Community Engagement Studio Toolkit

Meharry-Vanderbilt Community Engaged Research Core
Vanderbilt Institute for Clinical and Translational Research
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For more information, go to: https://victr.vanderbilt.edu/pub/community/
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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 received from patient or community stakeholders proved 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, health researchers will come to view community input as essential to the planning and implementation 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 is a process that 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 Community Partners Network, Matthew Walker Comprehensive Health Center and the Neighborhoods Resource Center 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.

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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 (Michener et al 2012). Engaging community members, patients, community health and social service providers in research is complex and 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. It has also been shown to increase community trust and strengthen research recruitment activities. The CE Studio creates a framework for stakeholders to review and provide immediate feedback to the investigator 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 for strengthening research proposals, the Community Engagement Studio was created 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 their priorities, values and needs.

A Translation Studio is a guidance session where investigators present their research ideas to a small group of academic experts for feedback and refinement. Studios can be developed for any stage of the research process: hypothesis development, design, implementation, data analysis, or dissemination and translation of findings. The Community Engagement Studio is similar in purpose, but brings together community stakeholders as experts.

The CE Studio can be a valuable experience for research faculty of all ranks, post-docs, fellows and graduate students who are interested in receiving feedback from their population of interest on the relevance and or feasibility of their research ideas. It provides a structured forum to gain valuable patient or community insight and has the potential to transform the way community and academic investigators work together. In a CE Studio, members of the researcher’s population of interest serve as experts. The researcher gives a brief presentation about the research project and poses specific questions to the experts. The discussion that follows is guided by a neutral facilitator to elicit authentic and constructive feedback. Advance preparation by the researcher and stakeholders is essential to success. To optimize stakeholder
participation, CE Studio sessions are scheduled at a time and location convenient to community experts, and the experts are compensated for their time. Feedback from researchers and stakeholders who have participated in past Studios indicates that the experience increases the researcher’s understanding of, and sensitivity to the community, and creates an awareness of stakeholder priorities, values and needs. Participating in a CE Studio often prompts researchers to reflect on the significance and impact of their work. Stakeholders have indicated that the experience increases their understanding of the research endeavor, including the motivation of the researcher, and how and why research is conducted.

For the research team, the benefits of participating in a CE Studio include:

- Access to community experts from different settings without the complexity of scheduling multiple meetings;
- Immediate feedback at different stages of project development and implementation;
- An opportunity to build a relationship with community partners and deepen the understanding of their population of interest;
- Exposure to a community’s cultural nuances and possible historical issues; assessment of the feasibility and appropriateness of their project;
- Buy-in from key stakeholders.

If conducted during the earliest stages of project development, a Community Engagement Studio can be an effective tool to develop a strong partnership with stakeholders. 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, intervention design, survey 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

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What is the difference between a focus group and a Community Engagement Studio?

Researchers often ask what makes a Community Engagement Studio different from a traditional focus group. Community Engagement Studios are not intended as research. They provide a quick way to gain stakeholder input on the development or implementation of a research project. Institutional Review Board (IRB) approval is not needed to conduct a Community Engagement Studio as the stakeholders are not research subjects, but rather serve as experts or consultants. Focus groups, in contrast, are conducted with the use of an explicit interview guide where all questions have been pre-identified. In a focus group, the emphasis is on the subjective experiences of the group as opposed to the individual. CE Studios are used to dig deeper into the individual’s experience as it might relate to the group. CE Studio stakeholders may 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 CE Studio, the discussion is not limited to specific questions as it would be in a focus group. This allows the facilitator to focus the conversation 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.

Community experts listen while a researcher explains her work.

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3) The CE Studio Team

The CE Studio is implemented by a team that includes faculty, staff responsible for managing the 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 stakeholders.

Community Navigator
The Community Navigator’s responsibilities include recruitment and orientation of the stakeholders who serve on the expert panels, managing the logistics of the Community Engagement Studio, and following up on any resulting actions and recommendations (see Appendix A for Community Navigator Job Description). The Community Navigator is also responsible for making sure the appropriate documentation is completed for each Community Engagement Studio including capturing the stakeholder feedback from each session and the completion of evaluation surveys, and forms needed to process payment of the experts (e.g., external consultant form and the IRS W9).

The ideal candidate for the Community Navigator position is a person who has worked extensively in the community, but is also familiar with the academic research setting. While an understanding of research is helpful, it is critical that the Community Navigator be knowledgeable about working in stakeholder communities and has developed trusting relationships with key community leaders. Hiring from the community puts into practice some 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 guide the communication between the researcher and experts by creating a neutral environment that allows for open discussion. They should never interject their own opinions or bias into the conversation. The facilitator should have experience working with diverse populations and possess a strong understanding of power dynamics and how those dynamics can impact the dialogue of group conversation. Ideally, the facilitator has received training in facilitation that teaches skills and techniques that enable them to work with groups of individuals that may have come from a range of social-economic backgrounds and have varied learning and communication styles.

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.

A neutral facilitator can help balance power differences between researchers and community members.

Faculty
The faculty members of the team are available to provide guidance on identifying the population of interest, defining the questions that will be posed to the experts and coaching the researchers on communicating effectively with non-researchers and integrating the input they receive from the experts. The CE Studio team includes faculty experienced in patient-centered outcomes, community-engagement, comparative effectiveness and community-based participatory research.
4) The Researcher

Translational researchers of any rank 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 shared with the researcher early in the process – often before the CE Studio is formally requested.

Preparing for the CE Studio usually requires two meetings with the researcher and if appropriate, with key members of the research team. In the first 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 2-3 main 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. At the second meeting, the CE Studio Team will review the presentation, making suggestions so that the language and images are appropriate for non-researchers, and 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.

Coaching the Researcher

The Community Engagement 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 work to non-researchers. Furthermore, they are accustomed to being the expert in the room. 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 first planning meeting, when giving instructions on the preparation of their presentation and when giving 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.

In preparing the presentation, the researcher must remember the expert panel needs 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.
The Researcher’s Presentation

Preparation: The presentation must be brief. No longer than 15 minutes total. It can be difficult to explain research concepts and procedures in layman’s terms, 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 layman’s terms. Keep text to a minimum and avoid complex tables, formulas and diagrams. The researcher should share the presentation with a non-researcher at least once before the CE Studio, and ask for feedback.

Presentation Template (See Appendix C for sample presentation)

PowerPoint is a favored method of presentation among researchers. This format can be effective in a Community Engagement 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. Questions for the expert panel (these represent the specific areas the researcher needs community input on – no more than 2 or 3 questions)

“The facilitator briefed me in advance about listening, which I really needed.”

Researcher

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5) The Community Experts

Community members, be they patients, caregivers 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 experts bring different experiences to the table providing the researcher with insights into the community of interest 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.

The Ideal Community Expert:

- Is a member of the population or community of interest and/or extensive knowledge of population or community of interest (by training or service)
- Shows evidence of leadership or advocacy for the population or community of interest
- Has good verbal communication skills
- Has good listening skills
- Has a desire to learn about research

Community experts should be recruited in a way that will ultimately create 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:

- 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-based organizations that serve specific populations (e.g., seniors, youth, parents)

Stakeholder recruitment may initially focus on the specific needs of the researchers that are requesting a CE Studio, but the end goal should be to create 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 CE Studio experts, bringing their unique experiences and perspectives to research. Written parental permission is needed for experts 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. Experts are compensated $25.00 per hour (generally $50.00 per CE Studio). The rate of $25/hour is based on the local average value of volunteer time as estimated by The Independent Sector https://www.independentsector.org/volunteer_time.

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

The 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 that would be useful. The Guide also outlines the purpose of the CE Studio, the role and expectations of the expert panel and the specific steps of the CE Studio. Because many of the experts may not be traditional community “gate-keepers” and are typically not familiar with research, the Community Navigator should be prepared to answer basic questions about the CE Studio process and purpose.
The following is a list of common questions commonly asked by community experts when recruited for a CE Studio:

**Q. What makes me an expert?**
A. Your expertise is your knowledge of a particular community and/or your experience with a health issue either personally or as a caregiver. 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 successful.

**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 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 Expert examines research recruitment materials.
6) Getting Started

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 the application can be completed online and will be connected to an online database 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.

Cost
CE Studio costs include expert compensation, facilitator fees, food, supplies and staff time. We encourage researchers to include CE Studio costs in their grant proposals as institutional money is never guaranteed. The average cost is $1,500-$2,000, depending on the number of community/patient experts who participate (see Appendix G for cost estimates). CERC CE Studio costs are paid for through an institutional voucher system, covered by CTSA and institutional funds. The costs of up to two CE Studios per researcher can be covered through this voucher system. Researchers who need additional CE Studios are encouraged to include the cost in their own grants.

7) Logistics

Scheduling a CE Studio can be surprisingly complex. The time and location are determined based on the majority of stakeholder’s availability. 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 stakeholders should be present for each CE Studio. Sometimes life gets in the way and experts have to drop out. For this reason, it is recommended that a minimum of 10 stakeholders be recruited to ensure adequate participation. Food appropriate to the time of the meetings should be provided, i.e. breakfast, lunch, dinner or snacks. Many stakeholders will be coming from work or other activities. It is important that the location is convenient and easy to find and parking is available. The room should be equipped with a computer and
projector for the PowerPoint presentation and large enough that all of the participants are seated with enough space to eat and take notes during the meeting.

Step-by-step planning process

- Schedule planning meeting with researcher, and CE Studio team (facilitator, community navigator and faculty member).
- Identify potential stakeholders for the expert panel that fit researcher’s request.
- Provide orientation to stakeholders who have not previously participated in a CE Studio.
- Determine availability of all parties starting with the experts. Most CE Studios are held in the evenings and/or on the weekends as community members often are not able to take off from work to participate.
- Secure a location that is convenient to the stakeholders who will be in attendance.
- Meet with researcher/research team a second time 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.
- Mail or email a brief description of research project and questions to members of the expert panel and project related material if applicable (e.g., a survey that will be reviewed) in advance of the meeting when possible.
- Copy complete set of forms needed. Include any materials that will be reviewed by Experts, brochures, posters, etc.
- Confirm the attendance of all experts.
- Arrange for food and drink to be on location.

What to bring:

- 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.

The Meeting
The location of the meeting should be chosen based on convenience and accessibility for the 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. All participants should be welcomed warmly when they arrive. The meeting will progress in this way:
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.
- At the conclusion of the meeting, both researchers and stakeholders are asked to complete an evaluation survey. The expert evaluation is included in the Expert Orientation Guide (Appendix E) and the researcher evaluation can be found in Appendix H.

Writing experts’ comments validates their input and keeps the discussion on track.

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8) Following Up

For the researcher: A summary including the Community Navigator’s notes and verbatim written from the expert panel is shared with the researcher within one week of the CE Studio. See sample summary, Appendix I.

For the stakeholders: 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. Depending on the length of the study, it’s good to give the experts periodic updates on the project as well as any findings that are 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-through.”

Community Expert

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9) Impact
By mid-2015, CERC completed 43 CE Studios for 34 researchers and engaged 238 patient and community stakeholders, with an average of eight stakeholders per session. The projects represent a broad range of health topics and types of research, including clinical trials and comparative effectiveness research. Forty percent (17) of the CE Studios focused on minorities and underrepresented groups.

Researchers
The 34 researchers who completed CE Studios hold faculty appointments across all ranks, including 21 junior investigators and 9 full professors. They represent a wide range of disciplines, including cancer epidemiology, biomedical informatics, pulmonary and critical care, neurology, human genomics, obstetrics, and clinical pharmacology. Four researchers sought multiple CE Studios to query different stakeholder groups (e.g., patients and community providers) or address distinct topics (e.g., survey design and participant recruitment). The most common reasons for requesting a CE Studio were to obtain input on research design, participant recruitment and retention and dissemination of results.

Evaluations completed by researchers indicated that they felt that the stakeholder input improved the quality of their research. Overall, researchers were very satisfied with the CE Studio and agreed or strongly agreed that the right stakeholders were at the table and that the feedback was appropriate. The researchers also indicated that that the experience increased their understanding of and sensitivity to the study populations; that the stakeholder input informed the feasibility of their project; and that their strategies for recruitment and plans for dissemination were improved.

Stakeholders
The community stakeholders that have participated in CERC’s CE Studios represent a broad range of health conditions, level of education, socioeconomic status and race and ethnicity, including populations often considered hard to reach. Most of the stakeholders are women (68%) and 55% identify as members of racial and ethnic groups that are typically underrepresented in research. Education ranges from high school diploma to terminal professional degrees. Fifty-six have participated in more than one CE Studio and 12 have taken on additional research roles including advisory council, research team, co-author and IRB committee and Co-PI.

In post-CE Studio surveys, stakeholders reported an overwhelmingly positive experience: 97% strongly agreed or agreed that they received enough information from the investigator to give appropriate feedback and 99% believed their feedback would improve the project. Almost all stakeholders 99% reported that the CE Studio was worth their time and 98% indicated they would be willing to participate again.

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10) Marketing

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.

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APPENDICES
Appendix A

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.

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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. The average cost is $1,500-$2,000, depending on the number of community/patient 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.

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

Primary Care Clinic
Cardiology
Coordinated Care Clinic

The Cost of Care
- Taking care of yourself is expensive...
- It's even more expensive if you have a heart attack...

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)...

$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**

- Eligible patients
  - Enrolled in Vanderbilt Health Plan
  - Receive Primary Care at Vanderbilt
  - Are “High-Risk” for Development of CVD
- Randomization
  - Coordinated Care Strategy
  - Usual Care Strategy
- Risk factor control
  - Patient Satisfaction and Patient Evaluation

• 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**

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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 here 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 here 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 here 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.

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

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. Changs 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’ll be 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!

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Appendix E

Expert Orientation Guide

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

Sponsor Award No: 3-UL1-RR025747-02S1
Sponsor Award No: UL1 RR024975 from NCRR/NIH
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 form 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 medications, devices, diagnostic products and techniques, and treatment regimens.

**Comparative Effectiveness Research (CER)**: the direct comparison of existing treatments to determine which 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 Engaged Research Core (CERC)**: The CERC offers assistance to both researchers and community organizations. CERC helps build community-academic research partnerships by offering training and assistance on the development and implementation of community-engaged research projects. [http://www.mc.vanderbilt.edu/victr/pub/community/](http://www.mc.vanderbilt.edu/victr/pub/community/)

**Community-based Participatory Research (CBPR)**: Community-based participatory research (CBPR) 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 (PCOR) 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.

**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/](http://www.mc.vanderbilt.edu/victr/pub/).
Appendix F

Sample Forms for *new applications*

Community Engagement Studio
Sample Forms
# Community Engagement Studio Expert Bio

## Contact Information

<table>
<thead>
<tr>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Street Address</td>
</tr>
<tr>
<td>City ST ZIP Code</td>
</tr>
<tr>
<td>Home Phone</td>
</tr>
<tr>
<td>Work Phone</td>
</tr>
<tr>
<td>Cell Phone</td>
</tr>
<tr>
<td>E-Mail Address</td>
</tr>
</tbody>
</table>

## Demographic Information

**Gender:** ___Male ___Female  
**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):__

## 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:
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 tell us whether you agree or disagree with the following statements:

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.
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

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
<th>Calculation</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Navigator</td>
<td>Prep meetings with researcher or research team: 2 hours</td>
<td>20 hours x $40/hour (based on $65,000 salary plus 24% fringe)</td>
<td>800</td>
</tr>
<tr>
<td></td>
<td>Recruitment and orientation of experts: 15 hours</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Meeting: 2 hours</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Written summary: 1 hour</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administrative</td>
<td>Meeting logistics and prep: 2 hours</td>
<td>4 hours x $17/hour (based on $28,000 salary plus 24% fringe)</td>
<td>68</td>
</tr>
<tr>
<td>Assistant</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Faculty</td>
<td>Researcher coaching</td>
<td>2 hours x $110/hour (based on $181,500 salary plus 21% fringe)</td>
<td>220</td>
</tr>
<tr>
<td>Facilitator</td>
<td>For prep meeting with researcher and facilitating and 2 hour studio</td>
<td></td>
<td>200</td>
</tr>
<tr>
<td>Experts</td>
<td>For participating in 2 hour meeting</td>
<td>2 hours x $25 x 10 experts</td>
<td>500</td>
</tr>
<tr>
<td>Meals</td>
<td></td>
<td>$12 per meal x 13 people</td>
<td>156</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td></td>
<td>$1,744</td>
</tr>
</tbody>
</table>

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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 tell us whether or not you agree or disagree with the following statements.

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 Review Board could be improved in the future.

1. 

2. 

3. 

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### Initial thoughts about the project:

1. There should be incentives for the group *not* in coordinated care center (CCC)?
2. Love the idea, if I could make time. Would my bill be zero balance or flat amount of $7K? Is there an upfront incentive for randomized group?
3. It’s an interesting, novel idea. Nice to see effort being made to fix a broken system.
4. Preventive care can be expensive (gym membership, yoga, etc.). This still sounds like a very physician-centered model of care; the *patient* has to be the one to lower risk: diet, exercise, etc.; Doctors can’t do it.
5. Like the concept. Lot of “ifs” and “buts”; i.e. weight is harder to manage when you’re older.
6. This could be a very good thing if it works
7. Where can I sign up? Whoever is footing the bill has the power. To modify behavior you need 1:1 ratio, force-feeding of information and support. Can’t just be from a provider.

### How do you feel about participating in the study? What concerns might you have?

7 Experts indicated yes, they would participate; 3 indicated maybe.

1. What information is the health center getting about my health condition? Will it affect my future insurance rates, etc.?
2. How long will this take?
3. Maybe share the percentages/statistics for risk of heart attack to encourage people.
4. Need to see snapshot of what participation looks like before I can decide on participating. How much time? How many visits? (i.e. number of visits, free Dayani membership, support groups)

### What would ideal CCC look like?

1. We learn from practice/education/others. How to cook your meals? Info/support around weight management.
2. Very interactive, with clear guidelines. Excite people. All in services in *one* place/location.
3. After-hours or weekend, with extended visits. 24 hours.
4. Dietician- Diet affects several risk factors (obesity, cholesterol, diabetes, etc.)
5. Personal trainers to motivate and show how and what to do.
6. Integrated, whole person approach: with offerings like acupuncture, meditation, yoga
7. Are cardiologists the right type of people to implement? This is so much bigger.
8) Control high BP. Some people don’t understand how to do this.
9) Need education. People are on different grade/education levels. Meet them where they are.
10) Mental health. Address emotional issues.
11) A multi-purpose space with gym, cooking class, people of different ages, not just with cardiologists. They are so many things that need to be changed.
12) Where people are economically is a factor in decision-making. What kind of food can they afford (fresh fruits/veggies), gym memberships, time to exercise.
13) Mental health - group activities are hard for me, but in the end I find them helpful.
14) Hands-on experiences are important.
15) Need someone to vent to... explain why I needed to eat that cake.
16) Motivation is key. Need someone or something to motivate you.
17) Peer-to-Peer. Offers tips and motivation more than someone in a white coat.
18) How to apply the education will be important. Break-out sessions tailored to your needs/interests. Diet change is number one.
19) Give patients choices about what they want to address first; diet, exercise, medications...
20) Staff/Volunteers from a lot of fields: personal trainer, art, mental health, health literacy (some scared/embarrassed).
21) Weight watchers group.
22) Someone who can personalize information and create a personal plan.
23) Consider income of participants. What can they afford to buy?
24) Dietician/health coach.
25) How to manage stress.
26) Medication education.
27) Core focus of visits with off-shoots of supplements.
28) Case management- mentor.
29) Selection of staff is important; they have to be able to relate to people/be someone that cares.
30) Set up so that there is a reward/incentive sooner; i.e. ticket to a Titans game.
31) Staff who make people feel comfortable.
32) Needs to be fun! When you leave you think “that was great!”.
33) Phone app to track/monitor health status; surveys.
34) Not too specific/need choices so everyone can plug in where it works for them.

Incentives should feed back into program.

The $7K financial incentive:

1) Wouldn’t look away from it, but would prefer something sooner.
2) Have a plan for people who are low income. The $7K might not be a motivator or factor the way it is structured.
3) Like the concept, but not everyone will see the incentive as worth it. Money might not be a motivator.
4) $7K I could access, maybe? Odd thing psychologically. You get rewarded if you do have the heart attack.
5) I’m a hope for best/prepare for the worst type so I like it.
### Ideas for Incentives:

1. Fit bits.
2. Subscription to health/fitness magazines.
4. Incentive tied to risk factor; specific session, etc.
5. $10 Kroger gift card would be nice. I’m easy, just something to get me started.
6. Massage or 1:1 with personal trainer; something service-based.
7. Weight watchers (for free).
8. Tickets to things; i.e. theater tickets/entertainment.
9. “Try this meal” samples people can take home.
10. Something to ID people who are participating (wristbands/chain to promote program).
11. Leave with basket of healthy foods/groceries to make specific meals.
12. Frequency of incentives: often and frequently; more often in the beginning 3, 6, 10 weeks, then quarterly.
13. Tie small incentives to meeting small goals.
15. Something monthly.

### Barriers to participation:

1. Difficulty accessing the program- wait times, parking, hours of operation.
2. If it’s too “Jenny Craig”; don’t want “same old thing”.
3. Time commitment; hours of operation and regular business hours may not work.
4. What if you move, leave Vanderbilt, are laid-off?
5. If it feels like a deception. If I go and it’s not what was promised. I don’t want to waste my time.
6. Privacy issue; who has access to my data?
7. Fine print. Hope to be in group that gets intervention.
8. Not having a support system.
<table>
<thead>
<tr>
<th>Strengths</th>
<th>What was good about project?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project not really clear yet. Study design sounds fine.</td>
<td>Idea of incentivizing improved health behavior.</td>
</tr>
<tr>
<td>Very good info.</td>
<td>Hearing others point of view - win-win.</td>
</tr>
<tr>
<td>Motivates me to do something.</td>
<td>The personal approach to the area of need and risk factors.</td>
</tr>
<tr>
<td>Excellent concept.</td>
<td>Having the $7K coverage in the worst-case scenario; no cost.</td>
</tr>
<tr>
<td>The project is a great overall idea, that when put into place could help many people.</td>
<td>The willingness to put the project together to actually help people overcome risk factors.</td>
</tr>
<tr>
<td>Easy group to recruit from. Connections to VUMC will ease the way.</td>
<td>Goals are brilliant. Trying to humanize medicine and treatment; collaborations across disciplines.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What challenges do you think the project will have in the community?</th>
<th>What would you like to see the researcher do differently?</th>
</tr>
</thead>
<tbody>
<tr>
<td>If it’s not truly sensitive to poverty, literacy, race it will fail.</td>
<td>Like the idea! Keep developing this!</td>
</tr>
<tr>
<td>How to change?</td>
<td>Keep working.</td>
</tr>
<tr>
<td>Frequency of meeting times and sources of information being delivered.</td>
<td></td>
</tr>
<tr>
<td>Finding and keeping people that are as motivated about the program.</td>
<td></td>
</tr>
<tr>
<td>Only open to Vanderbilt staff; biased group?</td>
<td></td>
</tr>
</tbody>
</table>

**Additional Comments**
Appendix J

SAMPLE CE STUDIO FLYER

Community Engagement Studios

WHAT IS A COMMUNITY ENGAGEMENT STUDIO?
A structured guidance session that engages patients, consumers, and other non-academic stakeholders in biomedical and clinical research, where they may serve as experts and provide feedback from a community perspective.

BENEFITS TO RESEARCHERS
◊ Community access simplified
◊ Building relationships with community partners
◊ Defining essential characteristics of study
◊ Immediate feedback at all stages of research
◊ Increased participation of hard-to-reach populations
◊ Strategies to disseminate results in community settings

BENEFITS TO COMMUNITY
◊ Community voice is heard
◊ Engagement in how and what type of research is conducted
◊ Ownership of opinions and valued input
◊ Ability to impact research process

Contact Tiffany Israel to schedule a Studio at 875-5665 or at tiffany.israel@vanderbilt.edu

Previously Engaged Disciplines
◊ Neurology
◊ Pulmonary and Critical Care
◊ Cancer Epidemiology
◊ Bioinformatics
◊ Human Genomics
◊ Cardiology
◊ Obstetrics
◊ Cancer Biology
◊ Clinical Psychology
◊ Behavioral Genetics
◊ Clinical Pharmacology

Focus of Past Studios
◊ Research Design
◊ Recruitment and Retention
◊ Dissemination
◊ Partnership Building
◊ Implementation
◊ Ethics and Consent
◊ Research Question Development

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