# A Thematic Analysis of the Impact of Community Engagement Studios on Community Experts' Attitudes, Desires, and Understanding of Research

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**Abstract**

Community Engagement Studios (CE Studios) are consultative sessions designed to provide community feedback on all stages of the research process from design to dissemination. CE Studios allow researchers to examine ways to enhance clinical and translational research by engaging with community members. Community members who are part of the patient population or target audience are defined as community experts. The purpose of this study is to examine community experts' attitudes, desires, and understanding of research resulting from their participation in CE Studios. We conducted thematic analysis across three separate questions. Ten major themes emerged from the data: involvement, togetherness, trust, value, confidence, community engagement, community connectedness, encouraging others to participate, increasing knowledge and awareness, and respect. One overarching theme of inclusion was also presented in the data. Results indicate that CE Studios provide a space for community experts to gain a better understanding of the multifaceted research process, provide insight into ways to target historically excluded populations, and increase experts' trust, confidence, and respect for researchers and the research process. Moreover, community experts felt connected to their community by participating in CE Studios and expressed interest in encouraging others to participate. Research studies should capitalize on CE Studios as a strategy to engage community members throughout the research process. Future research should determine whether CE Studios serve as a springboard to other leadership roles for community members and whether patient engagement models have a greater impact on patients and communities of color, rural environments, and other patient populations.
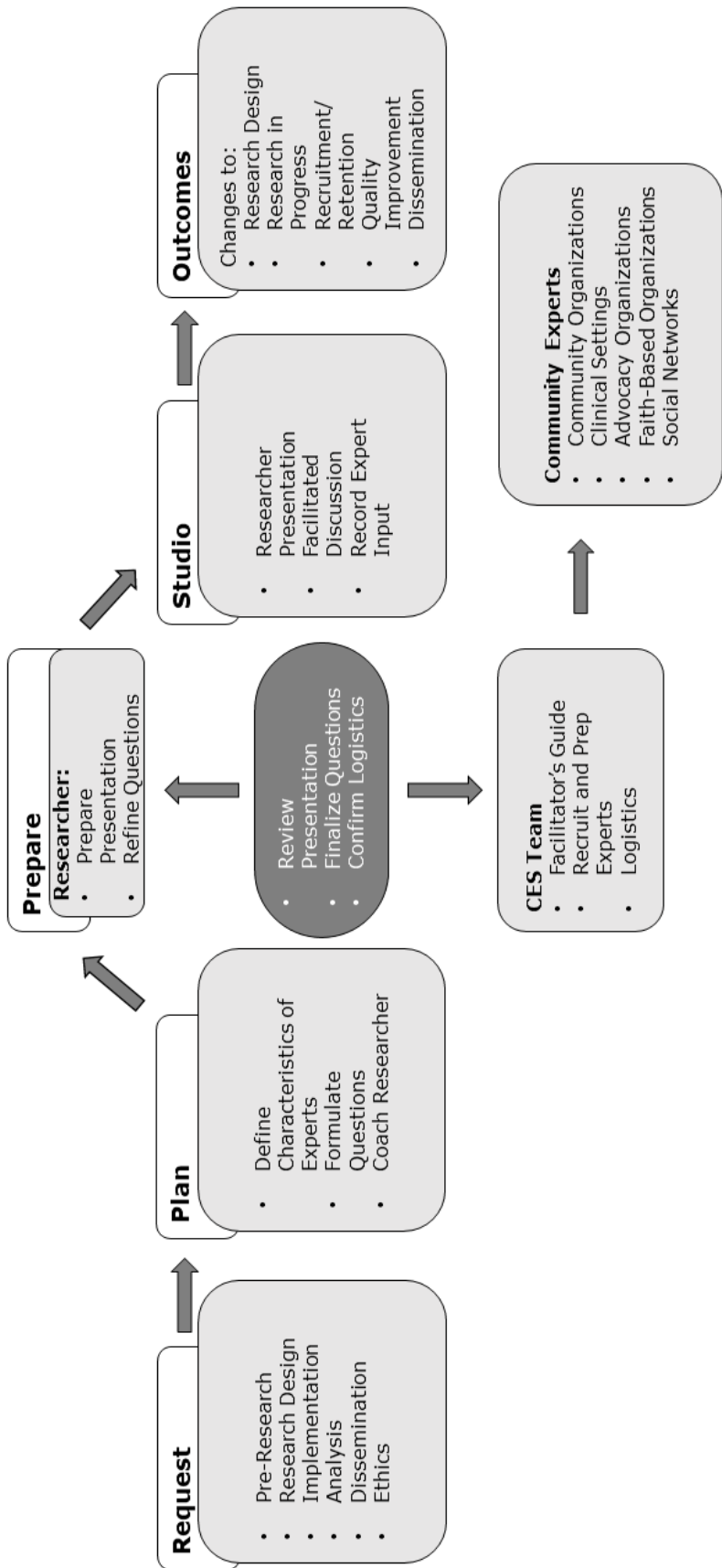
Recipients of NIH-sponsored Clinical and Translational Science Awards (CTSAs) are charged with creating more efficient ways of translating research to practice that ultimately impacts patients (Kain, 2008). Integrating patient and community feedback into research is critical to accomplishing this mission and can help to address multiple issues, including recruitment and retention of study participants, adherence to interventions in the context of research, and dissemination of research findings to the community at large (Bodison et al., 2015; Joosten et al., 2021; Selker & Wilkins, 2017). Studies have shown that engaging the community early and throughout the research process can increase the speed at which findings are translated into practice and improve the likelihood that these discoveries will be adopted by the population of interest (Bodison et al., 2015; Joosten et al., 2021).

Supported by a CTSA Award and the Office of Research at Vanderbilt University Medical Center (VUMC) and established as a strategic academic partnership between Meharry Medical College and VUMC, the Meharry-Vanderbilt Community Engaged Research Core (CERC) brings together academic leaders and community stakeholders to promote meaningful community and patient engagement throughout all phases of research. CERC offers a multitude of supportive and consultative services to both researchers and community-based organizations (Joosten et al., 2021). Services may be used to address issues that impact the health outcomes of patients and communities and to build communities' capacity to engage in research. Additionally, CERC services aim to support clinical trial decision-making and to translate and disseminate research findings into community practice more effectively.

Using the Clinical and Translational Research Studio as a template (Byrne et al., 2012), CERC developed the Community Engagement Studio (CE Studio) model to invite patient and community stakeholders to bring their own lived experiences with specific health diagnoses and knowledge of communities to the research process (Joosten et al., 2015). The CE Studio process has been described elsewhere in detail (Joosten et al., 2015). In brief, it is initiated by a researcher request and reviewed/ approved by the CE Studio team. The researchers and CE Studio team next hold a planning meeting with the goal of setting the context for the research

**Figure 1.** Steps of the Community Engagement Studio (CE Studio) Model

**Request**
- Pre-Research
- Research Design
- Implementation
- Analysis
- Dissemination
- Ethics

**Plan**
- Define Characteristics of Experts
- Formulate Questions
- Coach Researcher

**Prepare**
**Researcher:**
- Prepare Presentation
- Refine Questions

Review Presentation
- Finalize Questions
- Confirm Logistics

**CES Team**
- Facilitator's Guide
- Recruit and Prep Experts
- Logistics

**Studio**
- Researcher Presentation
- Facilitated Discussion
- Record Expert Input

**Outcomes**
Changes to:
- Research Design
- Research in Progress
- Recruitment/ Retention
- Quality Improvement
- Dissemination

**Community Experts**
- Community Organizations
- Clinical Settings
- Advocacy Organizations
- Faith-Based Organizations
- Social Networks

The CE Studio model involves a researcher request, a plan, preparation, conducting the CE Studio, and an assessment outlining the outcomes of the process.

team, narrowing the focus for studio feedback, and defining characteristics of the target population. Following the meeting, the CE Studio team recruits a finite group of community experts and orients each one to the project and process. The studio opens with a 10-minute presentation by the study team, after which a member of the CE Studio team facilitates the CE Studio discussion. All research teams are provided a detailed summary of the conversation that highlights key recommendations captured verbatim from community experts' feedback. Researchers are then tasked with using the information to reexamine their research approach and/or tactics based on feedback from CE Studio participants.

The CE Studio model has been used to enhance patient recruitment, experiences, and participation in clinical trials (Johnson et al., 2015; Nielson et al., 2020), and it has been adapted to improve researcher access to rural and frontier populations (Coulter et al., 2019). Previous studies have also demonstrated the important role that CE Studios play in expanding clinical and translational science by engaging the community early and throughout the research process (Joosten et al., 2018). The CE Studio model has been used successfully for 11 years and has informed numerous national multisite clinical trials, including the "All of Us" Research Program (The All of Us Research Program Investigators, 2019). In addition to informing a range of clinical trial activities (recruitment, retention, study design, data collection, etc.), CE Studios have been used to improve internal hospital systems and behavioral health models and to develop new systems of care.

Stakeholders who participate in CE Studios are referred to as community experts. Community experts are classified not as research participants but as consultants tasked with providing input to the specified research study and compensated based on the local average volunteer rate (Joosten et al., 2015). Community experts represent a wide range of individuals and can include patients, care-partners, providers, and organizational representatives. Each CE Studio stakeholder group is made up of community experts representative of the researcher's patient population of interest or a finite group whose lived or professional experience can be utilized to inform the project. For example, a group of African American faith leaders may serve as community experts to inform a research project identifying strategies of implementation via a local faith network. Other CE Studios have included community experts diagnosed with a particular chronic health condition (e.g., diabetes or kidney disease) who are invited to discuss specific barriers that exist to participating in clinical trials.

Engaging the community consistently and authentically is challenging, and CE Studios serve to minimize this challenge. Despite growing research highlighting how CE Studios can inform research projects, to our knowledge this is the first study to qualitatively assess how CE Studios impact the community experts themselves. Therefore, the purpose of this study is to examine the impact of CE Studios on community experts' attitudes, desires, and understanding of the research process.

## Methods
### Study Setting and Design
We conducted a retrospective analysis to assess attitudes toward research, desire to engage in research, and understanding of research among

**Table 1.** Demographics of Community Experts

| Gender | N | % |
|---|---|---|
| Female | 67 | 58.3% |
| Male | 47 | 40.9% |
| Other | 2 | 1.7% |
| **Racial/ethnic identity** | | |
| White | 60 | 51.2% |
| Black/African/African American | 41 | 35% |
| Hispanic/Latino/Spanish | 9 | 7.8% |
| American Indian/Alaskan Native | 3 | 2.6% |
| Asian | 2 | 1.7% |
| Other | 2 | 1.7% |
| **Educational status** | | |
| Graduate degree | 42 | 35.9% |
| Some graduate school | 5 | 4.3% |
| Bachelor's degree | 40 | 34.2% |
| Associate degree | 7 | 6% |
| Some college | 17 | 14.5% |
| High school graduate/GED | 5 | 4.3% |
| 8th–11th grade | 1 | 0.9% |
| **CE Studio participation** | | |
| 1–4 | 95 | 82.8% |
| 5–9 | 10 | 8.6% |
| 10–14 | 6 | 5.2% |
| Not sure | 4 | 3.4% |

community experts who completed in-person CE Studios at VUMC between April and September of 2019.

*Participant Recruitment and Data Collection*

We identified community experts who participated in at least one CE Studio at VUMC during the study period. Potential participants were emailed an invitation to participate in the study. Once approved, participants were sent details to complete an online survey. Monthly reminders to complete the survey were sent via email. A $10 gift card incentive was provided to all participants who completed the survey. Study data were collected and managed using REDCap electronic data capture tools (Harris et al., 2009). All policies and procedures were approved by VUMC's institutional review board.

The survey collected basic demographic information and included questions from a larger online survey previously developed to address the experiences of community experts who participated in CE Studios. The following three open-ended questions were assessed for this study:

- *Attitudes.* Community experts were asked, "How has your participation in CE Studios impacted your attitude toward research?"
- *Desires.* Community experts were asked, "How has your participation in CE Studios impacted your desire to be engaged in research?"
- *Understanding of Research.* Community experts were asked, "How has your participation in CE Studios impacted your understanding of research?"

*Data Analysis*

Demographic data were summarized using descriptive statistics. Open-ended survey questions were reviewed by two researchers who coded the transcripts (Braun & Clarke, 2013). Thematic analysis, as outlined by Braun and Clarke (2013), was used to organize and analyze the data. Two researchers reviewed the qualitative data separately and convened to establish consensus on final themes resulting from the coded data. Researchers coded data until thematic saturation was met. Participants' responses were kept confidential.

## Results
### Demographics of Participants

A total of 117 community experts responded to the survey. Of the respondents, 84 completed the question assessing attitudes, 70 responded to the question addressing their desire to engage in research, and 74 completed the question addressing their understanding of research. The majority of participants were female (58%), had completed between one and four CE Studios (83%), and had at least some college (95%). The racial/ethnic breakdown of participants was as follows: White (51.2%), Black (35%), Hispanic (7.8%), American Indian/Alaskan Native (2.6%), Asian (1.7%), and Other (1.7%). One participant did not indicate gender identity and two did not disclose their number of completed CE Studios. Refer to Table 1 for the demographic breakdown of participants.

### Themes: Inclusion

Across the questions examining attitudes, desires, and understanding of research, one crosscutting theme of *inclusion* emerged in the data. Community experts addressed the importance of participating in research and the resulting outcome of engaging the community in various stages of the research process. Beyond the value they perceived for their communities, community experts themselves felt heard and appreciated being included in the research process. One participant stated:

> I appreciate knowing that care and concern goes into the population selection for the study. Knowing that such careful considerations are given, it makes me more apt to not only answer responses—but to engage transparently. When it feels like researchers truly care about your responses, it's easier to speak candid truths as opposed to saying what they want to hear.

This statement represents the benefits of involving community members in the research process and the candid responses received as a result. Attracting community buy-in is one of the goals of community engagement. As a result of participating in CE Studios, community experts also emphasized feeling the weight of their opinions on the research process. One participant stated that "the inclusion of opinions based on personal experiences raises their confidence in research results" and another mentioned that "it made me realize that the researchers really do care about what we have to say, much more than I thought originally." Community experts also felt the responsibility to resolve health disparities as a collective process involving researchers and community members and that "we are all in this fishbowl together in the process of finding solutions."

*Attitudes Toward Research*

Eighty-four participants (73%) responded to the open-ended question assessing their attitudes toward research. Five major themes emerged from the data: involvement, togetherness, value, confidence, and trust.

**Theme 1: Involvement**. Community experts expressed that their attitudes about research became more favorable as a direct result of their participation in CE Studios. Understanding the importance of being involved in the research process—not only for themselves but also for members of their community—was an overarching response. One participant discussed their underlying knowledge about research studies, but their direct involvement in CE Studios made them want to participate in research. They stated, "I have always thought research studies were important, but this project had me interested in participating." One community expert stated that they now "understand they [researchers] need insight from others who would be impacted by their research project." Participating in CE Studios prompted community experts to view how research can impact their health, indicating that "the experience has helped me to value my experience with my health in a different way."

**Theme 2: Togetherness**. Participating in CE Studios shifted community experts' attitudes toward togetherness. *Togetherness* was defined as the research process being a joint effort, with no one process falling solely on the hands of the researcher or members of the community. One community expert stated how they were "pleasantly surprised how much our input was incorporated into the researchers' next steps." Many participants also discussed the openness of the CE Studio environment, which made it easier for participants to communicate their ideas. One participant explained, "It was a welcoming environment to share ideas with people that were non-confrontational." CE Studios have encompassed an array of participants, from community members who have been impacted by certain health conditions to researchers themselves. One participant shared how their participation created a shift in their mindset when it came to conducting their own research. They explained:

> It made me think more about ways that research can include community members in the planning and execution phase. As I also conduct human subjects research, I feel that a CE Studio would be a good step in some of my future projects.

**Theme 3: Value**. Participants expressed how participating in CE Studios made them feel valued and, in turn, enhanced their understanding of the value of research. One community expert mentioned that they "came to respect the fact that others value my opinion when wanting to develop products, services, and solutions." Another community expert expressed that "they value the importance of being heard." Many participants echoed this experience. Furthermore, participants also expressed the value in communicating with members of the community during the research process, noting that research is not a one-size-fits-all approach. One participant stated, "By listening to all who participated, I realized how diverse our city has become and the importance of community input."

**Theme 4: Confidence**. Community experts' confidence in the research process increased because of their participation in CE Studios. One person stated that they felt "confident knowing what efforts are being made to ensure positive outcomes and improvement in delivery of objectives." Soliciting feedback from community experts demonstrated to them that researchers had a vested interest in obtaining positive health outcomes among the study population. Confidence in the research process extended beyond the specific study. Engaging in the CE Studio process increased CE experts' confidence in the "improvement of social science research." One participant expressed that they now "believe in the power of research and the countless possibilities it has to offer."

**Theme 5: Trust**. Trust was another major theme presented in the data. Community experts emphasized how participating in CE Studios enhanced their ability to trust the research process. Taking part in a CE Studio enhanced participants' understanding of the research process and in turn increased their "trust in research and researchers." One participant stated, "I am not as apprehensive about research or researchers as I was, being an African American, we have always been told not to volunteer for research or medical trials." Their experience as a member of a historically excluded population limited their desire to participate in research. However, this particular experience with CE Studios changed their perception of research participation. Several researchers also mentioned that the CE Studio created a trusting environment for participants to share their experiences and provide feedback on different aspects of the research study.

**Figure 2.** Overall Themes
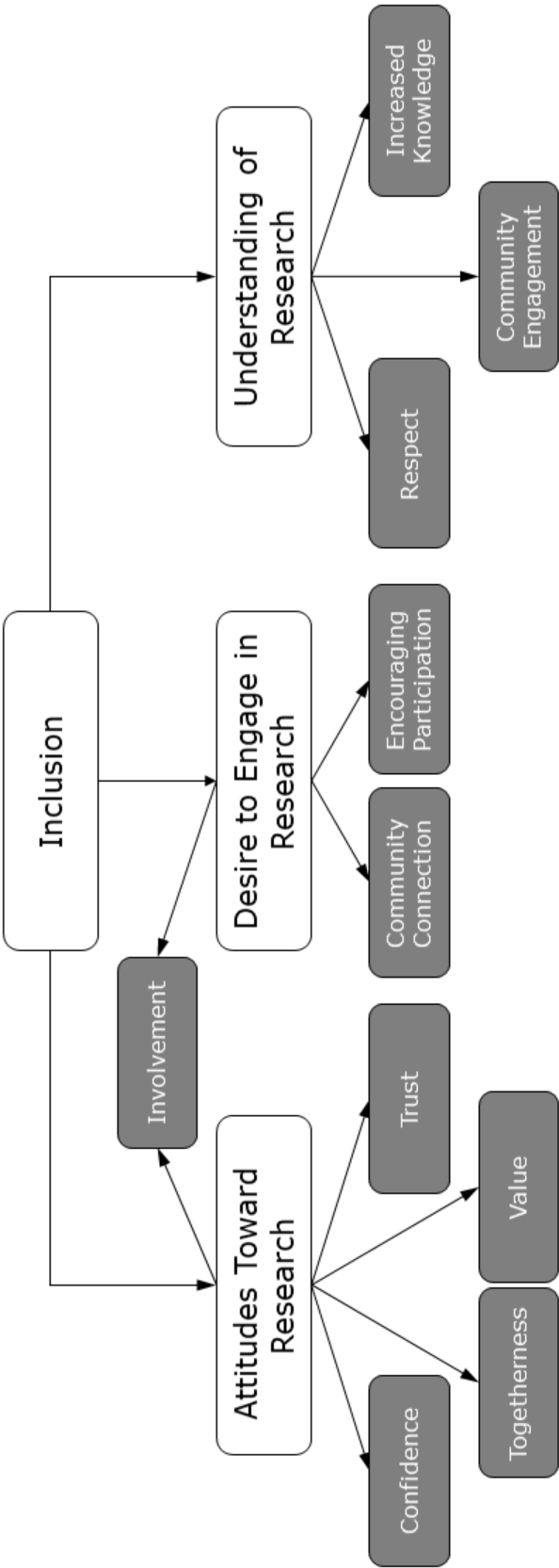


This visual model represents the relationship between themes across questions addressing community experts' attitudes toward research, desire to engage in research, and understanding of research.

*Desire to Engage in Research*

Seventy (61%) community experts responded to the open-ended question examining how participating in a CE Studio impacted their desire to engage in research. Three themes emerged: involvement, community connection, and encouraging others to participate in research.

**Theme 1: Involvement**. Community experts desired to become more involved in the research process as a result of their participation in CE Studios. This desire extended to future CE Studios and/or other research projects. Participants expressed a sense of gratification to be able to represent members of the community. One community expert stated, "I'm proud to be part of a process designed to have a positive influence in the lives and experiences of patients. I look forward to taking part in more CE Studios." Community experts also mentioned how their participation exposed them to other research opportunities. A participant indicated that their engagement in a CE Studio led to "an invitation to join the Adaptable Study," another research project soliciting input from community members.

**Theme 2: Community Connection**. Participants mentioned that their desire to feel connected to their community was directly impacted by their participation in CE Studios. One participant expressed, "It makes me feel more connected with my community being able to represent them and act as an advocate for people that couldn't be heard before these studios." Community connection also came in the form of sharing one's thoughts. A community expert indicated that they "have a desire to give back to my community and continue being able to give my opinions and experiences." Their idea of being connected to the community stemmed from sharing their experiences with researchers and other community members.

**Theme 3: Encouraging Others to Participate**. Several community experts mentioned encouraging others to participate in CE Studios. Their favorable experience with CE Studios prompted them to encourage other community members to participate in the process. A community member expressed their increased "desire to want to recruit participants that need to be served." Community experts' encouragement of others to participate in research extended beyond an immediate need to help the community; advancing science was also a desired priority. One participant stated that they "encourage friends and family members to participate in research studies," emphasizing that "it's great to be part of something that could help push science/medicine forward!"

*Understanding of Research*

Seventy-four (64%) community experts responded to the open-ended question examining how participating in CE Studios impacted their understanding of research. Three major themes resulted from reviewing the data: increased knowledge/awareness, community engagement, and respect.

**Theme 1: Increased Knowledge/Awareness**. Many of the community experts indicated that their participation in CE Studios increased their knowledge and awareness of the research process. Although some participants had a basic understanding of research, the depth of their involvement in research through the CE Studio demonstrated that research is a multifaceted process. One participant stated, "It shows me doesn't have to be in a lab or on a super difficult computer program. It can be just a group of people talking and sharing experiences." Participants also mentioned that they did not know the level of planning and preparatory work that went into developing a research project from start to finish. One community expert mentioned that they "did not realize the different stages a research study involved before research begins." Some participants were also unaware of the importance of reaching out to community members through all stages of the research process. A community expert explained, "The depth and seriousness researchers have with informing the subject of all aspects of the research process" was something that they learned from the CE Studios.

**Theme 2: Community Engagement**. Community experts mentioned that participating in CE Studios showcased the importance of engaging the community at all levels of the research process. Many participants were unaware of how important community input was when developing and completing a research project. One participant explained that they had no idea that "the community was needed in this manner." Additionally, participants mentioned that interacting with research team members created a space for them to share their opinions with validation. One participant expressed, "Getting to talk directly with researchers was interesting and I appreciate the forum that CES [CE Studios] provided for them and us as a community to listen and be heard." Participants appreciated the effort

researchers made to involve community members. One community expert stated that they were "glad to see them reach out for our participation because we need to work closely together to improve patient outcomes." Central to this theme is the importance of connecting with community members to understand the experiences of those who will potentially be impacted by the research.

**Theme 3: Respect**. Several community experts explained their respect for research and researchers. Participating in a CE Studio demonstrated the intricate process of research, which community experts expressed their appreciation for. For example, one participant stated, "I have a greater appreciation of good research and how it can help the community, and all involved in the research." Respect stemmed from being part of the research process and seeing researchers who valued community input and feedback. Refer to Figure 2 for a visual summary of themes generated from the online survey data.

## Discussion

The challenge that exists in clinical and translational sciences is identifying ways to engage the community authentically and consistently in research. This study provides strong evidence that CE Studios serve as an effective strategy to engage the community throughout the research process. Understanding community experts' attitudes toward research, desire to engage in research, and understanding of research resulting from their participation in CE Studios provides insight into the mindset of community members. Results suggests that involvement in CE Studios impacts participants positively and shapes positive attitudes toward research and future engagement. According to study findings, *inclusion*—defined as community members and researchers collectively working together to address health concerns in the community—was an overarching theme presented in the data.

Themes resulting from the analysis support the idea of interconnectedness. Involvement, togetherness, community connection, community engagement, and encouraging others to participate in research were all areas of importance for community experts. It was apparent in community experts' responses that they placed high value on being heard and contributing to the overall good of the community. In community-engaged research, confidence in researchers and trusting the research process are both significant components. Connecting with community members to create

a space where participants felt confident in the research process increased their level of respect for research and researchers. Additionally, several community experts expressed an increase in knowledge about what the research process entails. That increase in awareness further led to an increased respect for researchers associated with the amount of effort and detail necessary to navigate research projects. These results align with a previous study that quantitatively captured responses from community stakeholders participating in CE Studios, which indicated that an overwhelming majority of participants believed their feedback would improve the research project (99%; Joosten et al., 2015). However, the current study differs from the earlier study in that it captures the personal experiences of those participating in CE Studios and examines a perspective not outlined in detail in the literature.

## Implications for Research, Practice, and Policy

This study emphasized the importance of gathering opinions from community experts as it pertains to their experiences engaging in the research process. These experiences may be used to help inform research projects and provide insight into recruitment and retention of individuals from diverse demographics.

One of the most-cited barriers to engaging communities of color in health research is mistrust (George et al., 2014). This mistrust may originate from historical instances, such as the Tuskegee Study, or from personal experiences within the health care system (Griffith et al., 2021; Williamson & Bigman, 2018). This idea of trust is essential to building strong partnerships, especially among researchers and community partners (Wilkins et al., 2019). Although mistrust in the health care system was evident in participants' responses, it was also evident that participation in CE Studios has impacted the narrative around trust. Furthermore, underrepresented populations not traditionally engaged in research are represented in this study. Engaging underrepresented populations in CE Studios can serve as important step to repairing the legacy of fractures stemming from distrust in the health care system.

In addition, this study demonstrates the need to engage the community in all phases of the research process from implementation to dissemination. The conceptualization of this study and its design are heavily rooted in principles of community-based participatory research (CBPR). CBPR emphasizes building trust through equitable

partnerships and, in doing so, works to develop a deeper understanding of the needs within the community (Coughlin et al., 2017). Changing attitudes and developing a better understanding of the research process produces buy-in from community stakeholders and community experts, which leads to increased participation from both the individual and other community members.

Community experts appreciated an environment in which collaboration, respect, and confidence occurred simultaneously. Community stakeholder and patient representation is necessary to ensure that research is focused on community priorities and outcomes. Patient input can be used to inform discussions around funding, policy, and systems of care. Patient engagement in these spaces can build trust, identify strategic areas for improvement, and expedite dissemination of research findings to the community. Previous research has shown that collaboration between patients and researchers has led to new outcome measurements, refinement of research questions, and the overall empowerment of research participants (van der Scheer et al., 2017). Utilizing models similar to the CE Studio has the potential to increase participation, improve retention, and build needed connections in historically excluded communities. Future research should explore alternate data collection methods for gathering feedback from communities of color, including individual interviews and/or focus groups, which might be better suited for these populations than an electronic survey.

A study conducted by Danila and colleagues (2021) discussed how CE Studios assisted in the recruitment and preparation of community members participating in a research study designed to culturally tailor tools to enhance clinical trial recruitment. Future studies should examine how CE Studios could be used as a springboard to increase community participation in advanced leadership roles. Advanced leadership roles include, but are not limited to, advisory councils, community investigators, internal review boards, and other positions of influence. CE Studios may provide the baseline knowledge for community members to learn about the research process, leading to additional leadership roles within research. This trajectory is a critical step in the advancement of clinical and translational sciences. Future research should also determine whether patient engagement models (e.g., CE Studios) have a greater impact on patients and communities of color, rural communities, and other patient populations whose rates of inclusion in clinical trials are not reflective of the general population.

Financial allotments for community engagement policies and procedures are warranted. Policies targeting allocation of funding for community-engaged research at all stages of the research process are critical to maintaining and further exploring the impact of engaging community members in the research process. The shift toward financial compensation for community members and researchers should occur not just at the national level but at the institutional level as well. Developing institutional funding policies designed to promote community-engaged research are necessary for the advancement of clinical and translational sciences and ultimately for eliminating health disparities.

**Limitations**

A few study limitations must be noted. This project relied on self-reported data from CE Studio participants. Self-reported data is subject to recall bias. Although we had between 61% and 74% of participants respond to survey questions, we were not able to capture all community experts' experiences with CE Studios. Our participant pool was limited to researchers' needs for previously conducted CE Studios. However, those who completed the survey reflected a more racially diverse population than traditionally seen in clinical trial participants. Our study population also reflects a more educated population, with over 90% of participants having some type of exposure to college, which is higher than the general adult population. Results from this study are reflective of feedback received from a wide variety of individuals across numerous health conditions and research contexts. Like other findings from qualitative research studies, community experts' experiences are unique and not generalizable.

**Conclusion**

Findings from this study demonstrated that community experts play a critical role in the advancement of clinical and social science research, not only with their personal experiences as the target population of interest but also with their ability to share their experiences with others and encourage future participant involvement in research. This study reflects several positive outcomes resulting from community-engaged research, including but not limited to an increase in trust and confidence in the overall research process.

CE Studios have impacted community experts in a way that has increased their understanding of the research process, prompted them to connect with other members of their community, and value research and researchers. Community experts are a crucial component of the research process, and their experiences should be utilized and reflected upon as we work to reduce health disparities.

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