

# Community Engagement Studios: Community and Patient Stakeholder Engagement

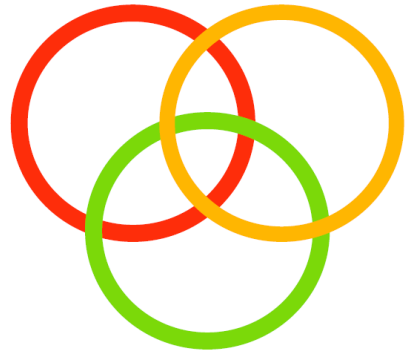
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# In acknowledgement and awe



## Community Engagement Studio Toolkit

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For more information, go to

<https://victr.vanderbilt.edu/pub/community/>  
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# Why do we need mechanisms like the Community Engagement Studio?

- ▶ Community input increases quality and relevance of research, but increasing public participation can sometimes be HARD
- ▶ Engaging stakeholders (e.g., community members, patients, community health and social service providers) in research can be complex and contingent on skills that the average investigator may not possess
- ▶ Many researchers are not prepared to identify, recruit, convene, and engage stakeholders
- ▶ It IS important to do so since it not only improves the research conducted but also increases community trust



# Purpose of the Community Engagement Studio (CE Studio)

- ▶ Guidance for researchers interested in getting feedback from stakeholders or on working in a community setting
- ▶ Community “experts” provide feedback on various aspects of a proposed or on-going research project including:
  - ▶ Study design
  - ▶ Intervention
  - ▶ Communication
  - ▶ Materials
  - ▶ Participant recruitment strategies
  - ▶ Sharing learning with the community
  - ▶ Applying research findings to practice
  - ▶ Many other contributions!!!



# Community Experts

- ▶ Individual who has lived experience or possesses first-hand knowledge of a particular community or health issue
  - ▶ Our experience is that sometimes the patient knows more about the disease and potential treatments (including non-medical approaches) than some medical experts
- ▶ A Community Expert has:
  - ▶ Interest in research
  - ▶ An ability to provide constructive criticism and be a voice for his or her community (share their experience, perspective, and thoughts)



# Benefit of CE Studio for Science

- ▶ CE Studios help assure that research meets the needs of people who are intended to benefit from the work
- ▶ Studios provide direct guidance of research by:
  - ▶ Cultivating research based upon a deeper understanding of patients' and communities' experiences
  - ▶ Increasing culturally appropriate methods
  - ▶ Increasing researcher understanding of and sensitivity to the patients and communities they are interested in
  - ▶ Strengthening academic-community partnerships (often improving long-term relationships)
  - ▶ Helping to assess the relevance, feasibility and appropriateness of research activities





# Benefit of the CE Studio for the Researcher

- ▶ Access to community experts from different settings without complexity of multiple meetings
- ▶ Immediate feedback on issues at different stages of project development and implementation
- ▶ Opportunity to build relationships with community partners and deepen understanding of the population (e.g., community's cultural nuances and historical issues)
- ▶ Assessment of feasibility and appropriateness of project
- ▶ Buy-in from key stakeholders
- ▶ Can lead to a more participatory approach to work
- ▶ Can validate the importance of their work (especially with junior investigators, it can be important to put a face to the science)



# CE Studio vs. Focus Group

- ▶ Community Engagement Studios are NOT intended as research
- ▶ IRB approval is NOT needed to conduct a CE Studio as the stakeholders are not research subjects but expert consultants
- ▶ Focus groups are conducted with the use of an explicit interview guide. While there are 2-3 main topics that will be discussed during a CE Studio, the discussion is not limited to specific questions. Issues that may not have been identified prior to the meeting, may turn out to be the most insightful.
- ▶ In a focus group, the emphasis is on the subjective experiences of the group while CE Studios are used to dig deeper into the individual's experience.
- ▶ CE Studios and its experts are focused on the single thing they share in common, thus the conversation is on what is most helpful to the researcher and his/her project.





## WHAT IS THE DIFFERENCE BETWEEN A COMMUNITY ENGAGEMENT STUDIO AND A FOCUS GROUP?

Purpose	Inform development, implementation or dissemination of research	Qualitative data collection
Approach	Bi-directional discussion	Uni-directional
Participants	Consultants Identified as experts based on lived experience	Research subjects Screened, consented
Facilitator	Neutral – could be community member Not affiliated with research project Uses techniques to balance power Uses guide for conversation: can diverge if relevant	Research team member Uses pre-approved script: cannot diverge
Preparation	Coaching for research team Orientation for community experts	IRB approval Consenting of research subjects
Compensation	Consulting fee	Participant incentive
Use of input	Participant comments and recommendation summarized CE Studio Team may help researcher interpret and apply recommendations	Participant comments transcribed Transcription qualitatively analyzed



# How Much Time does a CE Studio Require?

- ▶ A researcher/team can expect to spend less approximately 5 hours preparing for and participating in the CE Studio
  - ▶ Submitting initial request
  - ▶ Brief planning meeting with CE Studio Team (~1 hour)
  - ▶ Brief planning meeting with facilitator (~1 hour)
  - ▶ Preparing quick overview presentation on study/topic area (30 minutes - 1 hour)
  - ▶ 2 hours - CE Studio session
  - ▶ Fill out evaluation



# How does it work?

- ▶ Studio will take place in a community setting, during convenient hours (no more than two hours)
- ▶ 6-10 Community Experts participate
- ▶ 1-2 members of the research team attend
- ▶ Moderated by an experienced facilitator
- ▶ Researcher presents a brief overview of his or her project and poses specific questions to community experts, e.g.,
  - ▶ What barriers might exist for you or people you know to participate in this study?
  - ▶ What would be some effective ways to share what we learn from this study in your community?
- ▶ Facilitator leads and moderates the discussion
- ▶ At closing Community Experts will be asked to complete a brief comment and evaluation form that will be included with feedback to the researcher



# CE Studio Team

- ▶ Team includes a faculty researcher, staff to coordinate planning and logistics and a skilled, neutral facilitator.
- ▶ Team members must be knowledgeable about the research process and have experience engaging and maintaining relationships with diverse communities.
- ▶ May be helpful to hire a Community Navigator, responsible for:
  - ▶ Running planning meeting with researcher/research team
  - ▶ Identifying and preparing community experts
  - ▶ Managing logistics, e.g., ensuring appropriate documentation is completed for each CE Studio and processing forms for payments (e.g., external consultant form and the IRS W9)
  - ▶ Capturing community expert feedback from each session and the completion of evaluation surveys



# What if I were identified as an expert? How would I prepare?

- ▶ Complete an “application” (Bio Form) to join our list of Community Experts and indicate topics in which you may have experience or expertise.
- ▶ If applicable and available, background material on the research project or research topic might be provided to you in advance, so that you could read about the research project before the CE Studio. This is not always the case.
- ▶ If so, you may want to review and write down any thoughts in advance, so that they could be easily used during the CE Studio
- ▶ There is no need for additional preparation. You are matched to a specific CE Studio because of your particular experience, background or knowledge – you are already an expert!





# CE Studio Exercise

- ▶ Please break into small groups of 8 - 10
- ▶ Please select a scribe from your group
- ▶ Consider the following questions from an upcoming Studio as if you were a Community Expert (you are!):

In relation to Cancer Screening & Prevention:

- ▶ What content/various types of information might community members want or be receptive to?
- ▶ What might be preferred dissemination best practices?
- ▶ What are other barriers to access and/or receiving information?
- ▶ What are potential influences on the patient experience? The provider? Caregivers?





# Wrap Up

## Thank you!

Please feel free to reach out to us  
with questions or further discussion.  
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