | IRB-approved script | Agenda |
| **Commitment**                                   | 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*

## Resources Required for CE Studio Program

<table>
<thead>
<tr>
<th>Resources dedicated to our CE Studio program</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personnel requirements</strong></td>
</tr>
<tr>
<td>▪ 2 mid-level administrators (master’s level) @ 4-8 hours/week</td>
</tr>
<tr>
<td>- 4-5 CE Studios per year</td>
</tr>
<tr>
<td>▪ With additional entry level support (college degree) @ 8-10 hours/week</td>
</tr>
<tr>
<td>- 8 CE Studios per year</td>
</tr>
<tr>
<td><strong>Time required requirements</strong></td>
</tr>
<tr>
<td>30-48 hours per studio, depending on variables:</td>
</tr>
<tr>
<td>▪ recruitment efforts required</td>
</tr>
<tr>
<td>▪ in-person vs. virtual</td>
</tr>
<tr>
<td>▪ organizing childcare or simultaneous translation</td>
</tr>
<tr>
<td>▪ identifying appropriate location for meeting with appropriate resources</td>
</tr>
<tr>
<td>▪ identifying an appropriate facilitator</td>
</tr>
</tbody>
</table>
CE Studio IRB

➢ No IRB required ➔ IRB exempt
# 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.

**CE Studio Request**
- Details on project
- Study info
- Status of project
- Writing grant
- Study started
- Timeline

**Planning**
- Meet with research team
- Define researcher goals and expectations
- Identify experts
- Look at calendar
- Engage facilitator

**Preparation**
- Work with research team on discussion guide; provide example
- Provide researcher PPT template
- Review PPT prior to Studio
- Introduce research team to facilitator

**Meeting**
- Open meeting
- Introductions
- Ground rules
- Researcher presentation
- Facilitator-led discussion
- Start with expert intro
- End 10 min early
- Expert feedback (forms)
- Expert payment (if in person)

**Post-CE Studio**
- Follow up with experts re: forms
- Expert payment (if virtual)
- Provide final report
- Survey researcher, initial and 1-year follow up
- Facilitator survey

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
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 stakeholder 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.
Items to Provide to Research Team
After the first meeting.

- Slides template
- Discussion Guide example
- Budget template

<table>
<thead>
<tr>
<th>Items to Provide to Research Team</th>
<th>Description</th>
<th># of Hours</th>
<th># of Staff Needed</th>
<th>Total Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slides template</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion Guide example</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Budget template</td>
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<td></td>
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</tbody>
</table>

Cost of Organizing CE Studios

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

<table>
<thead>
<tr>
<th>Total Hrs</th>
<th>44-48</th>
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</thead>
<tbody>
<tr>
<td>Total $$</td>
<td>$3,080 - $3,360</td>
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</table>

Meeting Costs

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food*</td>
<td>$270</td>
</tr>
<tr>
<td>Gift cards ($50/expert, $200/facilitator)</td>
<td>$800</td>
</tr>
<tr>
<td>Facility fee*</td>
<td>$300</td>
</tr>
<tr>
<td>Child care*</td>
<td>$100</td>
</tr>
<tr>
<td>On-site translation*</td>
<td>$150</td>
</tr>
<tr>
<td>Materials translation*</td>
<td>$150</td>
</tr>
</tbody>
</table>

Total $$  $800 - $1,770

Grand Total $$  $4,000 - $5,130

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

Facilitator role

Good facilitation practices

Facilitator experience

Facilitator training

Compensating facilitators

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.
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
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)
Contacts

• Adrijana Gombosev: agombose@hs.uci.edu
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