

8-14-2019

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Published in final edited form as:

Prog Community Health Partnersh. 2019 ; 13(5): 103–112. doi:10.1353/cpr.2019.0043.

Engaging African American Men as Citizen Scientists to Validate a Prostate Cancer Biomarker: Work-in-Progress

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Abstract

Background—African American men (AAM) are underrepresented in prostate cancer (PCa) research despite known disparities. Screening with prostate-specific antigen (PSA) has low specificity for high-grade PCa leading to PCa over diagnosis. The Prostate Health Index (PHI) has higher specificity for lethal PCa but needs validation in AAM. Engaging AAM as citizen scientists (CSs) may improve participation of AAM in PCa research.

Objectives—Assess feasibility of mobilizing CSs to recruit AAM as controls for PHI PCa validation biomarker study.

Methods—We highlight social networks/assets of stakeholders, CSs curriculum development/implementation, and recruitment of healthy controls for PHI validation.

Results and Lessons Learned—Eight CSs completed all training modules and 139 AAM were recruited. Challenges included equity in research leadership among multiple principal investigators (PIs) and coordinating CSs trainings.

Conclusions—Engaging AAM CSs can support engaging/recruiting AAM in PCa biomarker validation research. Equity among multiple stakeholders can be challenging, but proves beneficial in engaging AAM in research.

Keywords

African American men; citizen scientists; community-based participatory research; prostate cancer; community engagement

Improving the health of AAM in the United States is a public health priority. AAM have higher rates of morbidity and mortality from many chronic diseases, including PCa.^{1,2} In fact, men of West African ancestry, including U.S.- and Caribbean-born Blacks, have some of the highest PCA mortality rates in the world.³ Compared with non-Hispanic White men, AAM have a 60% greater incidence of PCa and two to three times elevated PCa mortality.^{1,4} Although PCa screening using PSA is standard of care,⁵ there is marked overdiagnosis and overtreatment owing to the relatively low specificity of PSA.^{6,7} Ongoing controversies related to the risk versus benefit of PCa screening using PSA highlight overscreening, overtreatment, and increased morbidity related to potentially unwarranted biopsies and provider and patient uncertainty.⁵⁻⁷ These controversies may further widen the PCa disparities gap among AAM.⁵⁻⁷ To mitigate these controversies that may lead to barriers in screening, more research is needed to identify a biomarker with increased specificity and sensitivity to warrant further diagnostic testing.⁸⁻¹⁰ The PHI is a formula based on levels of total and free PSA, and a PSA prohormone called -2[pro]PSA, which is produced more in prostate tumors. The increased specificity of -2proPSA has been shown to increase the accuracy of PHI over PSA for identifying men with nonindolent PCa and can reduce the overdiagnosis of indolent nonlethal PCa. The studies that show that PHI may be more specific than PSA for lethal PCa in studies conducted in men of European ancestry.⁸⁻¹⁰ Thus, PHI has the potential to provide an innovative, less controversial screening biomarker than PSA but needs to be validated in AAM similar to ongoing validation studies among non-Hispanic White men.⁹⁻¹¹ AAM have traditionally been underrepresented in PCa research¹¹ and validation of the PHI as an effective PCa screening biomarker has not been conducted with AAM.¹⁰ Validation of an innovative PCa screening biomarker in AAM has the potential to address existing barriers in screening, thereby mitigating existing health disparities. Additionally, psychosocial factors continue to exist among AAM related to controversies associated with PCa screening using PSA. The lack of clear screening guidelines for primary care physicians for AAM, false positives of PSA, and the stress of biopsies further perpetuate fear and medical mistrust for AAM, thereby further deepening the disparities in both PCa screening and research participation among AAM.¹²⁻¹⁴ Given the potential diagnostic benefits of PHI as a PCa screening biomarker, there is a need for intentional outreach to AAM for research engagement and an urgency to validate PHI among AAM. We have a cohort of AAM undergoing prostate biopsy at three Chicago sites. This protocol aims to add 125 healthy AAM with normal PSA to serve as controls so that we

can do a stage I validation of the PHI to assess its distribution in controls, men with negative biopsies, and men with high-grade PCa.

Theory and prior literature have described the benefits of a diverse study team, including racial/ethnic diversity among the PIs,¹⁵ leveraging peer leaders,^{16,17} and patient engagement¹⁸ for eliminating health disparities. Yet, these areas of research rarely intersect. Often, diversity among PIs is discussed in relation to clinical or basic sciences^{18,19} and community-based participatory research approaches assume that researchers and PIs do not belong to the priority population and are regarded as “outsiders.”^{20,21} Our study informs this body of work through intentional conceptualization of all stakeholders, including AAM and one AA woman, who represent multiple PIs of the team, CSs, and community participants. The multiple PIs (four AAM, one AA woman) represent five academic and community organizations. Each CS is an AAM who is an informal leader within different segments of the AA community. Community participants are AAM whose lived experiences and health needs are a public health priority and are situated within these organizational and community settings.

Our conceptual framework illustrates that using community-based participatory research approaches and social networks across different stakeholder positions may optimize the effectiveness of partnerships between community-based organizations and academic partners. Below, we describe our 1) conceptual framework, 2) aims and study design using this framework for PHI validation in AAM, and 3) emerging outcomes and lessons learned in engaging CSs.

METHODS

Conceptual Framework

Figure 1 highlights how different members from the priority population may work together across different stakeholder positions and how community-based participatory research and social networks are connected to shared identities, norms, and experiences. Academic and community multiple PIs have 1) a substantial amount of exposure to and experience with research, 2) access to institutional resources, including the ability to obtain funding for research/clinical care (e.g., internal organizational grants, National Institutes of Health–related grants, clinical departmental support), and 3) formal partnerships with other community-based organizations, clinicians and researchers. CSs have 1) a substantial amount of exposure to their communities and experience supporting and advocating for others in their communities and 2) access to grassroots resources. Finally, community participants have their own personal resources through their personal and professional networks (e.g., family members as doctors), including access to community members that may not engage with health care systems.

Figure 1 provides examples of the benefits of shared representation across all stakeholder positions and consequent cohesion between stakeholders for short-term outcomes (awareness, self-efficacy, skills, knowledge, respect/tolerance, mistrust), intermediate outcomes (increased population access to and participation in research/clinical care), and long-term outcomes (improved population outcomes).

The PHI ChicagoCHEC Study

Multiple PI History, Relationships, Skills, and Capacity—The study team includes five organizations: Project Brotherhood (PB), the Chicago Global Health Alliance (CGHA), the University of Illinois Cancer Center (UICC), the Robert H. Lurie Comprehensive Cancer Center at Northwestern University (RHLCCC-NU), and Northeastern Illinois University (NEIU). Each of the stakeholders have local and/or national capacity in outreach and engagement and research facilitation of AAM. Each of the stakeholders help to facilitate the identification and engagement of the cohort of AAM as CSs and they each bring a unique perspective from a socio-ecological framework helping to engage men at multiple levels from the individual level (i.e., PB helps to provide direct services to AAM in Chicago), interpersonal level (i.e., the NEIU stakeholder has a track record of providing peer mentoring for AAM in classroom settings and has lived experience as PCa survivor), the organizational level (i.e., RHLCCC-NU expands the coverage of screening through patient navigation and timely follow up of screening), the community level (i.e., CGHA fosters coalition building with academic and community partners to expand resources for PCa screening), and the policy level (i.e., UICC translates research findings and have a publication history of developing policy briefs that inform stakeholders of recommendations of cancer screening among high risk populations).²²

PB—PB has more than 22 years of nationally recognized experience in patient engagement and addressing health disparities. Marcus Murray, a multiple PI, serves as the Executive Director of PB and is nationally recognized for his innovate grassroots methods to engage AAM.²³ PB has a proven track record of established trust among AAM in Chicago and has expertise in providing individualized care coordination for AAM that addresses the full context of the health needs of AAM, ranging from job and workforce development to health screening and navigation with culturally reflective medical providers and support teams. Their reputation has allowed researchers across UIC and RHLCCC-NU to engage and recruit AA men in barbershops and other community settings into clinical studies.

UICC—The UICC is one of the nation's first communityfocused cancer centers committed to addressing cancer inequities through a bench to community model. Multiple PI Dr. Karriem Watson is a nationally recognized expert in community–academic partnerships and engaging community partners as equitable partners in research and serves as the board chair for Community Campus Partnerships for Health.²⁴ Additionally, the UICC is one of only a few cancer centers directly affiliated with a Federally Qualified Health Center that further supports its ability to provide timely and comprehensive navigation to AAM.

NEIU—NEIU is a federally designated Hispanic-serving institution and ranks among the top public universities in producing a diverse workforce. Dr. Josef Ben-Levi, a multiple PI, is a scholar of ancient and medieval philosophy with expertise across various disciplines in the African diaspora and brings his lived experience as a PCa survivor. Dr. Ben-Levi has established community relationships and has served as a mentor to other PCa survivors. NEIU also has an affiliated community center, the Caruthers Center that served as one of the recruitment sites. The Jacob H. Carruthers Center for Inner City Studies was established in

1966 at NEIU to serve as an epicenter for cultural connectedness and social and civic engagement.²⁵

CGHA—The CGHA has expertise in leveraging partnerships and coalition building to improve access to health care for underserved populations and has led health promotion research with the multiple PIs. Dr. Tiffany McDowell is one of the multiple PIs based on her expertise in convening varied stakeholders for transdisciplinary work and in social network analysis. The CGHA has a local footprint in the Chicagoland area of conducting community based screening and health education and in conducting community engaged research with PB and RHLCCC-NU.

RHLCCC-NU—The RHLCCC-NU is one of two National Cancer Institute (NCI)-designated comprehensive cancer centers in Illinois, nationally ranked as a leader in research and scientific leadership. Multiple PI Dr. Adam Murphy is a National Institutes of Health-funded physician scientist who is a national leader in PCa disparities research that examines the intersection of socioeconomic factors, exposures, genetics and race with PCa risks.

The multiple PIs collaboration was built upon existing health advocacy collaboration and personal relationships. RHLCCC-NU, CGHA, and UICC partners have worked together in more than 15 health fairs and PSA screening events and multiple PIs from PB, CGHA, UICC, and RHLCCC-NU have collaborated on previous projects with AA barbers to address HIV, PCa and mental health among AAM.^{26,27}

RESEARCH AIMS AND METHODS

Aim 1: Recruit and Train a Cohort of 8 to 12 CSs to Support the Engagement of Their Social Networks to Inform Recruitment of a Cohort of Healthy Controls

Recruitment

Multiple PIs identified CSs who met the following eligibility criteria: 1) 30 years of age or older, 2) self-identified as an AAM, 3) had an established relationship with a multiple PI or institutional partner, 4) willing to participate in trainings and engage their social networks, and 5) were perceived by multiple PIs to be “influencers” who would be respected and embraced by the academic and AA communities. CSs were expected to: 1) commit to a 12-month partnership, 2) attend at least five trainings, 3) participate in at least two community events, and 4) engage their social networks. When considering the pool of CS candidates, there was an intentional focus to identify a broad representation of AA leaders from faith-based, civic, and fraternal affiliations as well as AA leaders with PCa cancer experience. Twelve individuals were invited to become CSs and eight ultimately agreed to participate.

CS curriculum

A CS training and engagement curriculum was developed and adapted from the evidence-based Open Educational Resources materials established by the University of Florida Clinical and Translational Science Institute CS Program (UF CTSI) Curriculum.^{28–30} The adapted curriculum includes a) training on the ethical conduct of research, b) modules on historical mistrust among AAs, c) asset-based approaches, d) modules that addressed

engagement, recruitment, and retention in culturally responsive ways, e) information to increase awareness of cancer disparities and cancer disparities research, and f) PCa cancer disparities materials.

The training series included five 2- to 4-hour modules with videos, PowerPoint slides, brief pre and post assessments, and an instructor guide. Session 1 oriented members to the program and gave an overview of CSs expectations, roles, and relationship building. CSs also completed CITI and UIC Institutional Review Board (IRB) Health Insurance Portability and Accountability Act of 1996 (HIPAA) training. Session 2 focused on cancer health disparities and provided brief overviews of prostate, lung, breast, ovarian, cervical, colorectal, and head and neck cancers and reviewed the functions of a cancer center. Session 3 provided an overview of recruitment versus engagement strategies, including the type of language to use (e.g., incorporation of Inner City Jive), materials to consider for recruitment (e.g., no flyers, general flyers, event/group-specific flyers), and locations that were optimal for individual CSs. Session 4 was dedicated to a training topic that CSs expressed a need or desire to learn based on baseline surveys and verbal feedback. Session 5 was a booster session to review or further discuss previous topics or focus on a desired skills building exercise.

The location and scheduling of the CS curriculum was decided by CSs. Documentation of informed consent was obtained before collecting data from all CSs. CSs received an annual stipend of \$2,400 for their work, disbursed in quarterly payments.

Data collection

Quantitative data were collected through a series of assessments. A baseline survey assessed demographic characteristics, PCa knowledge, skills training interests, participation in previous community engagement activities, health literacy, medical mistrust, and exposure to adverse childhood events.^{11,12,31–33} An evaluation conducted after each session included satisfaction and future improvement questions. A post-training survey is conducted every 6 months for the 2-year program period. This survey assesses knowledge, skills training, health literacy, medical mistrust, barriers and facilitators related to CS activities, and experiences in research participation and community engagement. Qualitative data will be collected to evaluate CSs impact on community reach and engagement, project experiences, barriers and facilitating factors faced as a CSs, awareness of community environments through others' lived experiences; awareness and advocacy for needed institutional and clinical resources; views academic and nonacademic perspectives; and individual capacity. Focus groups will be conducted during a selected time point in years 1 and 2. This mixed methods approach gives a comprehensive exploration of study constructs and project impact.

Aim 2: Expand Recruitment to 125 Asymptomatic AAM Aged 40 to 79 without Elevated PSA or PCa to Establish Normal Age-Adjusted Ranges for PHI

Recruitment

To recruit community participants, multiple PIs and CSs collaborated on 1) identifying local events (health fairs, PC screening events) and venues (churches, Mason's lodges, veteran's homes, primary care clinics) wherein AAM could be engaged via word of mouth and 2)

developing flyers tailored for specific community settings and each CS network. The stakeholder with the strongest connection to the specific community event or venue led recruitment for respective events. Each CS was expected to engage and facilitate recruitment of at least 10 to 12 men from their social network for a total of 80 to 96 recruited community members. Community members are also recruited through events that are planned specifically by a CS to target AAM from their own networks. Multiple PIs also leveraged their social networks to recruit 56 men. Men were recruited if they self-reported as Black or African Americans, were between the ages of 40 and 79, years and had no prior history of elevated PSA levels, abnormal prostate examinations, or a prior PCa diagnosis. We oversampled to account for the fact that some men would have elevated serum PSA and would be at significant PCa risk and not eligible as healthy controls. Men with elevated PSA were referred to their primary care physician or urologist to follow up the elevated PSA. Some of the men have undergone prostate biopsy and all men have been navigated to care to date. These men with elevated PSA of greater than >4.0 ng/mL are excluded from the analysis of this aim.

Community member engagement

Community member engagement events will be conducted until recruitment goals are met. Activities include a) completing the consent process, b) collection of blood and sputum samples, and c) completion of baseline survey conducted by an interviewer to each participant. Baseline surveys mirrored those completed by CSs. Blood and saliva samples collected are processed by the RHLCCC-NU multiple PI.

Aim 3: Compare the Distributions of PHI Scores and Serum PSA between Three Risk Groups: AA Community-Dwelling Low-Risk Men, AAM with Negative Prostate Biopsies, and AAM with High-Grade PCa

This is a phase 1 evaluation. We will establish the mean, range, and distributions of PHI among the cohort of 125 healthy AA controls recruited in aim 2.^{8–10} We then compare the mean, range, and distributions of PHI in true controls, negative biopsies, indolent PCa cases and potentially lethal PCa cases.^{34–36} The sputum collection will also aid in the PHI validation and confirm percent of African ancestry. The occurrence of high-risk PCa is associated with West African ancestry. Inclusion and exclusion criteria for the study is confirmation of Black or West African ancestry. Any participant not found to have greater than 10% of genetic West African Ancestry will not be included in the PHI validation analysis.³⁷ This criterion is based on data published by Bryc et al.³⁷ using 23andme.com data where almost no person self-reported as AA with less than 10% West African ancestry. Additionally, the use of return of genetic results in the form of African Ancestry will be assessed qualitatively to identify if the dissemination of African ancestry in research may serve as a motivating factor for AAM to participate in research. To date there are little data on the return of genetic information to AAM as a motivator for research engagement.^{38–40}

PHI CHICAGOCHEC STUDY: EMERGING DATA AND LESSONS LEARNED

We provide preliminary process data, lessons learned and solutions and recommendations related to aims 1 and 2.

Project Challenges: IRB

The CSs PHI CHEC Project was funded from the NCI U54 ChicagoCHEC Incubator Grant mechanism. The center established a well-coordinated plan to support the IRB approval process across the three institutions and the community partners. The full IRB approval was obtained across the sites based on the earlier lessons that the center had gained during its first round of pilot funding. Nevertheless, coordinating the IRB process across three institutions contributed to delays in recruitment. The addition of the CSs to the IRB approved protocol as key research personnel was also delayed owing to the scheduling challenges of CITI and HIPAA training of the CSs and other interagency agreement requirements.

Aim 1: Multiple PIs and CSs

The eight CSs represent PCa survivors ($n = 3$), faith-based leaders ($n = 2$), fraternity order member ($n = 1$), civic leader ($n = 1$), barber ($n = 1$), and a community social worker ($n = 1$). CSs and multiple PIs endorsed their relationships as long term (5–40 years), very strong, and forged through multiple initiatives for AA health (e.g., provision of barber services, research). Table 1 depicts baseline data. Overall, CSs largely had previous community organizing and volunteering experience, reported greater awareness of community health, were motivated to become CSs, wanted to gain skills in understanding community health priorities, and reported high self-efficacy with engaging different stakeholders. Most CSs seemed to have a high level of baseline PCa knowledge. To date five of five training sessions have been completed.

Scheduling to accommodate the schedules of all of the CSs is an ongoing challenge. Relatedly, the project coordinators were trying to use a one size fits all approach. In response, the PB multiple PI noted the importance of 1) tailoring communication based on individuals' preferences (e.g., phone, e-mail, text, all), 2) having a personal relationship built on mutual trust and respect between project coordinators and CSs, and 3) remaining flexible in planning and prioritization. Overall, the multiple PIs—especially those in academic institutions—have gained experience in the context of enabling multiple opportunities and ways for CSs to remain engaged.

Aim 2: Multiple PIs, CSs, and Community Participants

Multiple PIs and CSs have collaborated to engage and recruit AAM community-dwelling men as participants at three community events. To date, 139 AAM have been recruited and 125 remain eligible after excluding men with elevated PSA levels to participate in aim 3. The initial event was targeted to the faith-based community of one of the CSs. This event was part of a larger PCa screening event that was held at one of the local churches on the south side of Chicago where one of the CSs is a member. The other two events were based on the social network of one of the CS and multiple PI from PB. These two events were held at the softball fields of the Chicago Park District in collaboration with a softball league. The community recruitment event yielded 24 men during the first weekend and, owing to word-of-mouth publicity, yielded 46 men the following weekend. All events to date have recruited men directly through word of mouth centered on the CSs' social networks. Word-of-mouth

recruiting also resulted from softball players and spectators. Owing to the iterative nature of this project, IRB approvals of event flyers to further promote recruitment is often delayed.

LIMITATIONS

One critique of our approach is that the men we recruited are not from a population-based sample, which may limit the generalizability of the data. We attempted to balance our recruitment to reflect the city at large so that there was a range of education level and socioeconomic status. In fact, our data mirrors 2017 Chicago data with about 25% of men over 40 being age 65 or older in the city and our sample. In our sample, 28.2% of AAM are married versus 25.0% of AAM in Chicago; the median income was \$30,000 versus \$35,296 for AAM in Chicago, and the college educational attainment rate was 32.9% in our sample versus 37.5% for AAM in Chicago. Our sample size is small, but given this is a phase I validation we have greater than 80% power to detect differences in the distributions of both PHI and PSA in AA healthy controls, men with negative biopsies, low-grade PCa and high-grade PCa.

CONCLUSIONS

The early lessons learned in the CSs PHI CHEC pilot demonstrate that engaging AAM in research can be achieved through leveraging and maintaining trusting partnerships. Although early challenges existed related to scheduling a substantial group of solid stakeholders, this holistic, community-centric approach embodies a “for us by us” mantra of research that resonates with both the CSs and community participants. Additionally, variation in the research style and area of focus (i.e., traditional clinical trials vs. community engaged research and clinician scientists vs population health researchers) of the multiple PI team also required ongoing open communication and shared decision making. Last, there are broad needs to patient navigation for participants who were ineligible for the study owing to elevated PSA (14 to date) and required additional care coordination. The ongoing lessons learned by multiple PIs and CSs are providing key insights into best practices in engaging AAM in research. The partnership has continued work to do, including reaching its year 1 target enrollment as well as beginning data analysis. Future directions of the project include further mixed methods analysis of the social networks in engaging and recruiting AAM in research.

ACKNOWLEDGMENTS

Special thanks to the University of Illinois Cancer Center, Ms. Erica Martinez, and Dr. Erica Seltzer. We also thank Mr. Shaan Trotter from the Robert H. Lurie Comprehensive Cancer Center and Northwestern University and Dr. Rick Kittles from the City of Hope. We thank NCI Program Director Nelson Aquila, DVM, and Dr. Sonya Springfield, PhD, Director of the NCI Center to Reduce Cancer Health Disparities. Special thanks to the Administrative Core of the Chicago Cancer Health Equity Collaborative and Drs. Melissa Simon, Joe Feinglass, Robert A. Winn, Marian Fitzgibbon, Christina Ciecierski, and Lidia Filus. We thank the Community Engagement Core and the Planning and Evaluation Core of Chicago CHEC.

Work for this partnership was supported by the National Cancer Institute (U54CA202995, U54CA202997, U54CA203000). This work is also support in part by the Center for Health Equity Research Chicago (CHER Chicago) and the National Institute of Minority Health Disparities (U54MD012523) and NCI P20 CA202908.

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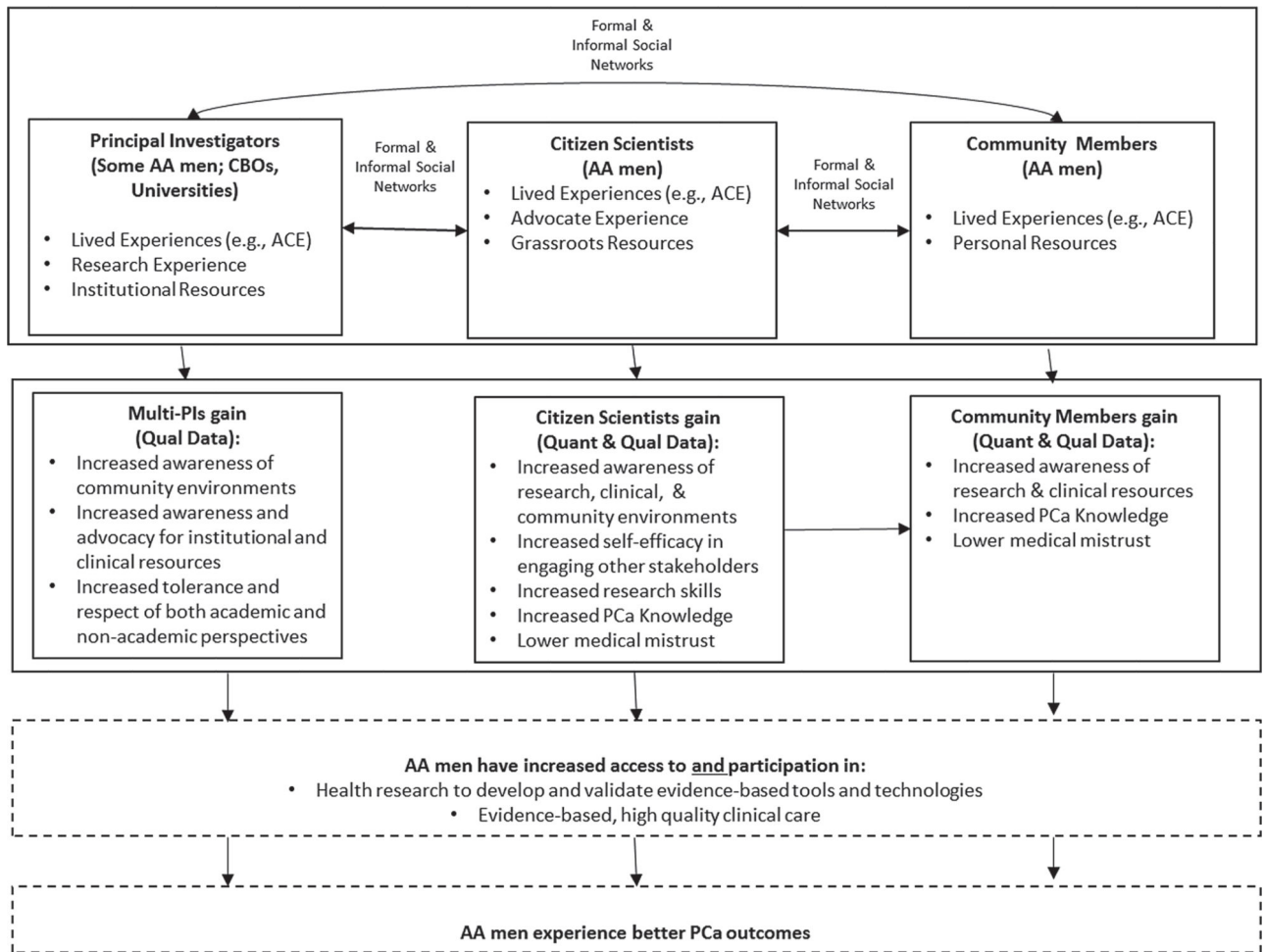


Figure 1. Conceptual Framework. Dotted Lines Indicate Associations Not Being Measured In This Study.

ACE = adverse childhood events; Qual = qualitative; Quant = quantitative

Table 1.Study Sample Characteristics ($n = 8$)

	<i>n</i>	%
Demographics		
Age (years)		
< 40	2	25
40	6	75
Marital status		
Married	5	63
Other	3	38
Community areas		
Bronzeville	2	25
Hyde Park	2	25
Calumet Heights	2	25
Burnham	1	13
Lawndale	1	13
Education		
High school graduate	8	100
Some college	8	100
Total number of adverse childhood experiences		
< 2	3	38
3–6	3	38
7–9	1	13
Prior experiences in health and community work		
In medical field	4	50
Community organizing/volunteering	6	75
CSs' motives, awareness, self-efficacy, and knowledge at baseline		
Motives		
Share my story	6	75
Support research	7	88
Prioritize research and funding	6	75
Improve cancer outcomes	8	100
Honor the legacy of a friend or family member	4	50
Conduct community outreach/reach other community members	8	100
Improve the health of my community	8	100
Increase knowledge and skills related to health, health care, and research	8	100
Perceived awareness of		
Cancer research	4	50
Health research	5	63
Cancer centers/cancer center programs	2	25
Community health issues	6	75
Specific skills of interest		

	<i>n</i>	%
Identifying important problems within your community	8	100
Identifying important strengths within your community	8	100
Writing/reviewing funding applications	6	75
Writing/reviewing research study procedures	6	75
Recruiting individuals to participate in research	7	88
Collecting data/information for research	5	63
Analyzing data	6	75
Helping to decide how to get information out to community	8	100
Helping to create long-term impact with studies that help	6	75
Helping to decide what the cancer center priorities should be	7	88
Self-efficacy in engaging other stakeholders (indicated very comfortable)		
Physicians	5	63
Health researchers	4	50
Community members to participate in research	7	88
Community members about their health/health care	5	63
Knowledge (correct answers in parentheses)		
The normal range for hemoglobin for a male is 13.3–17.2 g/dL. Joe's hemoglobin is 9.7 g/dL. Is Joe within the normal range? (No)	6	75
A biopsy of a tumor is done to (diagnose it)	8	100
If a patient has stage 1 cancer, it means the cancer is (localized)	6	75
The role of a physical therapist is to talk to a patient about emotional needs. (False)	6	75
A tumor is considered inoperable when it cannot be treated with (surgery)	6	75
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? (20)	6	75