Preliminary Evaluation of a Citizen Scientist Educational Curriculum Aimed at Engaging Black Men in Lung Cancer Early Detection Screening

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Abstract

This article describes an educational program to engage African American men as citizen scientists (CSs) and future research partners in a lung cancer screening project. We provide an overview of the curriculum used, the structure and format of the educational sessions, and associated educational outcomes. Furthermore, we describe lessons learned in the engagement of African American men as CS in community-based lung-health equity research. The CS educational program included five group-based sessions delivered through zoom. The educational curriculum was adapted from the University of Florida Citizen Scientist program and tailored to address lung health and the contextual experiences of African American men. Each session lasted 90 minutes. Pre- and post-test measures were collected to examine changes in knowledge, comfort, health literacy, research interests, and medical mistrust. Eight African American men completed the CS educational program. Attendance rates were high for each session (100%). Seven participants completed additional human subject research certification. Improvements were observed from pre- to post-test in participants' level of knowledge, comfort, and health literacy but not medical mistrust. CS reported the most interest in participating in research aimed to identify important community strengths and problems. Study findings suggest that it was feasible to deliver an online citizen scientist educational program designed to prepare participants to serve as partners in a lung cancer screening intervention for African American men. Results suggest the educational program has the potential to improve key outcomes including completion of regulatory training and increased research-related knowledge, comfort, and health literacy.

Lung cancer is the leading cause of cancer morbidity and mortality in the United States (US Department of Health and Human Services, 2019). Each year, approximately 234,000 Americans are diagnosed with lung cancer (Jemal et al., 2018), most diagnosed at an advanced stage of disease (Chandra et al., 2009). As such, the overall prognosis for individuals diagnosed with lung cancer is poor (i.e., the overall 5-year survival rate of 18.6%; Howlader et al., 2015). Stark racial and ethnic differences

exist in lung cancer outcomes, with African American men experiencing the highest incidence and mortality rates (Siegel et al., 2017). Nationally, lung cancer incidence and mortality rates are 15% and 18% higher among African American men than non-Hispanic White men (American Cancer Society, 2019). Observed lung-health inequalities among African American men are even more pronounced in urban areas characterized by racial segregation, concentrated poverty, and inadequate access to

health care and other health-promoting resources (Annesi et al., 2021; Kehl et al., 2019; Mitra et al., 2015).

Smoking is the leading preventable cause of lung cancer (Barta et al., 2019). In Chicago, overall smoking rates are twice as high among African Americans compared to non-Hispanic whites (27.6% vs. 13.2%, respectively; Illinois Department of Public Health). In Cook County, where Chicago is located, lung cancer rates among African American residents are significantly elevated compared to White residents (116.9 vs. 81.1 per 100,000 for men and 63.3 vs. 54.7 per 100,00 for women; Illinois Department of Public Health). Furthermore, the all-cause morbidity and mortality due to smoking are higher among low-income and African American smokers nationally and in the Chicago area due to a lower likelihood of quitting and the higher prevalence of illnesses exacerbated by smoking (e.g., diabetes). Despite these disparities, few studies prioritize the engagement and inclusion of African American men in clinical and translational research related to lung health, including lung cancer screening.

Detecting lung cancer at earlier, more treatable stages can significantly improve cancer survival rates (US Preventive Services Task Force, 2013) and reduce health-inequalities among African American men influenced by the stage of diagnosis. The National Lung Screening Trial (NLST) demonstrated that low-dose helical computed tomography (LDCT) lung cancer screening reduced lung cancer mortality rates by 15%–20% among older smokers with a history of chronic smoking (National Lung Screening Trial Research Team, 2011). As a result, the United States Preventive Services Task Force (USPSTF) provided a Grade B recommendation for lung cancer screening with LDCT now covered by Medicare, Medicaid, and private insurances (Chin et al., 2015; National Coverage Determination (NCD) for Screening for Lung Cancer with Low Dose Computed Tomography (LDCT), 2015). Despite the availability of this highly effective screening modality, awareness of and engagement in LDCT screening is low among both providers and patients. For example, using data from the Behavioral Risk Factor Surveillance System (BRFSS), Richards and colleagues (2020) reported that among those individuals with a smoking history who met USPSTF screening criteria, only 12.5% of eligible smokers had received a computed tomography (CT) scan for lung cancer in the prior year. Similar results have been reported using other national surveys and patient samples (Chalian et al., 2019; Lake et al., 2020; Veliz et al., 2019). In response, there have been calls to increase awareness and access to high-quality lung cancer screening, especially in high-risk and under-served populations (Haddad et al., 2020; Jenkins et al., 2018; Li et al., 2019; Matthews et al., 2018; Watson et al., 2016).

Cancer Screening

Barriers to cancer screening are well documented for African American men (Alexis & Worsley, 2018; Earl et al., 2022; Rutter et al., 2021; Shungu & Sterba, 2021). Previously identified barriers to prostate and colorectal cancer screening have occurred at multiple levels, including the individual (fear, knowledge, attitudes, and beliefs), the provider (bias, poor communication, lack of cultural humility), and the health care system (inadequate access to high-quality health care, lack of insurance; Assari et al., 2019; Forrester-Anderson, 2005; Fyffe et al., 2008; Gelfand et al., 1995; Leyva et al., 2016; Machirori et al., 2018; Reynolds, 2008; Shi et al., 2010; Shungu & Sterba, 2021; Woods-Burnham et al., 2018).

In relationship to lung cancer, preliminary studies suggest significant barriers to screening among African American smokers. First, eligibility for LDCT has been established to be lower among non-Hispanic Black than non-Hispanic White smokers, even among survey respondents with a similar duration of smoking (Li et al., 2019). Most African American smokers are low-frequency and intermittent/non-daily smokers (Li et al., 2018). As such, African American smokers are less likely to be eligible for lung cancer screening due to current guidelines contingent on high-frequency smoking (pack-years; Watson et al., 2019). In addition, research findings suggest that African American smokers have more concerns about the risks associated with LDCT scans and lower perceived benefits of screening (Jonnalagadda et al., 2012). Research studies also suggest that providers are less likely to talk to older African American patients than White patients about lung cancer screening (Chalian

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et al., 2019) or refer them for guideline-consistent screening (Japuntich et al., 2018). Even after referral to a lung cancer screening program, African American patients have significantly lower odds of receiving LDCT than Whites (Lake et al., 2020). Despite these disparities, few studies prioritize the inclusion of African American men in clinical and translational research related to lung cancer (Murray et al., 2019; Watson et al., 2020).

The Citizen Scientist (CS) Model

Health promotion initiatives based on community-based participatory research principles (CBPR) effectively reduce barriers to cancer screening across diverse population groups (Israel et al., 2013; Rodriguez, 2021). At its core, community engagement seeks to achieve equitable, meaningful, active community participation in all phases of the research process and highlights community capabilities to accelerate improvements in health (Matthews et al., 2018). Observed benefits of a community-engaged approach to research include enhanced recruitment and retention rates, external validity, and individual and community capacity building (Rhodes et al., 2017). Furthermore, community engagement helps to identify relevant cultural beliefs and barriers, and this information is imperative to the successful design of health promotion interventions (Matthews et al., 2019). However, community engagement strategies must evolve to ensure that African American men are included in and benefit from research to enhance health (Harley et al., 2020).

"Citizen Scientists" (CSs) represent an emerging community engagement approach that has the potential for understanding and addressing the important social issues facing many communities. CSs refer to laypersons who are not formally trained as scientists but trained to engage in research efforts responsive to community needs (Haklay et al., 2021). The citizen science approach, which is part of the broader participatory action field, typically has included systematic, scalable methods of resident-based data collection to support the scientific endeavor (King et al., 2020). CS programs have emerged as effective approaches for supporting community members to actively and meaningfully engage in research activities (Watson et al., 2019). Furthermore, CS models have proven valuable in increasing community engagement, knowledge and awareness of research, trust in scientific research, and the quality of research conducted (Bonney et al., 2016; Collier & Danis, 2017; Watson et al., 2019).

To date, few CS efforts have focused explicitly on engaging African American men as CS (Watson et al., 2019). However, a CS approach may potentially increase the involvement of African American men in lung and other health promotion research. As noted earlier, a citizen scientist approach extends existing community engagement strategies. Community engagement has been demonstrated to improve the benefits of health promotion research in underserved populations. Our research team members have previously collaborated with our community partner to develop and test a CS approach for increasing prostate cancer biomarker testing for African American men at elevated risk for prostate cancer (Watson et al., 2019). Building on the success of our prior study, we believe that the CS approach can increase the involvement of African American men in lung and other health promotion research in several ways. First, the extant literature has shown that representation matters. Health promotion initiatives developed for and led by African American men have successfully improved a range of health promotion outcomes (Wippold et al., 2021). Next, engaging African American men as CSs in a lung-health intervention provides an opportunity for the demographic group most negatively affected by lung cancer to directly inform strategies to increase uptake of evidence-based lung cancer screening. In addition, CS who come from the communities and social networks of the target population may help inform effective strategies for recruiting African American men that extend beyond well-established approaches such as churches and barbershops. Furthermore, they may be effective in developing and refining health promotion messaging and venues, platforms, and locations for targeted outreach methods. Cultural targeting has been found to increase the salience of health promotion messages and interventions by reflecting a community's values, perspectives, and preferences (Kreuter et al., 2003; Wippold et al., 2021). CS can be instrumental in developing content materials that speak to the lived experiences of African American men by identifying relevant cues to action and providing valuable "in-group" perspectives and insights.

Specific Aims

CS approaches have emerged as an innovative and effective community engagement approach. Educational curricula have been created to increase knowledge related to research methods and human protection guidelines (Condon & Wichowsky, 2018; Roche et al., 2020). However, to our knowledge, only one of the existing CS educational programs has been developed to educate African American men (Watson et al., 2019), and none have been specifically developed to engage African American men in lung research. As such, we completed an evaluation of adapted educational materials and formats for providing the educational background necessary for African American men to serve as CS in a lung-health promotion study. Specifically, we sought to determine the feasibility and potential benefits of CS curriculum and engagement procedures to prepare African American

men to participate as CS in a future lung cancer screening intervention with African American men who smoke. This article provides an overview of the curriculum used, the structure and format of the educational sessions, and outcomes associated with the program. Furthermore, we describe lessons learned in the engagement of African American men as CS in lung-health promotion research.

Methods

Research Design

This feasibility study was designed as a single-arm pre-post comparison. In collaboration with our community partner, Project Brotherhood, this feasibility study was implemented online from January to May 2021. This initial developmental phase was part of a more extensive research study, Supporting High-Risk African American Men in Research and Engagement in Decision Making (SHARED), funded by the National Institutes of Health. The overall objective of the larger parent grant is to examine the use of CS in increasing awareness and uptake of lung cancer screening among African American men (see Watson et al., 2020 for a complete description of the study protocol). The CS program was conducted in partnership with   Project Brotherhood. It was designed as a sustainable model to engage and inform the University of Illinios Chicago cancer center's research initiatives and enhance our mission to partner with communities to improve cancer-related health outcomes. The University of Illinois Chicago Institutional Review Board approved the CS engagement protocol (2017-1175).

Community Partners

This feasibility study was conducted in collaboration with Project Brotherhood, a community-based organization located on the south side of Chicago that served as the community partner on the project. Mr. Murray (co-investigator) is the Executive Director of Project Brotherhood and is nationally recognized for his innovative grassroots methods to engage African American men (Murray et al., 2019). Project Brotherhood has over 22 years of nationally recognized experience in patient engagement and addressing health disparities and has provided health services and support to more than 30,000 African American men and their families. Project Brotherhood has been a proactive community and academic partner in different projects across Chicago, including prior research on cancer screening among African American men. Project Brotherhood (PB) is a community organization that has played an integral role in advancing prostate cancer (PCa) research within two pilot projects supported by the Chicago Cancer Health Equity Collaborative (ChicagoCHEC). One of the study authors

(KW) has had a research partnership with our community partner, Project Brotherhood for more than 10 years and has collaborated on five funded and nonfunded research projects related to cancer-related health disparities among African American men. This project was first discussed with the Marcus Murray, the director of Project Brotherhood. The project was determined to meet the needs of the organizations' constituents and be consistent with previous research collaborations between the research team and the organizational leadership. Although community and academic partnerships create important opportunities for improving health for underserved populations, challenges can also exist in these relationships. Before the finalization of the study, we discussed important issues such as ownership of data, equitable balance of resources and leadership, and conflict resolution approaches. After approval by the executive team, the director of Project Brotherhood was involved in all aspects of this study, including design, implementation, and manuscript preparation.

In addition to our community partner, we established a community advisory board (CAB) to provide additional guidance to the research team. The nine-member CAB meets quarterly and has a role in each study-specific aim. Our CAB includes patients with a history of smoking, cancer-care providers, patient navigators, and researchers with expertise in tobacco cessation, African American men's health, and lung cancer. The CAB provided input on factors associated with the scientific rigor of the study, the implementation, scalability, and sustainability of the CS model, and the transferability of the framework and methods for other health disparity populations. Finally, the initial results from the CS educational program (results reported in this article) were presented to the Community Engagement Advisory Board (CEAB) of the Center for Clinical and Translational Sciences at the University of Illinois Chicago. The CEAB has extensive experience in providing consultation and feedback on health disparity research with the aims of increasing the overall success, benefits, and cultural safety of methods used.

Theoretical Framework

The Murray Model (Murray et al., 2019), a community empowerment model developed by our community partner and study co-investigator (MM), informed the development of the larger lung cancer screening project. The Murray model was based on the adaptation of multiple theoretical frameworks and conceptual models, including the health belief model, community empowerment model, elements of community-based participatory research, and ideas of "manhood" (Courtenay, 2000; Israel et al., 2013). The Murray Model (see Figure 1) is a culturally specific adaptation of the community empowerment model that has been used to inform the equitable

Figure 1. Murray Model of Engaging AA Men in Research, Health Delivery, and Service.

engagement of African Americans in health research design and implementation (Julion et al., 2021; Tharakan et al., 2022; Watson et al., 2020). The model posits that interventions to advance health equity among African Americans require the integration of four fundamental tenets. The first is the employment of evidence-based practices for health prevention, screening, and treatment that have been developed and evaluated with African Americans. The second tenet focuses on community empowerment and building capacity grounded in Indigenous knowledge, leadership, and approaches. Here, the model emphasizes the inclusion of African Americans as "lived experience" experts and equal partners in the research endeavor. The third tenet is the integration of Afrocentric and other culturally informed practices that foster a sense of community and pride. Furthermore, the fourth tenet speaks to a holistic approach to health promotion that emphasizes whole-body wellness and not just the health of specific body parts (e.g., lungs). This later tenet acknowledges the importance of the mind, body, and spirit in creating wellness among African Americans.

Recruitment of Citizen Scientists

CS recruited for this study were the following: (a) aged 30 years or above; (b) identified as African American; (c) skilled at engaging African American men; (d) able to attend all educational sessions; and (e) willing to engage their social networks and peers as potential participants in the research project. Principles of social network theory were used to inform our recruitment efforts. Social network theory focuses on the role of social relationships in transmitting information, channeling personal or media influence, and enabling attitudinal or behavioral change (Borgatti et al., 2018; Valente & Pitts, 2017). An innovative strategy was used for recruiting the CS. Each of the CS was recruited from the social networks of the research team members using direct outreach, word-of-mouth, and referrals. A research assistant contacted potential participants to inform them about the program's purpose, determine eligibility and obtain written informed consent from interested and eligible individuals. All enrollment data were stored in a secured research electronic database.

Citizen Scientist Educational Program

The purpose of the CS Program was to increase individual and community capacity by engaging a cadre of community members to provide their expertise, life experiences, and reach/social networks in their respective communities to inform research processes of research studies conducted by the University of Illinois Chicago Cancer Center. The CS educational modules were adapted from the established, evidence-based University of Florida Clinical and Translational Science Institute CS Program (UF CTSI) Curriculum (University of Florida Citizen Scientist Training program, 2021; Bonney et al., 2016; Collier & Danis, 2017). The UF CTSI is Open Educational Resource material developed as a model for other groups to start CS Programs. The original curriculum consists of seven modules that contain videos, PowerPoint slides, brief post-assessments, and an instructor guide.

Informed by the Murray model (2019) and the extant literature, the standard CS curriculum was adapted to address community engagement and health inequality research with African American men. The initial adaption of the curriculum took place as part of a funded research project focused on the involvement of African American men as CS in a study on increasing prostate cancer screening (Watson et al., 2019). Starting from the curriculum established by the UF-CTSI, the investigative team adapted the generic curriculum to focus on addressing cancer inequalities associated with prostate cancer. Consistent with the original UF-CTSI curriculum, the educational program provided participants with foundational information on the role of CSs, foundation principles of basic, behavioral, and translational research, institutional review boards, human subjects protections, and accessing research materials. In addition, additional information included modules on institutional racism in

health care and research, medical mistrust in the African American communities, lung cancer 101 (understanding lung cancer screening and treatment), and clinical trial participation. Community empowerment principles were infused throughout the curriculum and included promoting social change, building social agency, and the role of CS in the reduction of lung-health inequalities.

The methods of Kreuter et al. (2003) were used to culturally target the CS curriculum to focus on the content of lung cancer health inequalities among African American men. First, the curriculum underwent peripheral level targeting, that is, the inclusion of images, colors, and text that increases the salience of the materials for African American men (images of African American men, a focus on health equality, images of tobacco products targeted to African Americans. Next, evidential targeting took place in which statistics related to inequalities in lung cancer risk, incidence, and mortality for African Americans were included. Linguistic targeting included the use of language and terms used by African Americans (i.e., references to "squares" instead of cigarettes). Constituent-involving targeting includes the inclusion of members from the target population. To address this level of targeting, we highlighted the personal stories of the African American men who were members of the research team and their shared beliefs in the importance of involving African American men in research to reduce health inequalities related to cancer. Finally, sociocultural targeting included addressing cultural beliefs, norms, or values as a means for increasing cues to action (i.e., biblical text related to health promotion, being "free" of any type of bondage, including nicotine addiction, fighting the predatory targeting of African American communities by the tobacco industry).

The engagement sessions took place from January to May 2021 through Zoom, an online videoconferencing platform (Zoom Video Communications, Inc., 2016). The educational sessions were led by team members (KW, MM, DO, JBL) who contributed to the adaptation of the prior CS curriculum, which focused on prostate cancer and was targeted to be inclusive of the needs and experiences of the African American communities (i.e., racial differences in cancer incidence and mortality; Watson et al., 2019). The adapted CS curriculum included five educational modules conducted over 5 weeks (see Table 1). Each educational session lasted 90 minutes. Every session employed a two-way interaction approach and ended with the research team evaluating the knowledge and understanding of the CS about the content provided. Fidelity measures were developed in the CS instructor training guide to ensure uniformity in the content and delivery of training materials for the CS. All participants were compensated $250 per session for their time and efforts.

Measurement

Study participants completed a brief online survey before and after CS educational sessions. The pretest included 42 questions, and the post-test included 36 questions (demographic questions were asked at post-test). The average completion time for both surveys was 15 to 20 minutes to complete. The survey was created in REDCap (Harris et al., 2009), an online survey platform that is easy to navigate and reduces data entry errors. After completing informed consent, all CS received an online link to an electronic survey developed in REDCap (Harris et al., 2009). The measured demographic variables included age, race, gender, relationship status, education, and income. Health Literacy was measured using the 6-item Cancer Health Literacy Test (Dumenci et al., 2014). The CHLT-6 separates patients with limited cancer health literacy from those with adequate cancer health literacy with a high degree of precision. Scores range from 0 to 6, with higher scores indicating higher cancer health literacy levels. Health literacy questions were coded 1 if answered correctly and 0 if incorrect. The number of correct responses out of 6 was calculated for each CS pre and post-educational session. Medical mistrust was assessed using the Medical Mistrust Index (MMI, LaVeist et al., 2009), a 17-item scale, which uses a Likert-type response with the following response codes: 1 = "strongly disagree," 2= "disagree," 3 = "agree," and 4 = "strongly agree." The Medical Mistrust Scale items were reversed scored, then a total average score and summed score pre- and post-training were calculated for each CS. Scores range from 17 to 68, with higher scores indicating higher levels of medical mistrust. To measure comfort in interacting with research stakeholders, we developed four items with three selection options: "not at all comfortable," "somewhat comfortable," and "very comfortable." Participants were queried about their comfort in communicating with physicians, health researchers, community members about research, and community members about health care. Self-rated knowledge about cancer research, health research, cancer centers, cancer center programming, and community health issues were measured using a Likert-type scale ranging from 1 = No knowledge to 10 = A great deal of knowledge. Participants were asked to rate their level of interest in eight different types of research-related activities (e.g., Writing or reviewing grant applications; Yes/No/Not Sure). Community participation was measured by the following: "Do you have any prior experience working or volunteering in the healthcare or medical field?" and "Do you have any prior experience working or volunteering with events or organizations that serve communities (i.e., community organization, nonprofits or charities)?" (Yes/No).

Table 1. Overview of Educational Curriculum.

Modules	Session 1		
Module 1/Session 1	Learning objectives	Materials covered	Lead
Welcome and orientation	Introduce the Citizen Scientist program Discuss the Citizen Scientist curriculum as an open educational resource Describe the activities involved in the Citizen Scientist curriculum	1.1—Welcome and program vision 1.2—Citizen Scientists: What are they? What do they do? 1.3—New employee orientation (site-specific content) 1.4—Intellectual property and confidentiality 1.5—Citizen Scientists in action: Forming a mission statement	Research team
	Session 2		
Module 3-4/session 2	Learning objectives	Materials covered	Lead
Sponsored research	Define research Restate the steps in the research process Cite the steps of the research process for which Citizen Scientist's input is most valuable	3.1—Research 101 3.2—Federal funding for research 3.3—How to read a research article 3.4—Citizen Scientists in action: Research team meeting	Research team
	Learning objectives	Materials covered	Lead
Clinical and translational science	Describe translational science Articulate how a Citizen Scientists can help shape translational science projects Explain the ultimate goal of translational science	4.1 Translational sciences 101 4.2—Types of research 4.3—Case study: Citizen Scientist role in translational science 4.4—Citizen Scientists in action: Research study review	Research team
Medical mistrust in the African American community: The early origins	History of institutional racism and the exploitation of African Americans to advance medicine Make apparent how medical mistrust toward the medical profession has a long and uncomfortable history among African Americans who still bear the scars of those times in their memory and personal experiences. Explore cases studies of how enslaved Africans were used as inexhaustive supplies of bodies for physicians of the antebellum era to learn human anatomy	Pillars of American medicine Critical Race Theory All case studies	Dr Levi
	Session 3		
Module 2/session 3	Learning objectives	Materials covered	Lead
Research privacy, protection, and ethics	Discuss the importance of an Institutional Review Board (IRB)	2.1—IRBs and Human Subjects Research	Research team
Human subject in research	Express the difference between a human and non-human research subject	2.2—Research Ethics	
Information privacy and security	List the different types of IRB approval for research studies	2.3—Informed Consent	
		2.4—Consent for Research vs Clinical Care	
		2.5—Citizen Scientists in Action: Working as a Citizen Scientist	
Lung cancer 101	Understand lung cancer screening and treatment of lung cancer quality, access to care, opportunities	Lung cancer as a public health issue and surgical standard care Understanding the stages of lung cancer and its impact on care and recovery Research disparity in lung cancer screening Lung cancer radiation historical trends Lung cancer screening guidelines historical trends Technology advancement and disparities in care	Dr Odell

Table 1. (continued)

	Session 4		
Module 5/session 4	Learning objectives	Materials covered	Lead
Reading and accessing research materials	Understanding research language	5.4—Accessing a Primary Research Article	Research team
	Reviewing research materials	5.5—Reading a Primary Research Article	
	Questioning validity of research materials		
	Learning objectives	Materials covered	Lead
Enrollment disparities in cancer clinical trials	Understand how cancer doctors choose which treatment to recommend to patients	Time of extraordinary discoveries in cancer science	Dr Ryan Nguyen
	Review disparities between cancer clinical trial and the United States and University of Illinois Chicago patients populations	Clinical trials and the Food and Drug Administration's approval pipeline	
	Outline barriers to adequate cancer clinical trials	The constant change in treatment guidelines and science and its impact on providers	
	Session 5		
Session 5	Learning objectives	Materials covered	Lead
Review session	Revise key points from the previous four sessions highlighted by Citizen Scientists	Review of the importance of Research.	Research team
		Review of the difference between an observation study versus a clinical trial.	
		Review of research, safety, and protection of human participants.	
		Review of the Institutional Review Board.	
		Review of research participants' rights.	
		Review of informed consent in research.	
		Review of inclusion and exclusion criteria.	

Data Analysis

Data analysis was conducted in Stata v.17. Due to the small sample size, we only report descriptive statistics including means, frequencies, and percentages correct.

Results

Demographic Characteristics

Table 2 presents the demographic characteristics of the $N = 8$ men who participated in the CS educational sessions. All participants were African American, cis-gendered males and had completed at least 1 year of a college education. The average age of participants was 48 years (range 37–66), and the average yearly household income was $76,875. Three CS (37.0%) reported having had prior experience working or volunteering in the medical field, and seven (87.5%) had previous experience working or volunteering with community events or organizations.

Pre-Post Test Evaluation

Table 3 displays the pre- and post-test outcomes following the CS educational sessions. Attendance at the educational sessions was high, with 100% of participants attending each of the five sessions. In addition, seven of the eight CS (87.5%) completed the Collaborative Institutional Training Initiative's (CITI) human subjects and the Health Insurance Portability and Accountability Act (HIPAA) online certification programs. As presented in Table 2, the percentage of participants who correctly answered questions related to cancer health literacy increased for four of the six items measured. All mean scores on self-perceived knowledge related to understanding cancer and health research issues, community health issues, and the roles and priorities of cancer centers in research increased from pre- to post-test. The number and percentage of CS that selected "yes" to a research interest versus "no" or "not sure" pre- and post-training was calculated. At post-test, the two highest research interest areas identified were examining important community problems and strengths (100% interest). We observed increases in self-rated comfort in communicating with various stakeholders associated with research. At post-test, the majority of CS reported feeling very comfortable communicating with physicians ($n = 7$, 87.5%), researchers ($n = 7$, 87.5%), and talking with community members about research ($n = 7$, 87.5%) and Health ($n = 6$, 75%).

Table 2. Demographic Characteristics of Participating CS (*N* = 8).

Demographic Variables	n/mean	%
Race—African American	8	100.0
Gender—Male	8	100.0
Age	47.6	Range = 37–66
Married	3	37.5
Single	3	37.5
Divorced	2	25.0
College 1 to 3 years (some college or technical school)	5	62.5
College 4 years or more (college graduate)	3	37.5
Family size	3.25	Range = 1–6
Income	76,875	Range = 50,000–130,000
Prior experiencing volunteering or working in the health care or medical field	3	37.5
Prior experience working or volunteering at events that serve community members.	7	87.5

Table 3. Pre- and Post-Test Evaluation Scores (*N* = 8).

Construct	Pre-test	Post-test
Health literacy—% correct	% (*N*)	% (*N*)
- The normal range for hemoglobin for a male is 13.3 to 17.2 g/dl. Joe's hemoglobin is 9.7 g/dl. Is Joe within the normal range? (yes/no)	100 (8)	75 (6)
- A biopsy of a tumor is done too . . . (remove it/diagnosis it/treat it)	87.5 (7)	100 (8)
- If a patient has stage 1 cancer, it means the cancer is (localized/in nearby organs/in distant sites)	62.5 (5)	100 (8)
- The role of a physical therapist is to talk to a patient about their emotional needs (true/false).	62.5 (5)	87.5 (7)
- A tumor is considered "inoperable" when it cannot be treated with . . . (radiation therapy/surgery/chemotherapy)	75.0 (6)	62.5 (5)
- Sally will get radiation therapy once a day, Monday through Friday. If Sally has therapy for 4 weeks, how many times will she get radiation therapy? (5/10/20)	87.5 (7)	100 (8)
Knowledge about health research—mean score		
- Cancer research	4.4	7.0
- Health research	4.9	7.3
- Cancer center	3.9	5.8
- Cancer center programming	4.0	5.6
- Community health issues	6.9	7.8
Interests related to research— % interested		
- Writing or reviewing research study procedures	50.0 (4)	62.5 (5)
- Analyzing or interpreting research findings	62.5 (5)	62.5 (5)
- Writing or reviewing funding applications	75.0 (6)	75.0 (6)
- Helping to decide cancer center priorities	87.5 (7)	87.5 (7)
- Recruiting individuals to participate in research	87.5 (7)	87.5 (7)
- Collecting data/information for research studies	100 (8)	87.5 (7)
- Identifying important community problems	100 (8)	100 (8)
- Identifying important community strengths	100 (8)	100 (8)
Comfort— % very comfortable		
- Comfort talking to physicians	62.5 (5)	87.5 (7)
- Comfort talking with health researchers	75.0 (6)	87.5 (7)
- Comfort talking to community members about research	75.0 (6)	87.5 (7)
- Comfort talking to community members about health care	62.5 (5)	75.0 (6)

On average, participant mistrust toward health care organizations did not change from pre- to post-test (*M* = 41.6 vs. *M* = 42.3; see Table 4). However, two specific items related to mistrust increased following the educational sessions. These items were "You have to be cautious when dealing with health care organizations" (*M* = 2.4 vs. *M* = 3.0) and "Healthcare organizations have sometimes done harmful experiments on patients without their knowledge" (*M* = 2.9 vs. *M* = 3.5).

Discussion

African American men experience some of the highest cancer incidence and mortality rates among all Americans.

Table 4. Pre- and Post-Test Scores on the Medical Mistrust Scale (*N* = 8).

Medical mistrust scale	Pre	Post
You'd better be cautious when dealing with health care organizations.	2.4 (0.7)	3.0 (0.5)
Patients have sometimes been deceived or misled by health care organizations.	2.9 (0.6)	2.8 (0.9)
I trust that health care organizations will tell me if a mistake is made about my treatment.*	2.1 (0.6)	2.3 (0.5)
Health care organizations often want to know more about your business than they need to know.	2.3 (0.5)	2.3 (0.9)
When health care organizations make mistakes, they usually cover them up.	2.4 (0.5)	2.5 (0.8)
Health care organizations have sometimes done harmful experiments on patients without their knowledge.	2.9 (1.1)	3.5 (0.5)
The patient's medical needs come before other considerations at health care organizations.*	2.4 (0.5)	2.3 (0.5)
Health care organizations are more concerned about making money than taking care of people.	2.8 (0.7)	2.6 (0.9)
Health care organizations put the patient's health first.	2.6 (0.5)	2.9 (0.6)
Health care organizations do not always keep your information totally private.	2.4 (0.9)	2.4 (1.1)
Patients should always follow the advice given to them at health care organizations.*	2.5 (0.5)	2.3 (0.7)
I typically get a second opinion when I am told something about my Health.	3.1 (0.4)	3 (0.5)
I trust that health care organizations check their staff's credentials to make sure they are hiring the best people.*	1.9 (0.4)	1.8 (0.5)
They know what they are doing at health care organizations.*	2.1 (0.4)	1.8 (0.5)
Sometimes I wonder if health care organizations really know what they are doing.	2.6 (0.5)	2.4 (0.7)
Mistakes are common in health care organizations.	2.4 (0.5)	2.8 (0.9)
I trust that health care organizations keep up with the latest medical information.*	2 (0.5)	2 (0.9)
Total mean score	2.4 (0.3)	2.5 (0.3)
Total summed score	41.6 (5.0)	42.3 (5.2)

Notes. Values are mean (*SD*). Scores range from 1 to 4, with four representing the most mistrust.
*Represents reversed coded items.

Innovative and culturally centered models for increasing outreach, engagement, and equitable partnerships with African American males are needed to chart a pathway toward more equitable health outcomes. Engaging underserved populations in research as CS is an emerging strategy to address the underrepresentation of racial/ethnic minority populations in research. Community-based participatory approaches, including citizen scientist models, can increase the engagement of diverse populations of community members in health equity research efforts (Watson et al., 2019). Here, we adapted a standardized citizen scientist curriculum to increase knowledge of the foundational tenets of research and human subjects and include information about lung cancer among African American men. Guided by a culturally informed model of community engagement (Murray et al., 2019), the purpose of the study was to evaluate the feasibility and benefits of an educational program aimed at preparing a community sample of African American men to serve as CSs.

Most pilot feasibility studies explore several methods and procedures such as recruitment of participants, delivery of an intervention, benefits of the intervention as designed, and retention (Stewart et al., 2020). Indeed, feasibility testing is an important but often overlooked aspect of intervention development for diverse populations (Stewart et al., 2020). In terms of recruitment, we achieved our goal of engaging eight African American males from diverse parts of the metropolitan area. Our recruitment efforts were informed by principles of social network theory. Social network theory focuses on the role of social relationships in transmitting information, channeling personal or media influence, and enabling attitudinal or behavioral change (Liu et al., 2017). Three of the members of the research team identity as African American males. Each tapped into their social networks to identify African American males with a history of community engagement, activism, or high levels of connectivity to other networks of African American men. These individuals were approached about the project and provided information about the study's goals, the role of CS in research, and the expected responsibilities associated with participation. Mistrust of research can be high among communities of color. Recruiting CS from the social networks of trusted health disparities researchers led to successful recruitment outcomes.

The feasibility of delivering the educational program was high, with weekly attendance rates at each of the five sessions at 100%. In addition, most CS completed additional regulatory requirements, including the Collaborative Institutional Training Initiative (CITI) and Health Insurance Portability and Accountability Act (HIPAA) certifications. Several strategies were used to ensure high levels of participation in the educational sessions. First, the social

networks of the principal investigators were used to recruit CS. CS were selected based on interest in and stated commitment to serve as research partners on the study. These existing ties and relationships increased the level of initial trust and engagement with the project. Next, the educational sessions were scheduled based on the participants' schedules. Due to COVID-19 restrictions, each of the educational sessions was offered through the Zoom platform, which reduced logical barriers to attendance such as commuting time, transportation to and from the events, and the cost of parking at a university setting. After the dates for each educational session were established, reminder texts were sent to participants the day before and the day of each session. Finally, participants were reimbursed for each of the educational sessions attended.

Demonstrating the ability to establish a foundational level of research knowledge is an essential component of establishing CS as partners in community-based strategies for improving health inequalities. We examined the pre- and post-differences in cognitive factors associated with research participation among the CS. Improvements were observed among the CS on several important outcomes. First, overall comfort levels in talking with a range of stakeholders associated with health research, including physicians, researchers, and community members, improved from pre- to post-test assessment. The most significant increase in comfort levels was observed in talking with physicians (40% increase). This improvement may have been due to the exposure to two physician-researchers who delivered specific CS educational modules to the participants. There was also an increase in self-rated knowledge about cancer-related health research. However, improvements in health literacy were mixed, with the percentage of correct responses increasing in four out of the six items on the health literacy measure. Only slight variations were observed in questions related to medical mistrust from pre- to post-test. Notably, levels of mistrust increased related to two items. One of the educational modules presented to the CS provided detailed information on the history of discrimination and mistreatment of African American patients within the health care system and described the research violations that have led to increased oversight by institutional review boards. This detailed overview of historical information about the treatment of African American patients in research and health care settings may have increased levels of awareness and, by extension, appropriate mistrust. Finally, areas of research interest remained much the same from pre- to post-test, with the highest percentage of CS reporting research interests related to identifying essential community problems and strengths.

Retention of participants is an essential aspect of ensuring the feasibility of an approach. In addition to 100% completion of the educational sessions, we retained all participants to complete the post-test assessment measures. A range of strategies was used to ensure retention. These strategies included continued contact with the members of the research team that helped to recruit them as CSs, emails, and phone communication regarding dates and times for follow-up activities, and working to create a strong bond and shared identity among the men as CSs engaged in important work that may be beneficial to the men in their communities and social networks. Another important retention activity is to continue engaging the CS with continuing education and skill-building opportunities to increase their capacity to serve as CS in the next phase of the study.

Lessons Learned

Several important lessons were either reinforced or learned in completing this project. First, as has been reported in the literature, community engagement is a critically important element of ethically and effectively working with communities that have been historically marginalized or damaged within the context of research (Crooks et al., 2021). To that end, it is essential to integrate multiple community perspectives in intervention development (Molina et al., 2019). The use of community advisory boards as key stakeholders has demonstrated benefits in the quality, effectiveness, and cultural safety of community-focused research projects (Matthews et al., 2018a, 2018b, 2018c, 2018d). Throughout the CS curriculum adaptation development, we have sought continuous feedback from our community advisory board. In addition, establishing a partnership with a trusted community-based organization is essential to appropriate and sustainable engagement with marginalized and underserved communities. Community-academic partnerships have the potential to overcome the legacies of mistreatment and resulting mistrust among community members. However, intentionality related to equitable distribution of financial resources associated with the study, equity in project leadership, and effective management of institutional factors is critical (Matthews et al., 2018b). Representatives from the community partner organization should be involved in the project, including project conceptualization and development, roles and responsibilities, and budget creation to ensure equity. Consistent with the guidelines for a well-functioning research team (Bennett et al., 2018), plans should be put in place to establish the governance and organizational structure of the team, procedures for resolving conflicts, and processes for making decisions on scientific directions and resource allocation.

Engaging community partners as co-investigators in community-based participatory research (CBPR) requires

certification in the rules, ethics, and principles governing research. Specifically, exposure to the regulatory and compliance aspects of the ethical conduct of human subjects' research builds the capacity of laypersons to engage as research team members and community advocates meaningfully. Most of the CS engaged in this project completed required National Institutes of Health CITI and HIPAA training. However, as previously reported in the literature (Anderson, 2015; Calzo et al., 2016), the lengthy and content dense online regulatory modules were burdensome to participants, resulting in less than 100% completion rates. Although our CS were highly educated, most human research ethics training programs are geared toward learners with existing research experience. Other approaches to increase community members' knowledge about the ethical conduct of research have been created. For example, *CIRTification* is a human research ethics training program designed specifically for community research partners (Anderson, 2015). Efforts have been made to promote acceptance of these more accessible, flexible, and engaging processes to teach human subjects' research and obtain institutional review board certification (Yonas et al., 2016). Nevertheless, uptake of these community-centric programs by university IRB has been limited. Increased advocacy is needed to educate IRB panels about the need for and effectiveness of programs to educate community members about the ethical principles and practices associated with research (Anderson et al., 2012).

This project was funded and initiated during the COVID-19 pandemic, which created barriers to conducting typical research and community engagement practices. As such, the engagement activities were altered to protect the health and well-being of all participants. All activities were transitioned to a remote zoom platform. Much has been described related to the digital divide in this country based on race/ethnicity, including during the COVID-19 pandemic (Eruchalu et al., 2021). The "digital divide" refers to the unequal access to and proficiencies with technologies based on demographic factors such as age, education, and race/ethnicity (Gilbert, 2010). Recently published data suggest that at least 21 million people in the United States do not have access to the Internet (Federal Communications Commission, 2019). Despite our team's ability to successfully migrate to online activities, this may not be true for all cohorts of CS. Nevertheless, we successfully pivoted from in-person to online activities, including virtual team meetings, electronic survey and data collection approaches, and zoom to deliver the educational sessions to the CS. An extensive assessment of the resources, experiences, and preferences of CS regarding the use of technology-supported engagement activities must be conducted before the development of implementation strategies to ensure successful engagement of CS. To be clear, the results of the needs assessment should not be used to disqualify a CS from participation (e.g., "You must have Internet access to join the team"). On the contrary, it should be viewed as appropriate and equitable to mitigate any barriers by providing CS with computer tablets, Internet access and offering computer literacy skills as part of the CS educational sessions, as needed.

Related to but not exclusively linked to the COVID-19 pandemic is the need to be aware of and sensitive to the priorities and well-being of CS engaged in health inequality research. Regardless of income or educational levels, it is essential to remember that many CS of color will belong to and reside in communities differentially affected by ongoing health inequalities and emergent social issues. Research findings have documented the effects of racism and systematic bias on African Americans' health and life opportunities in this country (Williams et al., 2019; Williams & Wyatt, 2015). Crooks and colleagues (2021) highlighted the importance of the ethical conduct of research in African American populations at the intersection of COVID-19 and the Black Lives Matter movement. Their recommendations included understanding the impact of ongoing trauma due to the dual pandemics of COVID-19 and systemic racism, acknowledging historical context and maltreatment of African Americans in research, ensuring diverse research teams, and engaging in open and honest conversations with African Americans populations to address their needs better. Finally, the authors stressed the importance of recognizing the impact of trauma on the lived experiences of our community partners (CS) in our practices. We have remained aware of these realities for our CS throughout this study.

In line with a CBPR approach, we have adopted the theoretical framework developed by our community partner. The Murray Model is a culturally specific adaptation of community empowerment models that aims to inform the equitable engagement of African Americans in health research design and implementation. The Murray Model is an adaptation of multiple theoretical frameworks and conceptual models, including the health belief model, community empowerment model, elements of community-based participatory research, and ideas of "manhood." Given the explicit focus on community engagement with African American men, the Murray model is appropriate to the overarching objectives of this study. Furthermore, the model has been cited in three peer-reviewed manuscripts since being published in 2019, indicating its use and applicability for community-engaged health research (Julion et al., 2021; Tharakan et al., 2022; Watson et al., 2020).

A basic tenet of community-engaged research is to build capacity and health among those who are partners. CSs may experience many of the same systematic barriers to optimal health information and health care access as members of the larger communities, they will be engaging. As with technology literacy, efforts to increase CS knowledge and access to care are vital to improving the equity of all team members. Our educational curriculum was adapted to focus on lung cancer risk and eligibility for lung cancer screening. During the educational sessions, two of our CS with a history of tobacco use realized they were eligible for lung cancer early detection screening. These individuals discussed their potential eligibility, questions, and concerns about screening with one of the study principal investigators. Members of the research team were able to navigate these CS to lung cancer screening resources.

Limitations

Several limitations of this study should be noted. First, the total number of CS was relatively small. These smaller sample sizes are used to establish feasibility endpoints to establish parameter estimates to establish sample size estimates for future trials. However, feasibility studies are not expected to recruit sample sizes large enough to adequately power statistical null hypothesis testing (Tickle-Degnen, 2013). Instead, feasibility studies are designed to test an intervention in a limited way. Such tests may be conducted in a convenience sample, with intermediate rather than longer term outcomes, shorter follow-up periods, or limited statistical power (Bowen et al., 2009).

It should be noted that small sample sizes increase the risk for Type II errors—that is, failing to detect a difference between conditions when a difference exists. Despite the small sample size, all pre/post-test comparisons were statistically significant, except for the mistrust pre/post-test results for the mistrust scale. Additional evaluation of the educational modules is needed to confirm the benefits observed in this sample. Although each CS was from a single urban metropolitan area, each participant was from a different neighborhood within the city. The dispersion of CS across several community areas will increase the reach and diversity in future participants engaged by the CS. We examined changes in knowledge and attitudinal variables of interest from pre to post-test. However, we did not collect process evaluation data following each educational session. Although these data were collected in prior developmental work (Watson et al., 2019), the inclusion of this information may have been helpful to refine the content, format, or activities used in each of the educational sessions. Additional research will be needed to replicate study findings and continue enhancing the educational curriculum for CS focused on health inequalities among African American men.

Conclusions and Next Steps

The CS is emerging as an equitable means for increasing community engagement in health research based on crucial premises of community engagement, including equity, non-hierarchical engagement, respect for community knowledge, and community empowerment and capacity building. The CS model can potentially increase the involvement of historically excluded groups in research participation and knowledge generation. Furthermore, due to the cultural knowledge and understanding of CS of individuals living in communities disproportionately burdened by health inequalities, they seek to engage, outreach, education, and recruitment of groups experiencing health inequalities may be improved. In the next phase of the study, we propose an innovative community-based intervention project to engage African American men as CS to improve uptake of lung cancer screening among African American men who smoke.

Declaration of Conflicting Interests

The author(s) declared no conflicts of interest with respect to the research, authorship, and publication of this article.

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