Community Engagement Studio Toolkit 2.0

Tiffany Israel MSSW
Vanderbilt University Medical Center
Helena Farrow MPS
Nashville OIC
Yvonne Joosten MPH
Vanderbilt University Medical Center
Yolanda Vaughn MS
Neighborhoods Resource Center

Community Engagement Studio Toolkit

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1) Introduction and Acknowledgements

After participating in a Community Engagement Studio (CE Studio), researchers often remark that they wished they had done so earlier in the development of their research. The input they receive from patient or community stakeholders proves invaluable and in retrospect could have saved them a lot of time and effort in planning their research, in building community partnerships and in recruiting participants into their study. It is our hope that with the help of the Community Engagement Studio, researchers will come to view community input as essential to the planning, implementation and dissemination of their work.

Community members too value the opportunity not only to learn about research and how it can benefit themselves, their families, or their community, but also to contribute to its development and execution in a way that increases the researchers understanding of, and sensitivity to the community. As one of our community experts remarked:

> *"The Community Engagement Studio presents a unique opportunity to tap into the wisdom of community members. It empowers community members to contribute to the process of research in ways we have not seen before. We have only begun to see the benefits to both researchers and the community."*
> *Rev. Neely Williams, Community Partners Network*

We are grateful to our community collaborators at the Neighborhoods Resource Center and Nashville OIC who helped us develop and refine the Community Engagement Studio model; and to the many patients and community members who have served as experts, making each Community Engagement Studio a valuable learning experience.

2) Overview of a Community Engagement Studio

The Meharry-Vanderbilt Community Engaged Research Core (CERC) is a program of the Vanderbilt Institute for Clinical and Translational Research (VICTR), and a shared resource for academic researchers, research trainees, research staff, students and community organizations. CERC's mission is to bring together academic researchers and community members to improve community health and healthcare through community-engaged research. The Community Engagement Studio is one of the unique services developed by CERC to further this mission.

Community input can increase the quality and relevance of research, but enhancing public participation is one of the central challenges facing clinical research activities today (1). Engaging community members, patients, caregivers, community health providers, advocates and policy makers in research is complex. Many researchers are not prepared to identify, recruit, convene and engage these stakeholders or prepare them for participation in research in an advisory capacity or as part of a research team. The CE Studio creates a framework for stakeholders to provide immediate feedback to the researcher on specific areas of concern before the research project is implemented.

Recognizing the limitations of traditional approaches to population health and health disparities research, CERC's Community Advisory Council and community partners challenged us to develop new models for community engagement. Building on VICTR's Translation Studio model (2) for strengthening research proposals, the CE Studio was developed to help researchers interested in working directly with patients and other community stakeholders do so in a way that is culturally sensitive and in keeping with community priorities, values and needs.

The CE Studio can be a valuable experience for researchers at any stage in their career. Faculty, post-docs, fellows and graduate students and undergrads who are interested in receiving feedback from their population of interest on the relevance and feasibility of their research ideas have reported a positive impact on their projects and proposals. It 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. In a CE Studio, members of the researcher's population of interest (i.e., patients, caregivers, providers, community organizations, etc.) serve in a consultative role. Throughout this document, we will refer to them as **community experts**.

The researcher gives a brief presentation about his or her project and poses specific questions to the community experts. The discussion that follows is guided by a neutral facilitator to elicit authentic and constructive feedback. Advance preparation by the researcher and community experts is essential to success. Feedback from researchers and community experts who have participated in past CE Studios indicates that the experience increases the researcher's understanding of, and sensitivity to the community, and creates an awareness of community

(1) Michener L, Cook J, Ahmed SM, Yonas MA, Coyne-Beasley T, Aguilar-Gaxiola S. Aligning the Goals of Community-Engaged Research: Why and How Academic Health Centers Can Successfully Engage With Communities to Improve Health. Acad Med. 2012;87:285-91 10.1097/ACM.0b013e3182441680.
(2) Pulley JM, Bernard GR. Proven processes: The Vanderbilt Institute for clinical and translational research. Clin Transl Sci. 2009;2:180-2.

priorities, values and needs. Participating in a CE Studio often prompts researchers to reflect on the significance and impact of their work. Community experts have indicated that the experience increases their understanding of the research endeavor, including the motivation of the researchers and how and why research is conducted (3).

HOW COMMUNITY MEMBERS CAN IMPACT RESEARCH
• Prioritize research topics • Increase relevance to patients and communities • Strengthen recruitment and retention efforts • Increase dissemination and uptake of research results

If conducted during the earliest stages of project development, a CE Studio can be an effective tool to develop a strong partnership with community partners. For researchers who are not familiar with community engagement, it can open the door to a more participatory approach to their work.

Researchers from a variety of disciplines can benefit from participating in the Community Engagement Studio process. CE Studios have addressed issues of participant compensation, the culturally appropriateness of recruitment materials, participant retention strategies, simplifying the consent process and identifying entry points for community-based recruitment, design, ethical considerations and translation of research findings into practice.

"Just having the opportunity to refine the research approach before submission is critical to not only a favorable review but successful implementation when funded."

Researcher

(3) 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;90(12):1646-50 PMCID: PMC4654264. doi:10.1097/ACM.0000000000000794. PMID: 26107879.

The CE Studio is a consultative model and a quick way for researchers to get community or patient input on the development, implementation or dissemination of a research project. It is **not** a standing advisory board, a tool for recruiting research participants, or a data collection or research methodology such as a focus group.

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

The Community Engagement Studio Team

The CE Studio is implemented by a team that includes a faculty researcher, staff to coordinate planning and logistics and a skilled, neutral facilitator. The team members must be knowledgeable about the research process and have experience engaging and maintaining relationships with diverse communities.

Community Navigator

The navigator's responsibilities include running the planning meeting with the researcher/research team, identifying and preparing the community experts, managing logistics, and following up on any resulting actions and recommendations. The navigator is also responsible for making sure the appropriate documentation is completed for each CE Studio including capturing the community expert feedback from each session and the completion of evaluation surveys, and forms needed to process payments (e.g., external consultant form and the IRS W9). CERC uses a Community Navigator in this role (see Appendix A for Community Navigator Job Description).

The Community Navigator

- Is a boundary spanner – with experience working in the community, and familiar with academic research
- Has experience working in diverse communities
- Has demonstrated a capacity to build rapport and trusting relationships with key community leaders.

Hiring from the community puts into practice fundamental principles of community engagement such as mutual benefit, respect and community capacity building. A respected community member is likely to have access to networks unfamiliar to someone who works in an academic setting. Likely Community Navigator candidates include social workers, community organizers and community health workers.

Facilitator

The facilitator's job is to create a neutral environment that allows for open and frank discussion and guide the conversation between the researcher and community experts. A skilled facilitator does not interject his or her opinions or biases into the conversation. The facilitator should have experience working with diverse populations and possess the ability to balance the power difference that naturally occurs when researchers and lay community members come together. Ideally, the facilitator has received relevant training that prepares them to work with groups of individuals representing a wide range of social-economic backgrounds and have varied learning and communication styles.

While individuals can receive formal certification as a facilitator, it is not necessary to be an effective one. Individuals who are most successful in CE facilitation have been trained in the principles of community organizing and incorporate a participatory approach into their style of facilitation. Ideally, the CE facilitator brings to the table a perspective of how a stakeholder's perspective has been shaped by their experience in a environment where faith, class and race play an important part of who we are and how we see the world.

Key Facilitator Tasks:

- Explain discussion ground rules (e.g., be concise, don't interrupt, stay on track, and maintain confidentiality).
- Listen carefully to the presentation and comments, as a way to keep the discussion on track.
- Use the predefined questions as the discussion framework.
- Watch the clock: 1 1/2 -2 hours maximum.
- Politely move things along if someone is talking too much.
- In some cases, you will recognize that more needs to be said. Use probes and follow up questions when needed.
- Ask for examples when comments are unclear.
- Be comfortable with silence as people consider their answers.
- Guide the discussion without interjecting your own opinion and personal observations.

"Being a good facilitator is both a skill and an art. It is a skill in that people can learn certain techniques and can improve their ability with practice. It is an art in that some people just have more of a knack for it than others."
-Community Toolbox

<u>Faculty</u>

The role of the faculty member of the team is to provide guidance on identifying the population of interest, defining the questions that will be posed to the experts, coaching the researchers on communicating effectively with non-researchers and implementing recommendations from the community experts. The CE Studio team faculty must have experience in patient-centered outcomes, community-engagement, comparative effectiveness and community-based participatory research.

3) The Researcher

Clinical and translational researchers at any level or discipline may find the CE Studio to be beneficial. Those who are inexperienced in patient or community engagement or unfamiliar with the CE Studio will often have questions about the process. An FAQ (Appendix B) is available to answer many of these questions.

Preparing for the CE Studio usually requires a face-to-face meeting with the researcher or the research team. In the meeting, the CE Studio Team (community navigator, faculty and facilitator) will explain how the CE Studio works, and what to expect. The Team provides a presentation template, helps the researcher clarify the questions that will be posed to the expert panel, and discusses potential probing and follow-up questions for the facilitator to use to engage panelists. They will define the characteristics of the stakeholders needed for the expert panel, and suggest potential times and locations for the studio to accommodate the needs of the stakeholders. Prior to the CE Studio, the team will review the researcher's presentation, making suggestions so that the language and images are appropriate for non-researchers. The team will also coach them on communicating effectively with the expert panel. The second meeting is also an opportunity to finalize logistics and share information about the stakeholders who will be serving on the expert panel. The team will also share a draft of a CE Studio facilitation guide that will outline the key questions and prompters for the meeting.

To help narrow the focus of the CE Studio and to identify the specific group of experts for the panel, the navigator should be sure to discuss key areas of the project/proposal.

- What if any challenges are you anticipating? (Recruitment, retention, invasiveness)
- Is there a particular demographic that you feel will be more difficult to engage? (Age, ethnicity, class)
- What parts of the study do you anticipate to being the most arduous? (Consenting, duration)

In preparing the presentation, the researcher must remember community experts need to know:
- What the researcher is trying to find out, and why it is important.
- How the planned research might impact people who would serve as research subjects
- What kind of advice the researcher needs.

Effective Communication with Non-Researchers

The CE Studio gives researchers the opportunity to describe their work to a non-research audience. While a researcher's skillset generally includes communicating effectively with fellow researchers in classrooms, grand rounds, conferences and other academic venues, many are not prepared to communicate their ideas to non-researchers. Furthermore, they are accustomed to assuming the role of the expert. Coaching from the CE Studio Team can help them get the most out of this opportunity. The main opportunities to coach the researcher include the planning meeting, preparation of their presentation and feedback on the slides they plan to use for the meeting with stakeholders.

Here are the key concepts to convey when coaching researchers:
- The community experts, while not trained in research are the experts in the room.
- After making their presentation, the researcher's role is primarily to listen, asking and answering questions for clarification.
- Researchers often use a language that non-researchers may find difficult to understand so jargon, technical terms and acronyms should be explained clearly or avoided altogether.

The Researcher's Presentation

Preparation: The presentation must be brief – 10 to 15 minutes at the most. It can be difficult to explain research concepts and procedures in plain language, so it is important that the researcher devote adequate time to prepare. It is not appropriate to use a presentation that was previously prepared for an academic audience. Language taken from a research proposal or academic summary will probably need to be translated, replacing scientific jargon and acronyms with plain language. Keep text to a minimum and avoid complex tables, formulas and

diagrams. The researcher should share the presentation with the CE Studio Team in advance so they can recommend changes to improve clarity as needed.

Presentation Template <u>(See Appendix C for sample)</u>
PowerPoint is a favored method of presentation among researchers. This format can be effective in a CE Studio, particularly if images or diagrams are used.   However, PowerPoint slides, particularly those with a lot of text can also distract from the speaker so we recommend its use with caution. The presentation should be fairly short (no more than 10 slides) and should include:

1. Title of study, researcher name, researcher department/institution, date

2. Specific problem study will address (brief description of the purpose of the study and why the study is important to patients or the community and potential impact on/benefit to patients or the community)

3. Research question (what, specifically is the study designed to find out?)

4. Population or community that is the subject/ focus of the study. Why this population/community?

5. Study design: who, what, when, where, how (*include this slide only if the study design is relevant to the questions you will pose to the expert panel*)

6. Data collection/analysis (*include this slide only if the Analytical Plan is relevant to the questions you will pose to the experts*)

7. How will findings be used? (dissemination/utilization plan, translation for community use)

8. The template may be adapted for specific projects such as survey review, focus group feedback and quality improvement activities.

> *"The facilitator briefed me in advance about listening, which I really needed."*
> *Researcher*

5) The Community Experts

Community members, be they patients, caregivers, advocates or providers are the key to the success of the CE Studio model.   Ideally, they will represent diverse backgrounds and are connected to the community in various ways. Community members bring different lived experiences to the table and can provide insights from multiple perspectives. For example, a patient's caregiver may have a very different, but equally valuable perspective than a patient with a certain disease or condition.

WHAT TO LOOK FOR IN A COMMUNITY EXPERT
- Member of the population or community of interest   - Good verbal communication skills   - Good listening skills   - Desire to learn about research   - Willingness to share his or her experiences

Recruit community experts with an eye on creating a diverse pool of individuals who share an interest in improving the way research is conducted and leveraging research to benefit their community. There are numerous strategies that can be used in the recruitment process but it is important to look beyond the "usual suspects"- those individuals who are commonly called upon to serve on Boards, Coalitions and positions where they are asked to represent and entire community.

While community organizations may look very different from city to city and neighborhood to neighborhood, there are many common points of contacts for recruiting stakeholders:

- Community-based organizations that serve specific populations (e.g., seniors, youth, parents)
- Neighborhood leaders affiliated with associations or formalized community groups
- Resident Associations of Public Housing Complexes
- Parent Teacher Organizations/Associations
- Issue or disease focused community coalitions and advocacy groups
- Faith-based institutions that are active in outreach or service in neighborhood
- Health specific support groups or advocacy groups (e.g., Sisters Network, National Family Caregivers Association, Autism Society)
- Community health centers

Identifying people to serve as community experts will initially focus on the specific needs of the researchers that are requesting a CE Studio, with an end goal of creating a core group or pool of experts familiar with and committed to the CE Studio process.

A note on working with minors: Youth can also serve as community experts, bringing their unique experiences and perspectives to research. Written parental permission is needed for young people under the age of 18 and anyone working directly with minors (e.g., facilitator, community navigator) should follow their organization's policies regarding contact with minors, such as completing a background check or completing special training.

See Appendix D for sample recruiting materials (telephone script, email and flyer) for recruiting experts.

> *"…for me the (CE Studio) put more human impact on research being done. One thing is to see something on paper and then it's quite another when you are interacting with someone doing the work where they can explain things in different ways. It can be more humanizing. It made me feel closer to the research process…"*
> *Community Expert*

Compensation

The experience and knowledge that community experts bring to the research process is a tremendous asset and they should be appropriately compensated for their time. CERC bases its compensation rate (currently $25/hour) on the local average value of volunteer time as estimated by The Independent Sector https://www.independentsector.org/volunteer_time.

Community Expert Orientation

Each community expert completes an application form, which includes their health interests and areas of experience and/or expertise, including knowledge of a particular geographic community, population or condition. This information is needed when assigning stakeholders to expert panels. The coordinator/Community Navigator provides community experts with a formal orientation, either one-on-one or in small groups. Community experts receive an Orientation Guide at this time. The orientation includes a reviewing the guide discussing the purpose of the CE Studio and the role of the community expert and answering any questions about the process.

The Community Expert Orientation Guide (Appendix E) includes a job description, FAQs, a glossary of common research terms, and forms used during the meeting. Experts may also receive in advance documentation specific to the research project under review. The Guide also outlines the purpose of the CE Studio, the role and expectations of the expert panel and the CE Studio process.

The following is a list of questions commonly asked by community experts when recruited for a CE Studio:

Q. What makes me an expert?
A. Your expertise is based on your experience with a particular community and/or a health issue either personally or as a care giver. The researcher that has requested your advice values your opinions and your experience and would like to incorporate your feedback into his/her project in the hopes that it can be more relevant.

Q. I don't know anything about research. Why do you think I can help?
A. No prior knowledge of research is required to serve on a CE Studio expert panel. The emphasis is on your lived experience. Participating in the CE Studio however will allow you to learn more about research and how it ultimately could affect you or your community.

Q. Will I be paid for my time? I can't miss any work.
A. Yes, we always compensate our experts and provide a meal. You will be paid $50 for each CE Studio session and the Community Navigator will work to schedule the CE Studio at a time and location that is convenient to the majority of experts participating.

Q. How often to do I have to participate? What happens after the meeting?
A. If you indicate that you would like to continue as an expert, we will contact you anytime a CE Studio is requested that is a good match to your expertise. You can decline a CE Studio opportunity or ask to be removed from the list at any time. After each CE Studio, you will be contacted with an update on the research project that you advised on.

Community Engagement Studio Process
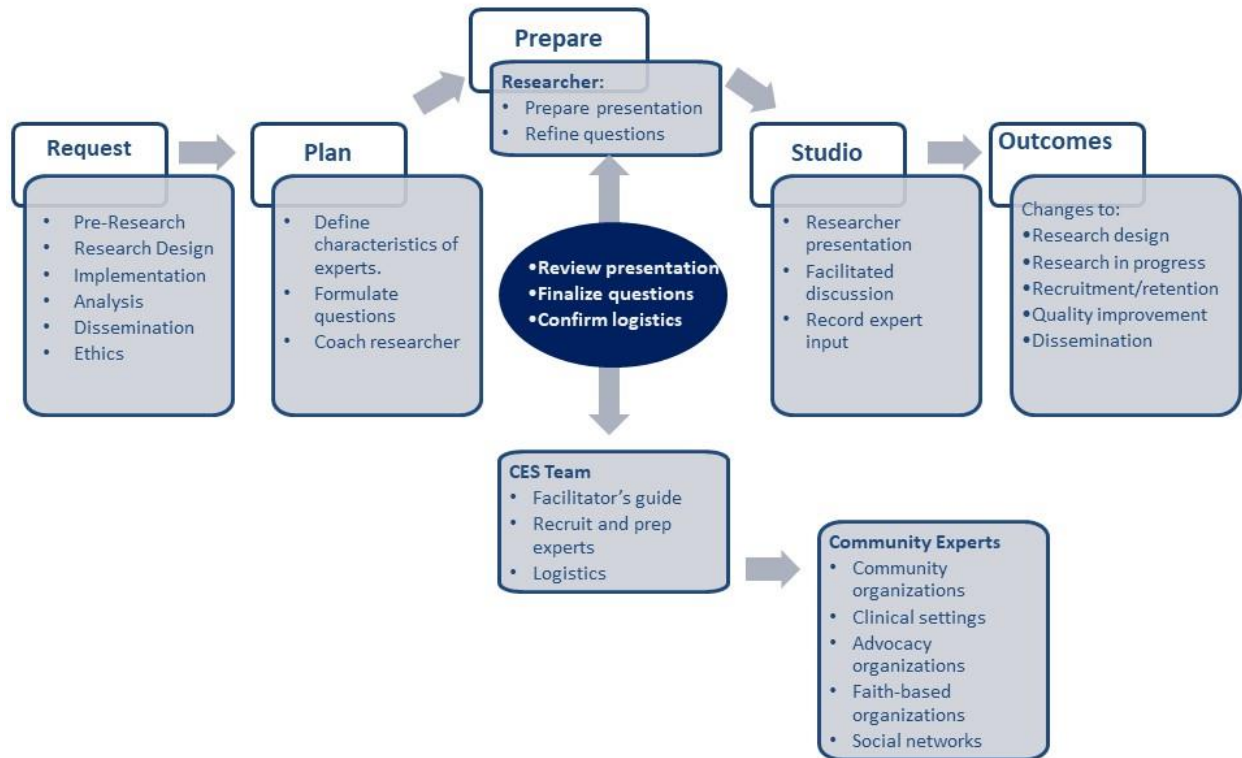
6) Requesting a CE Studio

A consistent, streamlined process for researchers to request a CE Studio will help expedite planning and implementation. The request should be in the form of a brief application and should include, at a minimum:

- Researcher/PI name
- Researcher contact info
- Name of project
- Purpose of the CE Studio
- Summary of the problem the project will address
- Target population (could be study inclusion/exclusion criteria)

Ideally, you will have an online process for researchers to request a CE Studio, using a database platform such as REDCAP. Many academic institutions have an online portal for vetting research support services requests.

Once the request for a CE Studio is approved, the researcher will be contacted by the Community Navigator to schedule a planning meeting.

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Cost
CE Studio costs include CE Studio Team time, compensation for the community experts, facilitator fees, food, and supplies. We encourage researchers to include CE Studio costs in their grant proposals as institutional support is never guaranteed. The average cost for a CE Studio is around $2,500, but this can vary depending on the number of community experts who participate (see Appendix G for cost estimates).

7) Scheduling

Scheduling a CE Studio can be surprisingly complex. The time and location are determined based on the majority of stakeholder's availability. Community experts new to the CE Studio should receive one-on-one or small group orientation to make sure they understand the purpose of the meeting and what will be expected of them.

Ideally, a panel of 8-10 community experts should be present for each CE Studio. Sometimes life gets in the way and experts have to drop out. For this reason, we recommend recruiting 10 - 12 people to ensure adequate participation. Food appropriate to the time of the meetings should be provided, i.e. breakfast, lunch, dinner or snacks. Choose a location is convenient and easy to find with adequate parking. The meeting room should be equipped with a computer and projector for the PowerPoint presentation and large to comfortably seat everyone.

Choose a location for the meeting that is convenient and accessible for the community experts. The academic medical center, while convenient for researchers, can be daunting for community members, so a community setting (e.g. community centers, community health centers, public libraries, etc.) may be more conducive to participation. Likewise, find a time that is convenient for community members who may not have flexibility during the weekdays due to work and other conflicts. Consider scheduling in the evenings or on weekends if necessary.

What to bring:
- Forms for Sign-in sheet, Expert Roster with Contact Info, Consultant Compensation. Forms, Expert Comment Forms, Expert and Researcher Evaluation Forms, Community Expert Applications.
- Flip charts, markers, name tags, pens.
- Researcher's presentation on jump drive.
- Laptop computer and projector if needed.
- Copies of researcher materials if needed such as study brochures, consent forms and recruitment flyers.

- Schedule planning meeting with researcher, and CE Studio team (facilitator, community navigator and faculty member).
- 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.

The Meeting

A not on note taking: Adults engage in different ways and with a variety of learning styles. To accommodate everyone, the CE Studio uses flip charts that are displayed around the room prior to the meeting. This method allows for all participants regarding of learning style to stay engaged in the studio as active participants. For those that learn by listening, they can easily focus on what is being said. For those who are more visual learners, they can always refer to what is being written on the flip charts. This also helps to ensure the note-taker is writing down exactly what is being said, as well as, allows experts to refer back to a point made earlier in the studio.
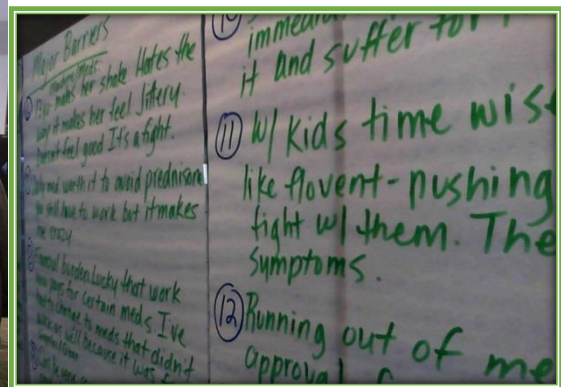
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STEP BY STEP: THE MEETING

- Facilitator and/or navigator greets all participants warmly when they arrive
- The Community Navigator passes around a sign-in sheet and assists the experts with any questions.
- 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 sheet, evaluation, paperwork needed to process payment).
- Facilitator explains ground rules: be respectful of other's opinions and experiences, keep confidential any personal info that might be discussed in the meeting, stay on topic and don't dominate the conversation.
- Researcher makes brief presentation (no more than 15 minutes) describing his or her research project and the specific questions for the experts' consideration.
- Experts have opportunity to ask researcher questions for clarification
- Facilitator keeps conversation on track, makes sure everyone's voice is heard.
- Community Navigator takes notes
- The facilitator reviews their responses and recommendations made during the discussion and the experts have the opportunity to provide additional feedback in writing.
- Ask both researchers and stakeholders to complete an evaluation survey. See community expert survey in Appendix E and researcher survey in Appendix H.

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8) Following Up

For the researcher: A recommendation report including the Community Navigator's notes and verbatim written comments from the community experts is shared with the researcher within one week of the CE Studio. We recommend highlighting specific recommendations as related to the topics that were discussed during the meeting. See sample summary, Appendix I.

For the community experts: Notify them of any changes or adjustments made as a result of their input. Items shared as follow-up may include updated outreach materials, policy and procedural changes or significant accomplishments of the study due to advice received during the CE Studio. If possible, give the community experts periodic updates on the project as well as any findings published or disseminated by the research team.
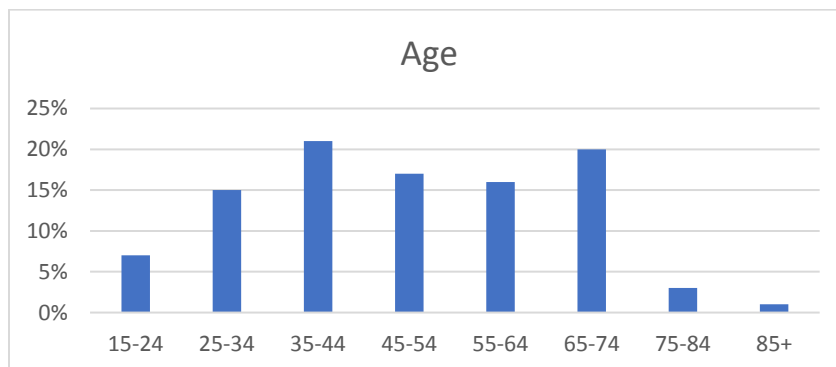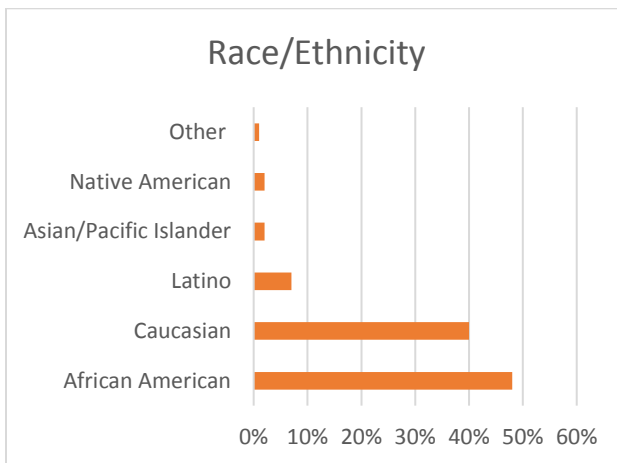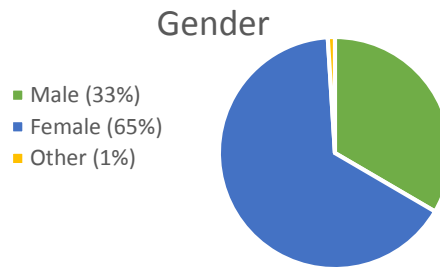
> *"Let us know what happened as a result of the studio. Be sure to make it clear that it was worth my time to be involved. I chose to be involved because I was interested in the topic, so just follow-though."*
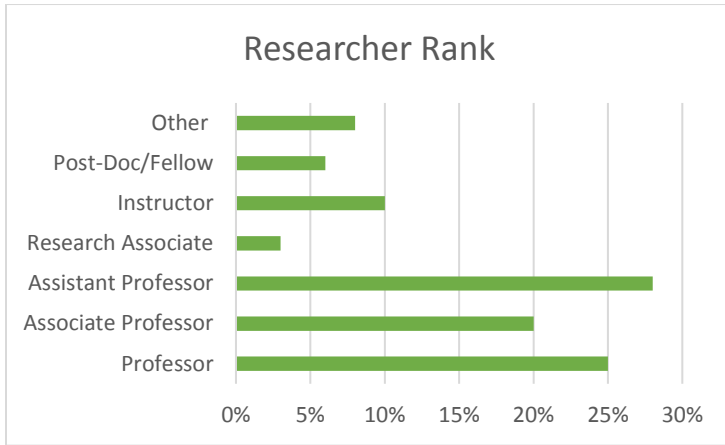>
> *Community Expert*

9) Metrics

Reflecting 90 CE Studios conducted by CERC between 2009 and 2017.
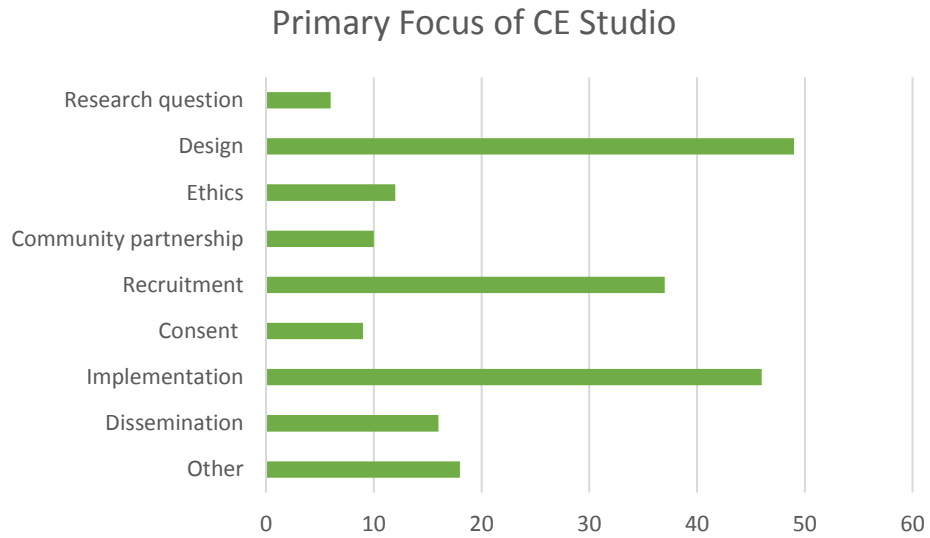
Community Experts (N=406)

Gender

- Male (33%)
- Female (65%)
- Other (1%)

Race/Ethnicity

Category	Percentage
Other	~1%
Native American	~2%
Asian/Pacific Islander	~2%
Latino	~7%
Caucasian	~40%
African American	~48%

Age

Age Range	Percentage
15-24	7%
25-34	15%
35-44	21%
45-54	17%
55-64	16%
65-74	20%
75-84	3%
85+	1%

Researchers (N=90)

Researcher Rank

Rank	Percentage
Other	~8%
Post-Doc/Fellow	~6%
Instructor	~10%
Research Associate	~3%
Assistant Professor	~28%
Associate Professor	~20%
Professor	~25%

0% 5% 10% 15% 20% 25% 30%

**TOP 10 DISCIPLINES OF RESEARCHERS REQUESTING A COMMUNITY ENGAGEMENT STUDIO**

Cardiology
Behavioral Health
Infectious Disease
Epidemiology
Critical Care Medicine
Pediatrics
Neurology
Radiology
Nephrology
Informatics

Primary Focus of CE Studio
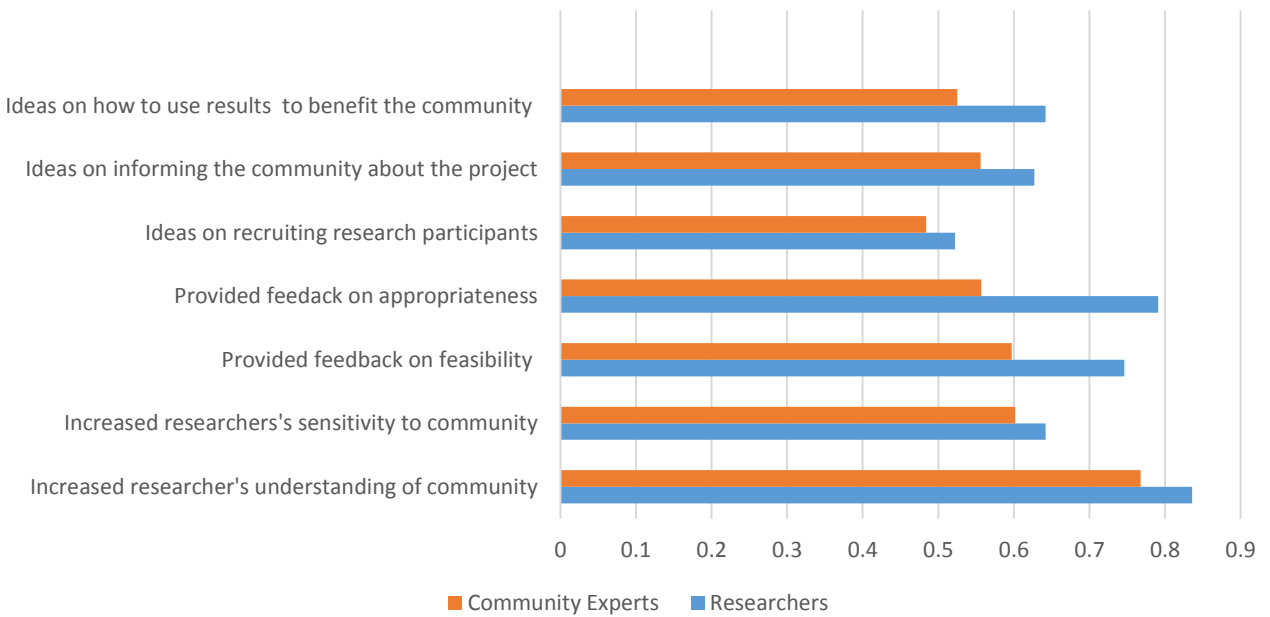
Focus	Value
Research question	~6
Design	~49
Ethics	~12
Community partnership	~10
Recruitment	~37
Consent	~9
Implementation	~46
Dissemination	~16
Other	~18

0 10 20 30 40 50 60

Evaluation Surveys:

Community experts will improve the quality of the research.

Community Experts | Researchers
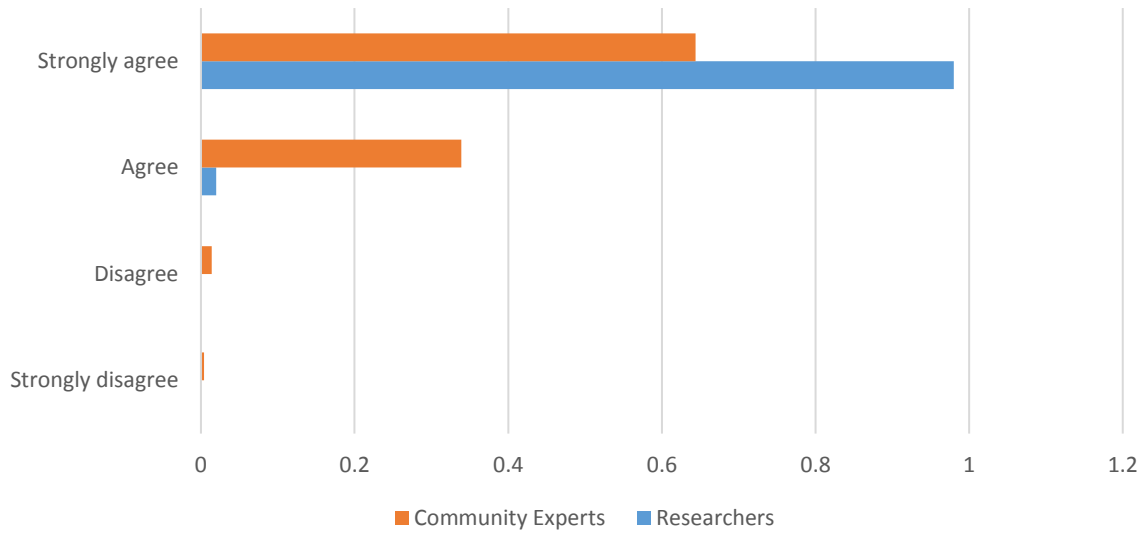
"What did the community experts contribute?"

Community Experts | Researchers

10) Promoting the CE Studio

The Institutional Review Board is one of the organizations within an academic institution that is likely to have a strong interest in the potential benefits of the CE Studio model. Presentations to IRB staff and committees will introduce them to the CE Studio as a way to integrate community perspectives into research design and implementation.   Building the awareness of IRB staff and committee members in regards to how patient and community stakeholders can inform and assist researchers in avoiding common pitfalls will enable them to refer projects when appropriate to the CE Studio process.

Other strategies to raise awareness about the CE Studio and gain support and buy-in include giving talks at department and research center meetings, grand rounds presentations, meeting with scientific review committees, getting on the agenda of community advisory councils of research centers or groups, and including information about the CE Studio in training sessions on patient and community engaged research.

Use internal communications such as electronic and print newsletters, and institution-wide and departmental publications to announce opportunities to learn about the CE Studio. You can also work with your institution's internal marketing and communications department to publish a feature story about a successful CE Studio from the researcher or community expert point of view. See sample flyer in Appendix J.

APPENDICES

Appendix A

Community Navigator Job Description

Community Navigator Job Description

Basic Qualifications
Education Required: Masters in public/community health, human and organization development, social work or related field.
Experience: Required months in field prior to employment: 24 months minimum

Notes:

Qualified candidates will have excellent oral, written and electronic communication skills and a record of accomplishment in community networking and collaboration building as well as demonstrated skill working with diverse communities of health and human service providers and consumers. Familiarity with local community, experience with academic-community partnerships and understanding of the principles of community engagement a plus.

Job Summary
The Community Navigator will assist with the planning and implementation of the Community Engagement Studio; work collaboratively with academic and community partners to build research collaborations; and assist with the development of an infrastructure to foster innovative community-engaged research by providing education, outreach and trust-building activities.

Key Functions and Expected Performance

1. Organize and support Community Engagement Studio activities, and follow up on any actions resulting in the activities.

2. Manage the flow of research projects through the Community Engagement Core and Community Engagement Studio.

3. Orient and support the community experts who participate in the Community Engagement Studio.

4. Identify and build professional relationships with community organizations and community advocates who have an interest in building academic-community research partnerships.

5. Develop and maintain mechanisms to communicate with community partners, increase interaction between community partners and academic researchers, and track the development of academic-community research partnerships.

6. Support community education and outreach activities.

Appendix B

FAQs for Researchers

Q. Why would I request a Community Engagement Studio?

A. Increasingly, both funders and researchers' are seeking cost-effective and time efficient methods that engage groups of stakeholders and patients to enhance current research practices and improve dissemination. The Community Engagement Studio (CE Studio) streamlines the process of gathering feedback by creating an infrastructure that works to empower community members to provide meaningful insight into all phases of research.

Q. What is the purpose of the Community Engagement Studio?

A. The CE Studio allows a researcher to gain feedback from his or her community of interest or patient group about issues pertaining to design, implementation, recruitment, retention and other potential barriers to participation.

Q. How much time will this Studio take?

A. The CE Studio requires a small investment of time. In total, a researcher spends on average less than four hours of his or her time preparing for and participating in the CE Studio.
- 15 minutes online- Submitting initial request
- 30-45 minute - Planning meeting with CE Studio Team (Community Navigator, Facilitator, CERC Faculty)
- 30 minutes-1 hour- Preparing presentation
- 1 ½ -2 hours - meeting

Q. How much will this cost?

A. The CE Studio is currently paid for through an institutional voucher system. All expert compensation, facilitator cost, food, supplies and staff time is covered by the voucher. We encourage researchers to include CE Studio costs in their grant proposals as institutional money is never guaranteed. Actual costs run between -$2,000- $3,000 depending on staff time needed, location and number of community experts who participate.

Q. Can I recruit the experts for my study?

A. You may not use the CE Studio to recruit for your study. You may, however, share information regarding the study so that an expert can contact you or your research staff for more information outside of the Studio. Some experts choose to participate in the Studio and at times recruit others from their community.

Q. Why is there a facilitator? Can I facilitate myself?

A. The CE Studio utilizes a trained facilitator who has experience working with group processes and understands the principles of community engagement. The use of an independent facilitator allows a researcher to listen to feedback and ask for clarification without having the responsibility of leading the process.

Q. Can I pick or recommend specific experts to participate?

A. The Community Navigator is charged with the recruitment of experts. Ideally experts should not have a prior relationship with the researcher or the staff to ensure that feedback is open and honest.

Q. How can I help ensure that the Studio is scheduled in a timely manner?

A. Identifying the right experts and finding a date that works for everyone can be complex. Your prompt responses to emails and voicemails regarding your availability, clarification of your questions or patient population and any other info needed to move your Studio forward is critical to getting your Studio scheduled.

Q. Do I need IRB approval to have a CE Studio?

A. You do not need IRB approval. The CE Studio is a process to inform the development, conduct or dissemination of research but is not considered research itself. The stakeholders or community/patient experts who participate in the CE Studio are not research subjects, rather, they are advisors and/or consultants.

Q. Can the information from CE Studios be used for research purposes or publication?

A. It depends on how you intend to use the information. It is acceptable to describe the process and the input that you received. However, because the community experts are not research participants, you cannot provide details of who participated or analyze the input by any demographics.

For example:

> *We received detailed input from a representative group of stakeholders to help guide our evaluation. A group of consumers who have used the clinic was convened by our community engaged research core using a structured process called the Community Engagement Studio (CE Studio). The award-winning CE Studio uses best practices for community engagement and an experienced team to overcome barriers to engaging groups of stakeholders and facilitate meaningful input from stakeholders. From the CE Studio, we learned that consumers 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 CE Studio to streamline our registration process and provide more opportunities for consumers to engage with our interdisciplinary team. Overall the input we received from consumers was extremely helpful in understanding how our services are used and for improving operations.*

Q. What is the difference between a CE Studio and a focus group?

A. CE Studios are not intended as research. They provide a relatively quick way to gain patient or community input on the development or implementation of a research project. Focus groups are conducted with the use of an explicit interview guide where all questions have been pre-identified. In a focus group, the facilitator is more focused on the subjective experience of the group as opposed to the individual. CE Studios are utilized to dig deeper into the individual's knowledge and experience as it might relate to the study. The experts participating can come from a variety of backgrounds with one shared experience, like a particular health condition. While there are 2-3 main topics that will be

discussed during a Studio, the discussion is not limited to specific questions. This allows the facilitator to focus the discussion on what is most helpful to the researcher and his/her project. This is important, as issues that may not have been identified prior to the meeting, may turn out to be the most insightful for the research being discussed.

Appendix C

Sample Research Presentation

Preventing Heart Disease through Coordinated Care and Financial Incentives

Community Engagement Studio

Specific Problem Study will Address

- Cardiovascular disease (CVD) remains a leading cause of death and disability in the United States
- Risk factors for CVD are well-established
- Risk prediction models are widely available
- Modifying risk factors can help

But...

A Key Gap/Opportunity Exists

Primary Care → Coordinated Care → Cardiology

A Key Opportunity

Primary Care Clinic — Cardiology Coordinated Care Clinic

Blood Pressure
Cholesterol
Glucose/Diabetes
Tobacco
Physical Activity
Healthy Diet
Weight

The Cost of Care

Taking care of yourself is expensive...
Premiums
Rx Co-pays
Deductibles
$

It's even more expensive if you have a heart attack...
Co-insurance
Deductibles
$$$$

*For a heart attack, **your bill** can reach **$7,000 or more**...*

A New Kind of Financial Incentive

If you come to Coordinated Care Clinic...

If we see progress (not perfection)...

Premiums
Rx Co-pays
Deductibles
$

Co-insurance
Deductibles
$$$$

$7,000+

- Study will include patients who are:
  - High risk for CVD
  - In primary care at Vanderbilt
  - In Vanderbilt Health Plan

- Vanderbilt Health Plan wants to partner with us to find a better way to prevent CVD

Population

- We will identify high-risk patients

- We will place them in 1 of 2 strategies:
  - Usual care strategy
  - Coordinated care strategy

- We will compare:
  - Risk factor control
  - Patient satisfaction and evaluation

Research Questions
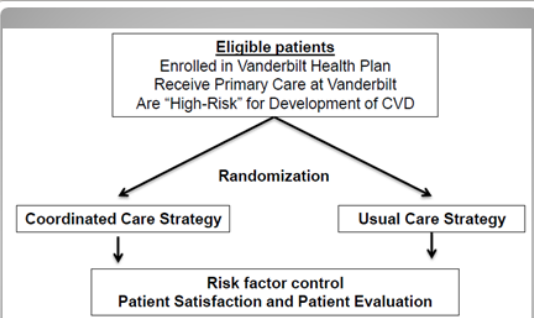
Study Design

- Study Results will help us:
  - Assess a new care model
  - Identify ways to improve care & risk reduction
  - Understand novel incentives

- If we prove this model works:
  - You help your health
  - You help your pocketbook
  - You help people you don't even know

How will findings be used?

Questions?

Would you participate in this study? Why or why not?

What would the ideal clinic look like?

Would financial incentive influence your decision to participate?

Specific Questions to Community Experts

Appendix D

Tools for Recruiting Community Experts

Email Communication to Community Experts

Single studio
Hello everyone.

This email is to inform you about an upcoming studio to be scheduled for the end of June. This studio will provide feedback on recruitment strategies, potential barriers to enrollment and the overall feasibility of a study with patients receiving care in the emergency room. As a reminder, the Community Engagement Studio usually lasts 1 ½ hours, and individuals from the community (or providers of care) give feedback and advice to help researchers improve upon their research projects.

The studio meeting will be scheduled at a time that is convenient for the majority of participants, a meal will be provided and you will be compensated $50 for your time.

Should you have any questions, please feel free to contact me at <insert email address here>.

Candidates for CHEST PAIN studio
1) Patients 45-65 years old in good health (no known heart condition) **who have sought emergency department care for chest pain**, were admitted to the hospital, then discharged with a final diagnosis that the heart was not the cause of chest pain.
2) Patients 45-65 years old **in good health (no known heart condition) who have sought emergency department care** within the past year and were discharged from the emergency department without being admitted.
3) Participants 45-65 years old in good health (no known heart condition except for high blood pressure).

We are not looking for participants with a past history of heart or vascular disease (including heart attack, heart failure, stroke, and pulmonary embolus), nor active cancer.

If you meet one of the qualifiers above and are interested in participating, please go to this link to indicate your availability. Please use your first and last name as the poll is private. I will be in touch by the end of next week with confirmation of date and time.

Many thanks for considering my request. Have a great weekend!
<insert name here>

Multiple Studios

Hello all.

I am emailing you because you have served as a Community Expert in the past, are a leader in the community who can share these opportunities with the community that you serve or, you completed a survey via ResearchMatch expressing interest in being involved.

We currently have several Community Engagement Studio opportunities that are in need of participants. I have described each studio in detail below and included a link to a scheduling doodle that will allow you to indicate your availability. **The Studio will last approximately 1 ½ hours and all consultants will receive $50, as well as a meal.** As a reminder, a Community Engagement Studio is a 1-time meeting that brings together patients and/or community members to discuss issues that can improve research proposals and projects.

Thank you in advance for your consideration and assistance. **You may forward this announcement to others who might be interested, but the person must contact me by email at** <insert email address here>.**or I will not have their contact info to follow-up.**   Please feel free to contact me should you have any questions or need additional information.

1) **Coordinated Care Clinic**: This studio will review and provide feedback on the design of a Coordinated Care Clinic Model that would work to prevent cardiovascular disease in high risk patients. The group will also give feedback on an incentive plan that waives fees associated with hospitalization for cardiovascular disease. ***You must have a Vanderbilt Primary Care Provider, be at-risk for Cardiovascular Disease** (diabetic, high blood pressure, overweight, and/or smoker, etc.) and be over the age of 18 to participate.   Indicate availability <u>here</u> with your **first name and last initial.**

2) **Improving Healthcare Systems:** This studio will discuss adverse events that occur during hospitalization (poor communication by providers, secondary infections, etc.)   The group will identify potential events and ways to prevent them. The group will also discuss their opinions on how adverse events may have affected them and their condition**. *You must have had a recent hospitalization (last 2-3 years) or care for a patient who was hospitalized**. You must also be 18 years or older. Indicate availability <u>here</u> with **your first name and last initial**.

3) **Diabetes Intervention**: This studio will discuss the design of a text-based diabetes intervention that incorporates family members. The group will discuss recruitment and messaging. You must be 18 years or older, **have diabetes AND ideally be a patient at a local Federally Qualified Health Center**. Indicate availability <u>here</u> with **your first name and last initial**.

4) **Community Experts who have had Head & Neck Cancer**: This studio will assist in generating an appropriate interview guide for a new study. Time and dates are TBD. Please email me at <insert email address here> if you are interested in participating.

Thanks again everyone!

Confirmation Email

Hello everyone.

I am emailing to confirm your attendance for the Community Engagement Studio on **"INSERT STUDIO TOPIC".** Each participant will receive $50 in compensation for their time which will be mailed to you following the meeting.   This will be a facilitated discussion with key questions that will be asked about your experience, and as always gathering your opinions will be the focus of our meeting. There are no wrong answers.

The meeting will be held on **INSERT SPECIFIC DATE AND TIME**. This was the time and date that worked for the majority of participants.

<div align="center">

Your lunch order will be your confirmation. Please send me your preference asap.
See below for choices.

</div>

INSTRUCTIONS SHOULD BE VERY DETAILED

As a reminder, the meeting will last no more than two hours. You will be coming to 2525 West End Avenue which is located across the street from Centennial Park. It is the same building where P.F. Chang's and Bread and Company are located. If you are coming down West End going towards downtown you will make a right turn onto Natchez Trace next to the Wendy's. You will then make an immediate left into the parking lot of the building. You will see the entrance to the parking garage directly in front of you. I will give you a ticket to validate your parking.

You will take the crosswalk across on the third floor. Enter the doors to the building and take the elevator to the **10th floor**.

You may also be able to find parking in the front lot of the building. In that case, enter through the glass doors next to Starbuck's and take the escalators to the top. The elevator is around the corner to your left.

Please email me your preference to confirm your attendance.

      <INSERT LUNCH OPTIONS HERE>

Please feel free to contact me should you have any questions before then. As always, thank you for your continued support!

I look forward to seeing each of you and thanks again for your participation.
<insert name here>

Sample phone script for an expert with previous CE Studio experience

Hello, Mr. /Ms. _____. This is _____ from the Vanderbilt University Medical Center.

How are you today?

I'm calling to discuss with you an upcoming studio. This studio will provide feedback on <insert description> recruitment strategies, potential barriers to enrollment and the overall feasibility of a study with patients receiving care in the emergency room. Have you received care through the emergency room before?

<If no> Thank you for taking the time to talk with me. While you don't qualify for this studio, I will be in touch about future opportunities.

<If yes> Ok. Do you think you would like to participate in this studio?

<If no> Ok. Thank you for taking the time to talk with me. I will be in touch about future opportunities.

<If yes> Great, I'm glad you would like to participate. As a reminder, the Community Engagement Studio is a 1-time meeting that lasts about 1 ½ hours. Individuals from the community (or providers of care) give feedback and advice to help researchers improve upon their research projects. We will provide a meal during the meeting and you will be compensated $50 for your time.

While I have you on the phone, I will read a list of times and days that we are looking at as options for scheduling the studio. Please tell me all of the ones that you would be available to attend. Once I have everyone's availability, the studio meeting will be scheduled at a time that is convenient for the majority of participants.

<Read the list of potential times and dates and write down the expert's availability.>

Thank you for your patience. Do you have any questions regarding the studio?   If you think of any please feel free to contact me at <insert email address here> or <insert phone number>.

I will be in touch by <insert time period> with confirmation of date and time.

Many thanks for considering my request. Have a great day!

Sample phone script for recruiting a new expert

Hello, Mr. /Ms. _____. This is _____ from the Vanderbilt University Medical Center.

How are you today?

I'm calling to discuss an opportunity to participate in a meeting where you would give feedback on a research project. These meetings are called Community Engagement Studios. The Community Engagement Studio is a 1-time meeting that lasts about 1 ½ hours. Individuals from the community, such as yourself, give feedback and advice to help researchers improve upon their research projects. We provide a meal during the meeting and you will be compensated $50 for your time.

The studio I am calling about today will provide feedback on <insert description, e.g., recruitment strategies, potential barriers to enrollment and the overall feasibility of a study with patients receiving care in the emergency room. Have you received care through the emergency room before?>

<If no> Thank you for taking the time to talk with me. While you don't qualify for this studio, would you be interested in future opportunities to participate? <If yes> Great, I'll send you an Orientation Guide that will give you more information about the purpose and process if the studios. If you complete the Expert Bio form and return it to me, I'll add you to our expert pool and contact you when another opportunity comes up. I can send that via email or mail. What is your preference?

<If yes> Ok. Do you think you would like to participate in this studio?

<If no> Ok. Thank you for taking the time to talk with me. I will be in touch about future opportunities.

<If yes> Great, I'm glad you would like to participate. I will send to you an Orientation Guide that will give you more information about the purpose and process if the studios. I can send that via email or mail. What is your preference?

<Write down preference.> Ok. I will send the guide to you today.

While I have you on the phone, I will read a list of times and days that we are looking at as options for scheduling the studio. Please tell me all of the times that you would be available to attend. Once I have everyone's availability, the meeting will be scheduled at a time that is convenient for the majority of participants.

<Read the list of potential times and dates and write down the expert's availability.>

Thank you for your patience. Do you have any questions regarding the studio or the process?   If you think of any please feel free to contact me at <insert email address here> or <insert phone number>.
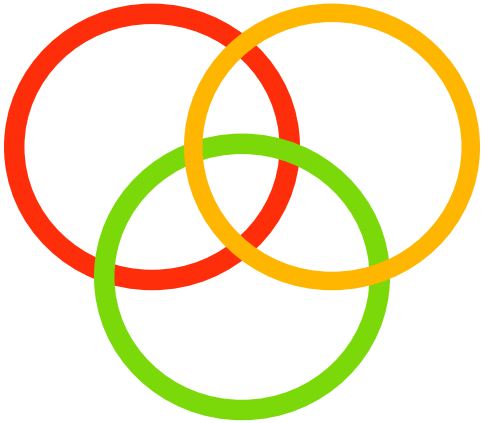
I will be in touch by <insert time period> with confirmation of date and time.

Many thanks for considering my request. Have a great day!

Community Expert Orientation Guide

Your guide to the Community Engagement Studio Process

Meharry-Vanderbilt Community Engaged Research Core

Vanderbilt Institute for Clinical and Translational Research

Dear Community Expert,

On behalf of the Meharry-Vanderbilt Community Engaged Research Core, we thank you for agreeing to serve as an Expert for the Community Engagement Studio. Our purpose is to support academic-community research partnerships that are focused on improving community health and healthcare. We created the Community Engagement Studio to provide a forum for researchers to hear, first hand from patients, caregivers, community care providers and community members how to plan and conduct research that is more relevant, patient-centered and impactful.

You have been invited to serve as an expert for a Community Engagement Studio because of your knowledge of a particular community or interest group or health condition and your interest in research. The Community Engagement Studio is a forum for learning for both researchers and community members, and we encourage you to offer honest feedback and constructive criticism, and serve as an advocate for your community.

We look forward to working with you and hope that the Community Engagement Studio is a positive experience for you.

Community Expert Orientation Guide

What is the purpose of the Community Engagement Studio (CE Studio)?
The Community Engagement Studio is a guidance session for health researchers interested in getting feedback from patients or working in a community setting. Community stakeholders serve on expert panels to provide feedback on various aspects of a proposed or on-going research project, including the design, intervention, communication materials, participant recruitment strategies, sharing learning with the community, and applying research findings to practice.

What is a Community Expert?
A Community Expert is an individual who has lived experience or possesses first-hand knowledge of a particular community or health issue.   A Community Expert has a desire to learn about research, an ability to provide constructive criticism, and a willingness to be an advocate for his or her community.

Why are Community Engagement Studios important?
Community Engagement Studios help assure that research meets the needs of people who live in a particular community, or are impacted by a specific health issue. Community Experts are one of the most important resources available to directly guide a research project that will impact patients and the community. Through the Community Engagement Studio, the Community Expert:
- Provides the research team with a deeper understanding of patients' and communities' unique circumstances.
- Increases a researcher understands of and sensitivity to the patients and communities they are interested in studying.
- Strengthens academic-community partnerships so that over time, universities become more and more effective in working with patients and communities.
- Helps assess the relevance, feasibility and appropriateness of the research activities.
- Enhances the success of research project by providing immediate feedback to the researchers.

How do I prepare for a CE Studio?
- Background material on the research project or research topic will be provided to you in advance, so that you can read about the research project before the CE Studio.
- You may want to write down any thoughts, concerns or questions in advance, so that they can be easily and promptly addressed during the CE Studio
- Complete or update the 1-page Bio form on file to match your expertise with researchers needs.
- There is no need for additional preparation. We are matching you to this specific CE Studio because of your particular experience, background or knowledge. Remember, you are already an expert!

What can I expect?

- The CE Studio will take place in a community setting, during hours that are convenient to the Community Experts. It will last no more than two hours.
- Up to ten Community Experts may participate in a CE Studio.
- Usually two members of the research team may attend, including the lead researcher and staff member.
- The CE Studio will be moderated by an experienced facilitator who is knowledgeable about the research process. In her opening remarks, the facilitator will make introductions and explain the ground rules for the CE Studio.
- Following the opening remarks, the researcher will give a brief overview of his/her project and pose specific questions for you to consider. Examples of questions include: What barriers might exist for you or people you know to participate in this study? What measurements and study outcomes are important to you? What would be some effective ways to share what we learn from this study in your community?
- The facilitator will lead the discussion to ensure that it stays on track, that all the experts have an opportunity to share their thoughts and it addresses the researcher's questions.
- At the close of the Community Engagement Studio session, you will be asked to complete a brief comment and evaluation form that will allow you to give additional feedback that might be helpful to the researcher. See the sample that is included in this Orientation Guide.

What happens following the CE Studio?

- The facilitator will summarize in writing the Community Expert's feedback for the researcher.
- You will complete a payment form to receive $50 in compensation for your participation.
- You will be asked to complete an evaluation for to help us monitor and improve the process and experience of everyone involved.
- If you are interested, we will contact you with updates on the study.

As a registered Community Expert we will keep your Bio on file and contact you if your area of expertise matches a researcher's CE Studio request. If you have any questions or would like to be removed from our Community Expert Resource List please contact, <insert contact person's name, email address and phone number>.

Glossary of Terms

Basic Science Research: The study of a subject to increase knowledge and understanding about it without a specific or immediate practical application. Examples include studies of cell signaling, genetic mutations associated with specific types of cancer and how tumors evade the body's immune system. The majority of medical researchers at Vanderbilt and Meharry Medical College are engaged in basic science research.

Clinical Research: Research that determines the safety and effectiveness of <u>medications</u>, <u>devices</u>, <u>diagnostic products</u> and techniques, and <u>treatment regimens</u>.

Comparative Effectiveness Research (CER): the direct comparison of existing treatments to determine with works best. CER has emerged as an important mechanism to improve health outcomes, accelerate the translation and dissemination of evidence-based diagnostic and treatment strategies and deliver more patient-centered healthcare.

Community Engaged Research (CEnR): A distinct approach to research involving the building of trusted and authentic partnerships between researchers and the community. CEnR requires that a relationship be built between the academic institution and the community in which it serves based on respect, trust and mutual benefit and addresses community needs and health issues as defined by the community itself.

Community-based Participatory Research (CBPR): Community-based participatory research is research that is conducted as an equal partnership between traditionally trained "experts" and members of a community. In CBPR projects, the community participates fully in all aspects of the research process. Community is often self-defined, but general categories of community include geographic community, community of individuals with a common problem or issue, or a community of individuals with a common interest or goal.

CTSA or **Clinical Translational Science Award**: A consortium of 60 medical research institutions working to improve the way medical research is conducted. The vision of the CTSA network is to reduce the time it takes for scientific discoveries to become treatments, practices or policies to improve health.

Dissemination: A planned process that involves consideration of target audiences and the settings in which research findings are to be received and, where appropriate, communicating and interacting with wider policy and health service audiences in ways that will facilitate using research findings in decision-making.

IRB or **Internal Review Board:** A committee of physicians, statisticians, researchers, community advocates, and others that ensures that any research done on and about humans is ethical and that the rights of study participants and communities are protected. All human subjects' research done in the United States must be approved by an IRB before they begin.

Human Subjects Protection: Laws set by the U.S. Department of Health and Human Services (DHHS) to protect a person from risks in research studies that any federal agency or department has a part in. Also called 45 CFR 46, 45 Code of Federal Regulations Part 46, and human participant protection regulations. Research institutions require that anyone engaged in research that involves humans must complete training in human subjects' protection.

Meharry-Vanderbilt Community Engaged Research Core (CERC): An inter- and intra-institutional, multi-disciplinary program that integrates the principles of participatory engagement in all aspects of its work. CERC is coordinated through the Vanderbilt Office for Community Engagement and serves as the community engagement core for both the Vanderbilt Institute for Clinical and Translational Research (VICTR) and the Meharry Clinical and Translational Research Center (MeTRC).

NIH or the **National Institutes for Health**: The primary Federal agency for conducting and supporting medical research. NIH is composed of 27 different institutes and centers.

Patient-Centered Outcomes Research (PCOR): Patient-Centered Outcomes Research helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options. This research aims to answer patient-centered questions as defined by individual patients.

PCORI or **Patient Centered Outcomes Research Institute**: A nonprofit organization recently established by the Affordable Care Act to improve the quality and relevance of research to help patients, caregivers, clinicians, employers, insurers and policy makers make informed health decisions. PCORI provides grants for comparative effectiveness research.

PI or **Principal Investigator**: The researcher in charge of an experiment or research project and the person responsible for the overall management and direction of the project. This PI may also be called the lead investigator or lead scientist.

Research Core: A shared resource or facility that offers support to researchers in a particular research area (e.g., cancer, health disparities, HIV/AIDS) or data collection/analysis methodology (qualitative research, biostatistics, cell imaging).

Stakeholders: We define stakeholders as "individuals, organizations or communities that have a direct interest in the process and outcomes of a research project." Stakeholders may be patients, caregivers, advocates, research volunteers and community leaders. The target stakeholders for the CRB are individuals with first-hand knowledge of a particular health issue or community and stakeholders are selected in direct response to the research topic. We refer to CRB stakeholders as "experts" and each is compensated for participation.

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Translational Research: This type of research transforms scientific discoveries into improved patient care, community-based practices and policies to improve health.

VICTR or **Vanderbilt Institute for Clinical and Translational Research**: VICTR works to transform the way ideas and research discoveries make their way to patient care and community practice. It does this through collaboration with a wide variety of research partners, by providing training to researchers, by funding new research, by developing new and innovative ways to involve the community in research, and by developing new informatics and biostatistical systems. http://www.mc.vanderbilt.edu/victr/pub/.

Community Engagement Studio Sample Forms

Community Engagement Studio Expert Bio

Contact Information	
Name	
Street Address	
City ST ZIP Code	
Home Phone	
Work Phone	
Cell Phone	
E-Mail Address	

Demographic Information

Gender: ___Male   ___Female   ___Other   Date of Birth: _____

Ethnicity:

___ African American	___ Asian/Pacific Islander
___ Caucasian	___ Native American
___ Hispanic/Latino	___ Other (describe):

Availability

During which hours are you available for community review board meetings?

___ Weekday mornings	___ Weekend mornings
___ Weekday afternoons	___ Weekend afternoons
___ Weekday evenings	___ Weekend evenings

Interests

What health related topics are you interested in or have personal experience with (check all that apply)?

___ Access to health care	___ Health care quality	___ Maternal/child health
___ Cancer	___ Health disparities	___ Men's health
___ Community health	___ Heart disease	___ Mental health
___ Diabetes	___ Health policy	___ Nutrition
___ Genetics	___ Health promotion/disease prevention	___ Obesity
___ Health behavior	___ HIV/AIDS	___ Women's health

___ Other topics (please explain):

May we contact you about future Community Engagement Studios?   ___ Yes   ___No

Agreement and Signature

By signing this application, I understand that the information I provide about me will be kept confidential. Furthermore, I agree that I will keep confidential any comments made during the Community Engagement Studio by either the other Community Experts or the presenting researchers.

Name (printed)	
Signature	
Date	

Community Engagement Studio Comment Form

Date: _____

Principal Investigator: _____

We appreciate your participation and value your time. In an effort to maximize the benefits for everyone involved, we have developed a Comment Form. Please comment on the points listed below during the course of the studio session. The facilitator will collect/review these comments at the end of the session and then summarize the feedback for group. (Please feel free to use the back of the page if necessary.)

1.	General thoughts about the project (strengths):
2.	What was good about the project?
3.	What challenges do you think the project will have in the community (weaknesses)?
4.	What would you like to see the researcher do differently (opportunities)?

Additional Comments:

Meharry-Vanderbilt Community Engagement Research Program
Vanderbilt Institute for Clinical and Translational Research
Community Engagement Studio - Community Expert Evaluation Survey

You have been asked to complete this survey because of your participation the Community Engagement Studio. The main benefit to completing this survey is to improve the effectiveness of the Community Engagement Studio, and the quality of the academic-community research partnerships that result. Your individual responses may be used as part of a research study and will be kept anonymous. There are no known risks to completing this survey, and your participation is voluntary. Refusing to participate will not have any impact on your opportunity to participate in the Community Engagement Studio in the future.

Please respond to the following statements and questions:

1. The scheduling/communications for this Community Engagement Studio session were handled in a timely and efficient manner.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

2. The allotted time for the Community Engagement Studio was sufficient.

    ☐ Too much time   ☐ Enough time   ☐ Not enough time

3. The Community Engagement Studio moderator managed the allotted time in order to address my questions and comments.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

4. The relevant experts were present at the Community Engagement Studio session.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

5. I was satisfied with the Community Engagement Studio session.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

6. The Community Engagement Studio process was worth my time.

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

7. The researcher's presentation gave me enough information to provide appropriate feedback.

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

8. The feedback provided by the community experts will improve the research project.

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

9. Would you participate in the Community Engagement Studio again?

☐ Yes   ☐ No

10. What do you feel was your contribution to the research project? Please check all that apply.
   ☐ Increased researcher understanding of the community
   ☐ Increased researcher sensitivity to the community
   ☐ Provided feedback on the feasibility of the project
   ☐ Provided feedback on the appropriateness of the project
   ☐ Ideas on recruiting research participants
   ☐ Ideas on how to inform the community about the project
   ☐ Ideas on how to use results of project to benefit the community

   Other, specify_____

11. Please suggest at least one way the quality of the Community Engagement Studio could be improved in the future.

   I.

   II.

   III.

Appendix G

Estimated CE Studio Costs

Community Navigator/Coordinator	Communication with researcher/research team including prep meeting, follow-up 3 hours Recruitment and orientation of experts: 15 hours Meeting, including setup and takedown: 4 hours Summary prep and follow-up communication with researcher : 3 hours	25 hours x $50/hour (based on $80,000 salary plus 24% fringe)	$1,250
Administrative Assistant	Meeting logistics and prep: 2 hours	4 hours x $20 /hour (based on $32,000 salary plus 24% fringe)	80
Faculty	Researcher coaching	2 hours x $110/hour (based on $181,500 salary plus 21% fringe)	220
Facilitator	For prep meeting with researcher and facilitating and 2 hour studio		200
Experts	For participating in 2 hour meeting	2 hours x $25 x 10 experts	500
Meals		$12 per meal x 14 people	168
TOTAL			$2,418

Appendix H

Researcher Evaluation Survey

Meharry-Vanderbilt Community Engagement Research Core
Vanderbilt Institute for Clinical and Translational Research
Community Engagement Studio – Researcher Survey

You have been asked to complete this survey because of your participation the Community Engagement Studio. The main benefit to completing this survey is to improve the effectiveness of the Community Engagement Studio and the quality of the academic-community research partnerships that result. Your individual responses may be used as part of a research study and will be kept anonymous. There are no known risks to completing this survey, and your participation is voluntary. Refusing to participate will not have any impact on your opportunity to use the Studio in the future.

Please respond to the following statements and questions:

1. The scheduling/communications for this Studio session were handled in a timely and efficient manner.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

2. The allotted time for the Studio was sufficient.

    ☐ Too much time   ☐ Enough time   ☐ Not enough time

3. The Studio moderator managed the allotted time in order to address my questions.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

4. The relevant experts were present at the Studio session.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

5. I was satisfied with the Studio session.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

6. The Studio process was worth my time.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

7. The expert feedback was conveyed to me in an appropriate way.

    ☐ Strongly agree   ☐ Agree   ☐ Disagree   ☐ Strongly disagree

8. This Studio session improved the quality of my project.

   ☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

9. Would you recommend a Community Engagement Studio session to a colleague?

   ☐ Yes   ☐ No

10. Would you request a Community Engagement Studio in the future?

    ☐ Yes   ☐ No

11. Would you request input again from the individuals participating in this Studio?

    ☐ Yes   ☐ No

12. What do you feel were the Studio experts' contribution to the research project? Please check all that apply.
    ☐ Increased my understanding of the community

    ☐ Increased my sensitivity to the community

    ☐ Provided feedback on the feasibility of the project

    ☐ Provided feedback on the appropriateness of the project

    ☐ Ideas on recruiting research participants

    ☐ Ideas on how to inform the community about the project

    ☐ Ideas on how to use results of project to benefit the community

    Other, specify_____

13. Did your Studio result in any of the following (check all that apply):
    ☐ Grant submission
    ☐ Manuscript submission
    ☐ Delayed grant submission
    ☐ Delayed manuscript submission
    ☐ Major proposal/manuscript revisions

    If you selected grant submission or manuscript submission, please specify the funding agency and/or the name of the journal:

14. Has your perception about the role of patient or community stakeholders in research changed as a result of the Community Engagement Studio?
    ☐ Yes
    ☐ No
    If yes, please describe how your perception has changed:

15. What, if anything do you plan to change as a result of the feedback you received from the Studio? (check all that apply)
  ☐ Research question
  ☐ Research design
  ☐ Level of community / patient engagement in research activities
  ☐ Recruitment/retention strategies
  ☐ Consent process
  ☐ Data collection
  ☐ Data interpretation
  ☐ Dissemination
  ☐ Change in number of questions (i.e. survey items)
  ☐ More patient-centered questions
  ☐ Less technical/medical jargon
  ☐ More culturally relevant questions
  ☐ I do not intend to change anything
  ☐ Other

  Please describe other:

16. To what degree has the community expert input impacted the community or patient-centered components of your project? This includes community or patient preferences, needs, wants and values.
  ☐ No impact
  ☐ Minor impact
  ☐ Neutral
  ☐ Moderate impact
  ☐ Major impact

17. Please suggest three ways the quality of the Community Engagement Studio can be improved in the future.

1.

2.

3.

Appendix I

CE Studio Summary and Recommendations
Personalized HIV Care

Recommendations	
Elements important in personalized care: 1. Consistent and open communication between provider and patients. 2. Continuity of providers is essential; doctors, nurses and staff. 3. Incorporate holistic approach to care that includes mental health needs. 4. Take into account the variety of cultural variances across all patient populations.	**How EHRs are used in personalized care:** 1. Genetic testing should be a part of PC with a focus on inter-provider and patient education to maximize impact. 2. Take extra care in educating patients about their own genetic testing results. 3. Use EHR data with patient permission and full transparency to address concerns regarding privacy, insurance, etc.
Recruitment and Messaging: 1. Raise awareness of opportunities to participate by building collaborations with community partners, i.e. community organizations, faith community, caregivers, etc. 2. Get the word out via patients or advocates who are active in the LGBTQ or HIV+ community. 3. Utilize multiple forms of outreach: people networks, social media, traditional media, and providers.	

Initial thoughts about this project?

- This is an awesome idea.
- The project could be very informative.
- I appreciate all of the work that goes into HIV care. This would complement it.
- I love to be involved in work that uses lab/science.
- This sounds very educational and interesting.
- This focus could require lots of time to truly personalize (patient volume issues).
- I like that you are listening to us who are actually go through HIV to shape the project.

What does personalized care mean to you?

- There must be good communication between all of my providers.
- Honesty from my providers and I cannot feel like I am being judged. I also value openness.
- I must be able to trust my doctor/staff with sensitive information.
- There is sometimes a lack of cohesiveness – care does not feel synced – not sure who to trust
  - I receive conflicting information regarding meds or treatments.
  - Doctor turnover means you have to start over to rebuild trust.
- The doctor should be very knowledgeable about my disease but also my health history.
- There should be a focus on education and delivery of information. Info should be shared in a variety of ways so all patients can understand it.
- The providers and staff should be able to focus on certain populations providing care personalized to their needs based on culture, generation, etc.
- Open communication with doctor is a must – I should be able to share things easily.
  - Consistency with doctor changes – I must then share info with new doctor.
  - Continuity of care is a top priority.
- I should be able to tell my doctor everything without fear of being judged.
- Trust is important, you expect your doctor to understand all medical issues.
- Consistency of nurses and staff is also important.
- I want to feel heard.
- Address mental health issues – incorporate into care.
  - Need to be able to talk about how my diagnosis is impacting my mental health.
- I want to know more about genetic testing. It should be used in my care.
- Family history is good to know to help inform treatment. Should be included.
- I want to test everything that is available that could improve my care or treatment.
- Doctors should be honest if he/she doesn't have the answers.
- Doctors should be able to explain in plain English what is going on.
- I don't want people to self-diagnose. Be careful with how genetic testing info is used.
- I have concerns with privacy of information.
- Info should be concise. "Dumb down." We need to know facts.
- Too much information can be stressful.

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How valuable is this in improving care? Is it important in the HIV community?

What's important?
- It is very valuable to feel like you have somebody caring to support you. (doctors/nurses/staff)
- Early intervention specialist important.
- Important to not see "stereotypes." Personalizing care could ensure that everyone is seen as an individual.
- Peer advocates can alleviate overwhelming feeling and can connect to patients as individual people.
- It is also important to address the big picture, not just individually. Like provider turn-over.

Reaction of Others in Community
- Some people may feel like you are in their business. Those who are afraid of their diagnosis.
- Be prepared for some push-back.
- Some people who are HIV+ have trouble with diagnosis/reality

EHR
- I prefer to see the same provide so that they can access my information, records, testing.
- If you are incarcerated, records are difficult to obtain.
- I don't like shared EHR.
- "Risky" – a lot of stuff "they" don't all need to know. They being patients who panic or don't know what to do with the info or providers who aren't treating me for HIV or might treat me differently.
- Particularly, genetic testing information. I don't need all of my providers to know everything.
- I don't have a problem sharing medical history.
- Concerned about insurance companies accessing information they could use to deny coverage.
- Maybe you're only seeing a provider for one specific issue that is not HIV related. Would you want them to know your status?

Personalized Care Layers
- Engaging multiple institutions is important – mental health providers/judicial/community orgs-communication is key.
- Include holistic approach – yoga, meditation, address stress.
- Stress is the issue all HIV patients deal with chronically. Include mental health component.
- Present info in a variety of ways (i.e. medical animation). What medicines do to your body?
- Address issues related to physical ability/activity or inactivity.
- Determine access and insurance status and level of patient involvement.
- Amount of time to see doctors can be a burden; streamline the process. See all providers on same day, testing, etc.
- Consider a patient's social life and its impact positive or negative (friends, family).
- Give resources for the patients or caregivers to access to supplement care and quality of life.
- Identify what needs should be met with individual patients.
  - Religious/cultural. Different cultures have different medicinal resources/beliefs.
  - Social supports.
  - Address beliefs that might impact adherence (stop meds for summer to cleanse).
- I can't think of a church, yoga class, etc. where HIV is even mentioned.

What would community-engaged personalized HIV care research look like?

- Time is a factor. But people would be interested. Be sure "the ask" is doable and reasonable.
- Develop partnerships in the community.
- Have patients give advice about how you design the projects.
- Include recruiting through patient networks; use word of mouth.
- People who are already engaged will be more likely to say yes.
- Need to raise awareness of opportunities. Most of us do not know how to participate.
- There should be agreed upon expectations.

How could we better collaborate with the community?

- Pull them all together. Invite them to be a part of this project.
- Include faith community; pastors/churches. This could help with stigma.
- Get the word out. Use a lot of different methods to reach people.
- Invite community partners to participate.

Written Remarks from Comment Form

General thoughts about the project:

- Educational.
- Excellent forum for the community to become aware of CFAR.
- Great project.
- Enjoyed giving input.

What was good about the project?

- Informative.
- Personalized health care would be incredibly valuable.
- Personalized care layers – glad to know.
- Looking into factors that help and hinder HIV care will greatly benefit the HIV community.

What challenges do you think the project will have in the community (weaknesses)?

- I think HIV people have (in general) horrible self-esteem and may feel like they have nothing to contribute.
- Time is a factor.
- Meeting the part of the HIV community that may be reluctant to participate.

Strengths	What was good about project?
• Project not really clear. Study design fine. • Very good info. • Motivates me to do something. • Excellent concept. • The project is a great overall idea, that when put into place could help many people. • Easy group to recruit from. Connections to VUMC will ease the way.	• Incentivizing improved health behavior. • Personal approach to need and risk factors. • Having the $7K coverage in the worst-case scenario; no cost. • The willingness to put the project together to actually help people overcome risk factors. • Trying to humanize medicine and treatment; collaborations across disciplines.
What challenges do you think the project will have in the community?	**What would you like to see the researcher do differently?**
• Will fail if not sensitive to poverty, literacy, race. • Frequency of meeting times and sources of information being delivered. • Finding and keeping people that are as motivated about the program.	• Include parents/caregivers. They play an important role and are also impacted. • ER staff – increase their awareness. They do not have basic knowledge of HIV.

Appendix J

SAMPLE CE STUDIO FLYER