

# COVID-19: An opportunity to engage African Americans and women in research on cardiovascular disease

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**Abstract: Introduction:** African Americans (AA) have been disproportionately affected with the COVID-19 disease experiencing 30%-60% of the deaths, while only making up 13% of the US population. Early data suggest that pregnant women and those with cardiovascular disease (CVD) may experience worse outcomes with severe coronavirus infection. There is an urgent need to incorporate AA and female perspectives into the design of research on the CVD complications related to COVID-19.

**Objectives:** The goal of this project was to incorporate perspectives of AA and female patients in developing research priorities and AN agenda related to COVID-19. Objectives included: (a) develop a strong, research-ready partnership capable of executing PCOR, (b) creation of a research agenda and a set of priorities on racial/sex-specific CVD disparities in COVID-19 which reflects the perspectives of AA's and women; (c) long-term objective is creation of a set of research questions suitable for clinical research using the AHA Registry.

**Methods:** The project used principles of active and adult learning within the framework of capacity building to build a strong, patient-centered vision of research needs. Different methods of obtaining patient input were used to identify questions suitable for research using the America Heart Association COVID-19 CVD Quality Improvement Registry: focus groups and town halls to identify concerns and interests vis-à-vis CVD and COVID research; narrative medicine methods collected compelling real-life, COVID-19 health stories; a research advisory council reviewed and prioritized research questions.

**Results:** Outcomes include a replicable method of obtaining patient-oriented input into the creation of a research agenda and a set of research priorities for COVID-19. Outputs include the establishment of a research advisory council and stakeholder training using the PCORI funded, PORTAL program resources; a catalogue of patient generated narratives on COVID-19 experiences in the voice of AAs and women, and a set of research questions suitable for research using the AHA Registry.

**Conclusion:** The project created a research ready stakeholder network, ready to develop a research agenda about COVID-19.

**Keywords:** Cardiovascular disease ■ COVID-19 ■ African Americans ■ Women ■ Community engagement ■ Patient centered outcomes research

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**Abbreviations:** AA, African Americans; CVD, cardiovascular disease; PCOR, patient centered outcomes research; PCORI, Patient Centered Outcomes Research Institute. © 2023 Published by Elsevier Inc. on behalf of National Medical Association.

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## 1. INTRODUCTION

The COVID-19 pandemic has shed new light on longstanding and wide-ranging health disparities in the United States. African Americans (AA) have been disproportionately affected by COVID-19, experiencing 30%-60% of the deaths while only making up 13% of the US population.<sup>1-6</sup> Risk factors such as hypertension, diabetes, advanced age, obesity, and established cardiovascular disease (CVD) are associated with increased morbidity and mortality from COVID-19.<sup>5,7-9</sup>

While racial disparities in CVD care are well-documented, less universally appreciated but equally as important are the racial disparities in maternal mortality. In 2020, 861 women died from pregnancy related complications compared to 700 women in 2019.<sup>10,11</sup> A recent study found pregnancy related mortality ratios were 4-5 times higher among AA women compared to their Caucasian counterparts.<sup>11</sup>

Advancements in treatment for COVID-19 will require research that includes all members of our diverse society in order to gain a comprehensive understanding of the disease process and therapeutics. Current evidence shows that an engaged community of stakeholders can increase the relevance of research, improve research recruitment and retention, and lead to the development of research which is meaningful to the community it is designed to serve.<sup>12,13</sup> Furthermore, there is an urgent need to incorporate the needs, preferences and perspectives of AA's into the design, execution and dissemination of research on the CVD complications related to COVID-19 given the disproportionate burden they endure from this disease. COVID-19 presents an opportunity and a teachable moment in which AA's can learn about patient centered outcomes research (PCOR), the research process, and understand the embedded protections potentially leading to a decrease in the mistrust of the process. The goal of this project was to incorporate the needs, preferences, and perspectives of AA and female patients in developing research priorities and agenda contributing to the future design of research

on the CVD disparities related to COVID-19. This paper describes the community-based participatory principles (CBPR) and methods utilized to develop a strong, research ready partnership capable of executing PCOR on racial and sex-specific CVD disparities in COVID-19.

### 1.1. Project goals

Patient-centered care refers to care that places the patient in the center of the process, incorporates their perspectives, and values; requiring health care providers to work collaboratively to coordinate the needs of patients.<sup>14</sup> Likewise, patient-centered outcomes research (PCOR), incorporates the patient's perspectives in the research endeavor. In this project, our team used these principles to establish a network of patients and key stakeholders to collaborate on developing a research agenda and setting research priorities to address the racial/sex-specific CVD disparities observed in COVID-19. The overarching goal of this project was to incorporate the needs, preferences, and perspectives of AA and female patients in the design of future research on the CVD complications related to COVID-19. An additional goal was to develop the skills of all stakeholders, creating meaningful partners in research. Our community stakeholders were recruited from the Greater Philadelphia area, with a predominant focus on the North Philadelphia section of the city. This section is a federally recognized safety net community.

## 2. MATERIALS AND METHODS

In 2021, Temple Heart and Vascular Institute (THVI) and the Office of Community Engaged Research and Practice (CERP) at Temple University developed the Collaborative for Cardiovascular Health Equity in North Philadelphia. The collaborative brings together the THVI and CERP with a shared mission to achieve cardiovascular health equity for the residents of North Philadelphia. Our collaborative team consists of 4 academic faculty members/staff, who self-identify with the following demographics: 2 African Americans, 1 mixed race, and 1 Caucasian team member. All members are female and of varying ages. Team members have expertise in cardiovascular medicine, and public health research using mixed-methods design. The project occurred from July 1, 2020-June 30, 2021.

To accomplish these goals, we aimed to: conduct focus group interviews to assess baseline knowledge regarding CVD research and COVID-19 among AA and female patients in Philadelphia, PA; hold social media events (e.g., Facebook town halls, Twitter chats) to solicit feedback from the larger community about CVD and COVID-19; convene a Temple research advisory council (TRAC) to

identify and help prioritize research themes and questions; and develop a compendium of individual experiences with COVID-19 using principles of narrative medicine. The anticipated end-products were a research-ready network, a prioritized research agenda for CVD and COVID-19 that reflects AA and female patients' experiences and concerns, and a pathway for the dissemination of new information into the stakeholder community.

### 2.1. The research advisory council

Using community participatory principles, our team established a network of patients and key stakeholders to collaborate on developing a research agenda and setting research priorities to address the racial/sex-specific CVD disparities observed in COVID-19. Specifically, we leveraged an existing relationship between the THVI, Triumph Baptist Church, (a large AA church (50,000 sqft facility) with average Sunday attendance of 1500 people, and a total membership of 6,000 who are supported by over 20 clergy) located in North Philadelphia, PA, and Temple Womenheart peer support group, of which THVI has been a member for 2 years. This existing partnership provided a large pool from which to recruit stakeholders for the town halls and focus group interviews, described in more detail below.

We convened a 6-member advisory council which met virtually for 1 h each month. The council was comprised of 6 members with diverse backgrounds. Two were leaders in faith-based organizations, 2 were heart disease patients, 1 was a medical student and 1 was an executive from a local community-based organization. In terms of demographics, most were women (n=4) and identified as Black (n=5).

Over the course of the first 3 months, the TRAC was trained in Patient Centered Outcomes Research (PCOR), stakeholder driven research, and how to design a research study and develop research questions using modules from the Research Fundamentals series developed by the Patient Centered Outcomes Research Institute (PCORI) and PCORI's PORTAL program resources.<sup>15,16</sup> We also trained TRAC in principles of narrative medicine, described below, and prepared them to write personal narratives of their own COVID-19 experiences. TRAC members completed a brief online survey after our first and last meetings to assess changes in understanding of the project and TRAC member's roles, perceptions of the partnership with the project team, and satisfaction with the experience. TRAC members were offered a \$50 Visa debit card for each meeting attended.

### 2.2. Focus groups

To assess baseline knowledge regarding CVD research and knowledge of COVID-19 and generate research questions

from the larger community of AAs and women, we held a series of virtual focus group interviews. The domains of inquiry included knowledge and experience with heart disease and COVID-19; awareness of COVID-19 and heart disease interactions; trusted information sources; experience with testing; vaccine concerns; COVID-19 experience during pregnancy. Emergent themes were also identified and explored, including mistrust of health care system and US Government, racism in particular as experienced in the healthcare system, stress and mental health. Community members were recruited to participate from the Temple Heart and Vascular Institute (THVI), Triumph Baptist Church (a large AA church), Temple Womenheart peer support group (THVI has been a member for 2 years), and through local community organizations. Focus group meetings lasted approximately 90 min and were held using the virtual meeting platform, Zoom. Participants received a \$25.00 Visa debit card as incentive. In all, 28 people participated in 5 focus groups. Each focus group met once. Three review sessions with original focus group participants and one session with TRAC were held to review and confirm our interpretations.

### 2.3. *Virtual town halls and Twitter events*

We held virtual town halls and Twitter chats to extend our reach into our stakeholder community. These events featured presentations on CVD and COVID-19, including vaccine development, by local health care providers, afforded a venue for attendees to ask questions, and solicited questions from the community that were translated into research questions. Attendees completed a brief online survey upon registration to capture demographic characteristics. We used Poll Everywhere software and Zoom's polling feature during the event to ask participants about their views of the COVID vaccine, and vaccine preferences (e.g., one shot vs two; vaccine maker). After the town hall, registrants were sent a Qualtrics survey that asked about their interest and experience with clinical research studies, beliefs and experiences with the COVID-19 vaccine, experiences with COVID-19 and seeking regular heart care during the pandemic, and their feelings about COVID disproportionately affecting Blacks. A total of 52 people participated in the 2 town halls. Complete demographic and survey data were available in 44% of the respondents.

### 2.4. *Narrative medicine*

Research questions were also generated from AA's and female patient's personal experiences with COVID-19 and CVD. Personal storytelling has been endorsed as a model of medical practice which combines science and storytelling. Developed in the 2000's, narrative medicine uses

storytelling to connect physicians and patients in a shared experience building empathy and improving communication.<sup>17,18</sup> Narratives are recognized for their ability to engage and transport receivers. We asked TRAC members and focus group participants to write about their own stories of COVID-19 related health challenges and triumphs. These compelling real-life, COVID-19 health stories were considered in the development of research priorities and questions. The narratives and the social connectivity and shared experience they evoked also helped to engage our stakeholder communities.

## 3. THEORETICAL FRAMEWORKS

Our approach was informed by Hawe and colleagues' conceptual model for capacity building based on the principles of adult and active learning.<sup>19,20</sup> The World Health Organization defines capacity building as, "the development of knowledge, skills, commitment, structures, systems and leadership to enable effective health promotion."<sup>21</sup> This project focused on developing the capacity of community stakeholders to affect changes in their own health and the health of their communities. Hawe and colleagues refer to this as "problem-solving capability" or the knowledge and skills to actively participate in the identification of health problems and the development of interventions to alleviate those problems.<sup>22</sup> For this project, this meant convening the TRAC and building a foundation of knowledge about PCOR, the research process, narrative medicine and developing research questions. We accomplished this using principles of adult and active learning, which embeds content in an environment of respect and partnership, orients the learner to the penultimate goal (i.e., developing a research agenda with questions), emphasizes the practical utility of the content, and provides opportunities for active involvement in the learning process.<sup>19,21</sup> We also followed the SEED method developed by the Center on Society and Health.<sup>23</sup> This method is designed to engage stakeholders in a process of developing research questions that are most relevant to them. Following this method, we identified and engaged stakeholders to participate; used focus groups and feedback sessions to identify conceptual frameworks and solicit research questions; reviewed and prioritized questions; and created a pathway to generating a formal research agenda.

## 4. RESULTS AND DISCUSSION

### 4.1. *Outputs and outcomes*

The team developed a set of short term and mid-range outcomes prior to project initiation which would de-

fine success. The short term outcomes of this project included: (a) the establishment of a research advisory council, (b) a comprehensive understanding of the capacity for PCOR efforts within the proposed community of patients, clinicians, public health researchers, and other stakeholders. Mid-range outcomes included the development of community capacity for PCOR, and the development and strengthening of a partnership based on reciprocity, transparency, honesty and trust. The project successfully achieved these pre-defined outcomes and implemented a stakeholder engaged process by which a research agenda was established, and plans put into place for implementation. The TRAC advisory council was active in all aspects of the SEED method: identifying and assisting with accessing participants in focus groups and town halls; reviewed results of information gathering, prioritized resultant research questions, and participated in planning for next steps. Replicability of this model is being demonstrated through a new PCORI award to implement this process within the Latinx community in North Philadelphia.

Our outputs included a research training program tailored to the North Philadelphia AA community, a portfolio of narratives that will be drawn upon for future insights, and a set of research questions. One of our project's goals was to link research questions generated by our community efforts to the American Heart Association Cardiovascular Disease Quality Improvement Registry for COVID-19) registry for investigation, where appropriate.<sup>24</sup> This registry provides data that can be used to understand the cardiovascular complications of COVID-19 and to inform institutional quality improvement and create benchmarks through retrospective data collection, ongoing analysis and feedback to hospitals and providers.<sup>25</sup>

Fifty-three research questions were identified through the focus groups, narratives and town halls. The TRAC was charged with prioritizing the research questions by assigning a numerical score to indicate importance. While none of the questions were considered unimportant, at least 3 emerged as top priorities. Furthermore, the Temple research team categorized each questions according to being answerable by the AHA Registry or by investigator-initiated research.

#### 4.2. Discussion

Several racial and sex-specific disparities exist in the execution of clinical research in the United States. First, women, African Americans and other racial and ethnic minorities are under-represented as participants in the clinical research conducted in the US today.<sup>26–29</sup> Secondly, there is a paucity of minority researchers and faculty members involved and trained in conducting research in the

US particularly on health disparities.<sup>30–32</sup> These disparities create challenges in the efforts to provide culturally competent medical care and to support research in health disparities and limits the development of medical therapies which address conditions which have a disproportionate impact on the patients from these minority groups.

Historically, the barriers to participating in clinical research as partners are similar among AA's, and women, they include; fear, mistrust and a poor understanding of the research process.<sup>28</sup> Additional barriers to the participation of AA's and women include limited awareness of clinical trials, lack of opportunities to participate, limited number of minority investigators and structural barriers such as transportation.<sup>33–35</sup> The COVID-19 pandemic presented a unique opportunity to engage AA patients and women and connect them with minority researchers, physicians and public health researchers creating a larger stakeholder community to become meaningful partners contributing to research on COVID-19, addressing the urgent need to incorporate the needs, preferences, and perspectives of these patients into the design, execution and dissemination of research related to COVID-19. These efforts could break down the cycle of mistrust, create innovative questions and solutions to the pressing problem of disparities in CVD outcomes among AA patients and AA pregnant women with COVID-19.

#### 4.3. Limitations

Our methodology has some limitations worth mentioning. Our team had to select participants who had access to the internet and had sufficient computer skills to navigate zoom. This could create a selection bias. The recruitment process for our focus groups and TRAC are subject to bias due to a lack of a diverse representation of other sectors of the AA or female population, such as the homeless, and the extreme elderly. However, our project focused predominately on a low income minority community which lived in North Philadelphia. This community is a federally recognized safety net community and thus did in fact include some of the most vulnerable populations of AA and women, reflecting a population the least engaged in research activities.

### 5. IMPLICATIONS

AA and female voices are seldom heard or solicited regarding their care. In this paper, we describe the methodology we used to establish a network of patients and key stakeholders to collaborate on developing a research agenda and setting research priorities to address the

racial/sex-specific CVD disparities observed in COVID-19, incorporating the voices of AA patients in the process.

This work demonstrates that community based participatory principles of shared decision making, engagement, capacity building, and a methodology focused on incorporating the needs, preferences and perspectives of AA and female patients can drive the design of a future research agenda on the CVD and other complications related to COVID-19. As a result of this work, there is a research agenda with specific research questions as well as a network of committed community members who will be able to help move the agenda forward.

## DISCLAIMER

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