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FULL-LENGTH ARTICLES

Building Trust for Community-Engaged Research: Recommendations From a Qualitative Study

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Background

Community engagement is crucial for public health research and detailed, step-by-step best practices for fostering it are needed. This study aimed to identify barriers and facilitators for public health research in three underserved Atlanta communities, explore effective community engagement methods, and propose practices for involving communities in all research phases, from study preparation to outcome dissemination.

Methods

Eight focus group discussions (3 with African American adults, 3 with older adults, and 2 with refugee and immigrant (RIM) participants) were conducted between November 2022 and March 2023. We coded the transcripts using NVivo 12, reviewed them, wrote memos summarizing each code's outcomes, and synthesized the results through discussions.

Results

Participants identified historical mistreatment and mistrust, inadequate information about research and the utilization of data, discomfort with data collection procedures, legal risks, language barriers, and discrimination issues as barriers to participation in research. Facilitators were categorized into extrinsic and intrinsic rewards of engaging in research. The extrinsic rewards included pragmatic compensation, such as cash or food, their interest in the topic, and the potential health benefits from participating in the study. Intrinsic rewards provided a greater sense of purpose and buy-in for research engagement such as the potential to contribute to positive change for their family and community. Based on barriers and facilitators, four main ways were suggested to build trust with the community for conducting research, including 1) establishing close relationships with "community champions", 2) building a research team with

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shared demographic characteristics of the community, 3) enhancing research transparency and clarity, and 4) using effective modes of recruitment, data collection, and dissemination.

Conclusion

Successful community engagement in research requires a holistic approach that prioritizes relationship-building through community champions, transparency in research methods and dissemination of findings back to the community, and cultural sensitivity. This approach to research emphasizes research "with community" versus "on community." Understanding community members' diverse motivations and preferences in recruitment/retention and data collection is key to successfully engage underserved populations in research.

BACKGROUND

Racial and ethnic minority groups disproportionately experience health disparities in the US (Borrell & Vaughan, 2019) and remain underrepresented in health research due to numerous factors including a lack of trust in research/researchers and concerns about mistreatment and exploitation (Bonevski et al., 2014). It is crucial to develop effective approaches for engaging underserved and overburdened communities in health-related research projects.

Research and public health practice are more successful with community engagement in research design and implementation (Fleming et al., 2022; Frerichs et al., 2015; National Institute of Environmental Health Sciences & National Institutes of Health, 2000). Community-engaged research is increasingly recognized as an innovative approach that meets community needs, enhances the translatability and sustainability of research, thus addressing health disparities (Frerichs et al., 2015; Han et al., 2021). Community engagement can be integrated into every phase of research (Han et al., 2021). While a few systematic reviews have explored barriers faced by disadvantaged or minoritized groups in sampling, recruitment/retention, and data collection (Bonevski et al., 2014; Yancey et al., 2006), there remains a gap in showing effective strategies for study preparation (e.g., establishing research teams or refining research ideas) and outcome dissemination to the community. The development of strategies to foster community engagement throughout the entire research process, from initial study planning through dissemination, is not yet fully elucidated. For example, although a previous study highlighted that building trust with community members and other stakeholders is crucial (Han et al., 2021), it lacks specific guidance on how researchers should approach this or whom they should engage with. Additionally, studies previously underscored the importance of sharing research findings with participants (Bonevski et al., 2014; Couzos et al., 2005; Hing et al., 2010; Neville Isaacs et al., 2011; Webb et al., 2010); however, there has been little focus on the specifics of how, where, and when to do so. There is a need for supported and continued efforts to better understand and

evaluate best practices for enhancing community engagement, particularly regarding understudied populations such as immigrant communities (Huslage et al., 2021).

Metropolitan Atlanta (metro-Atlanta) in Georgia, USA, is unique as a racial-ethnic 'majority-minority' area (i.e., in which more than half of its residents represent social, ethnic, or racial minorities). With approximately 2.2 million Black residents, Atlanta ranks second in the United States, representing 5% of the nation's total Black population (Moslimani et al., 2024). Almost half of Atlantans (47.6%) living within the city limits in 2022 identified as Black American, and 12% were persons 65 years and over (Census, U. S., 2022). Even with the prevalence of health disparities among Black Americans, they remain underrepresented in research. Metro-Atlanta also includes the city of Clarkston, which has been designated as a refugee resettlement city since the 1990s and is now renowned as "the most diverse square mile in America" (Shaer, 2017). Between 2018 and 2022, two out of five Clarkston residents were foreign-born individuals, with over half (51%) primarily speaking a language other than English (Shaer, 2017). Despite its diverse and underserved population, few studies have focused on fostering community-engaged research for this area.

With its diverse population, various health-related issues, and numerous higher education institutions, metro-Atlanta is a prime location for understanding the needs, concerns, and apprehensions of people from understudied communities to engage in research. Our study aligned with previous studies that emphasized flexibility and customization of different methods to accommodate participant circumstances (Couzos et al., 2005; Fox et al., 2010; Shedlin et al., 2011), thus ensuring the most effective outreach to community members. Therefore, our qualitative study aimed to identify barriers and facilitators for health-related research within three underserved and understudied communities (older adults, Black Americans, and refugees/immigrants/migrants). Additionally, we explored effective strategies for engaging these communities in research and proposed detailed step-by-step practices for involving them in all phases of research.

METHODS

Overview

The Southern Urban Research for Growth and Equity (SURGE) project at Georgia State University used a community-oriented approach to understand (1) the most prominent health concerns in disadvantaged communities in metro-Atlanta and (2) how to engage these communities in health-related research. The current paper focused on communities' insights to increase participation in research. The results are reported according to Standards for Reporting Qualitative Research (O'Brien et al., 2014) and are presented in the participants' language.

Focus Groups Procedures

We conducted eight focus groups: three with African American adults, three with those aged sixty-five and above (older adults), and two with refugee/immigrant/migrant (RIM) participants between November 2022 and March 2023. We conducted 2-3 focus groups per population following the recommendation that two to four groups per category is sufficient to achieve saturation (Hennink et al., 2020). Each focus group had between 10 and 15 participants. The inclusion criteria were being at least 18 years old (65 for the older adult groups), residing in the Atlanta metropolitan area, and having English language proficiency. We recruited participants through community-based organizations (CBOs; e.g., senior recreation center, addiction treatment center, wellness and resource hub, church, etc.), and held focus groups at the community organizations' facilities or at Georgia State University. The CBOs representatives and our Community Advisory Board (CAB) were involved in the recruitment process through their review of/approval of recruitment materials and contact with participants; they also reviewed and provided feedback on the focus group guide.

Participants completed a brief (2-5 minutes) demographic survey followed by a 60-75-minute focus group discussion. Discussion questions covered salient health issues in their communities, the acceptability and feasibility of participating in clinical research, and the acceptability of various study procedures (i.e., providing bodily fluid samples, physical activity, longitudinal studies, taking surveys, etc.). Saturation was assessed during the thematic analysis process, where data from each successive focus group were compared to identify recurring patterns and the emergence of new themes. By the final focus group, no new themes were identified, indicating that data saturation had been reached. To ensure participant privacy, participant names were not recorded, and participants were asked not to use real names during the focus groups. Discussions were audio recorded and professionally transcribed. Each participant received $100 in cash. This study was approved by the Georgia State University IRB.

Data analysis

LP developed the preliminary codebook by reviewing the transcripts and recording prominent themes. This preliminary codebook was then circulated among all authors and revised. Following this, three coders (co-authors TPTT, AKA, and ISS) independently coded one transcript using NVivo 12. Subsequently, the three coders met with another team member with expertise in qualitative data analysis to discuss any discrepancies in coding and resolve them. They also refined code definitions, resulting in the creation of the master codebook. The remaining transcripts were divided and coded individually. Following a qualitative description approach (Neergaard et al., 2009), eleven team members reviewed the coded transcripts, wrote memos summarizing the findings for each code and engaged in discussions to

synthesize these results. The first authors consolidated all memos and wrote the first draft of the manuscript, which was subsequently reviewed and revised by all co-authors.

Reflexivity Statement

Our research team is characterized by racial, ethnic, and other sociodemographic diversity (e.g., men and women; people identifying as African American, Asian, and White; varying ages, countries of origin, and education levels). Throughout the process of study planning, data collection, and data analysis and interpretation, team members reflected on and discussed ways in which our backgrounds, motivations, and values may influence our perspectives on the methods and results (Muhammad et al., 2015). We also engaged with a Community Advisory Board (CAB), which included representation from relevant community-based organizations, religious/spiritual organizations, healthcare organizations, and elected officials. Through quarterly meetings and interim feedback, the CAB guided data collection and interpretation. After data collection, our team participated in townhall meetings with each of the communities in which we presented preliminary results, elicited community feedback, and engaged in discussion about future directions. Thus, the research team took advantage of opportunities to explore and acknowledge the researchers' positionality and potential biases and power dynamics occurring within the research process.

RESULTS

The demographics for the overall sample (N=92) and specific subgroups (34 African American, 30 older adults, 28 RIM) are shown in Table 1. The mean age was 53 years, and 55.7% of the participants were female. Among the older adults, 86.7% identified as African American, while the RIM group was primarily White (46.4%) and Asian (28.6%), from various Middle Eastern and Asian countries. Nearly half of the African American and RIM participants had a university or post-graduate degree, compared to less than 30% among older adults. Over 90% of the older adults were retired or unable to work, while about half of the African American and RIM participants were employed full-time.

Across all focus groups, the three main themes discussed were research barriers, research facilitators, and building trust within the community when conducting research. Based on the results, we propose recommendations for community-based research studies, which are presented in Table 2.

1. Research barriers

Participants identified historical mistreatment and mistrust, inadequate information about research and the utilization of data, discomfort with data collection procedures, legal risks, language barriers, and discrimination issues as barriers to participation in research.

Table 1. Demographics of study participants

	Total (n=92)	African American (n=34)	Older Adult (n=30)	Refugee, Immigrant, or Migrant (n=28)
Age, mean (sd)	53.24 (21.31)	48.53 (20.29)	72.70 (6.67)	35.21 (14.25)
Sex, n (%)				
Male	42 (45.7)	15 (44.1)	12 (40.0)	15 (53.6)
Female	50 (54.3)	19 (55.9)	18 (60.0)	13 (46.4)
Race, n (%)				
American Indian/Alaskan Native	1 (1.1)	0 (0.0)	1 (3.3)	0 (0.0)
Asian	8 (8.7)	0 (0.0)	0 (0.0)	8 (28.6)
Black	61 (66.3)	34 (100)	26 (86.7)	1 (3.6)
White	16 (17.4)	0 (0.0)	3 (10.0)	13 (46.4)
Other races	2 (2.2)	0 (0.0)	0 (0.0)	2 (7.1)
Spanish, Hispanic, or Latinx, n (%)				
Yes	2 (2.2)	1 (2.9)	1 (3.3)	0 (0.0)
The highest educational level, n (%)				
Grade school or some high school	6 (6.5)	1 (2.9)	2 (6.7)	3 (10.7)
Completed high school	22 (23.9)	5 (14.7)	10 (33.3)	7 (25.0)
Completed technical/trade school/ community college	5 (5.4)	1 (2.9)	4 (13.3)	0 (0.0)
Some university, no degree	17 (18.5)	10 (29.4)	5 (16.7)	2 (7.1)
Completed university degree	22 (23.9)	10 (29.4)	2 (6.7)	10 (35.7)
Post-graduate degree	15 (16.3)	7 (20.6)	6 (20.0)	2 (7.1)
Employment status, n (%)				
Employed for wages-full time	30 (32.6)	18 (52.9)	0 (0.0)	12 (42.9)
Employed for wages-part time	9 (9.8)	3 (8.8)	2 (6.7)	4 (14.3)
Self-employed	4 (4.3)	2 (5.9)	1 (3.3)	1 (3.6)
Unemployed	9 (9.8)	4 (11.8)	2 (6.7)	3 (10.7)
Homemaker	1 (1.1)	0 (0.0)	0 (0.0)	1 (3.6)
Student	7 (7.6)	3 (8.8)	0 (0.0)	4 (14.3)
Retired	31 (33.7)	7 (20.6)	24 (80.0)	0 (0.0)
Unable to work	5 (5.4)	0 (0.0)	4 (13.3)	1 (3.6)
Annual household income, n (%)				
Under $10,000	11 (12)	4 (11.8)	4 (13.3)	3 (10.7)
$10,000-29,999	29 (31.5)	6 (17.6)	15 (50.0)	8 (28.6)
$30,000-44,999	9 (9.8)	2 (5.9)	2 (6.7)	5 (17.9)
$45,000-59,999	8 (8.7)	4 (11.8)	2 (6.7)	2 (7.1)
$60,000-74,999	8 (8.7)	7 (20.6)	0 (0.0)	1 (3.6)
$75,000-99,999	5 (5.4)	3 (8.8)	2 (6.7)	0 (0.0)
$100,000-149,999	5 (5.4)	4 (11.8)	1 (3.3)	0 (0.0)
$150,000 and over	3 (3.3)	2 (5.9)	0 (0.0)	1 (3.6)
Prefer not to say	5 (5.4)	2 (5.9)	2 (6.7)	1 (3.6)

Note: Numbers do not add up to 100% because of missing data from 4 participants in the RIM groups.

Historical mistreatment

Participants in the African American and older adult focus groups discussed the historical mistreatment of African Americans by medical, research, and professional staff, bringing the Tuskegee Study as an example of exploitation and abuse in health-related research:

Table 2. Recommendations for engaging underserved communities in health-related research.

Topic	Items
1. Study preparation	
1.1. Choose a research topic	• Consider topics that are both interesting and significant to the community. • Ensure that the outcomes of the research will have a meaningful and positive impact on their community.
1.2. Build trust with the community champions	• Identify community champions, including not only individuals with formal leadership roles or community-connected persons (e.g., ministers, community leaders, stakeholders, health providers) but also informal and untitled leaders (e.g., trusted church members). Build a close relationship with them. • Engage community champions as a 'bridge' to reach out to community members, introducing the study and recruiting eligible participants.
1.3. Build a research team with a demographic congruency	• Include community champions, community members/stakeholders on the research team. • Include researchers who are demographically similar to the target population. • Establish a research team that values and respects ethnic, racial, and cultural diversity within the community.
2. Study recruitment	
2.1. Use the appropriate modes of recruitment	• Depending on the target population and study topic, identify the most effective recruitment methods. • In-person recruitment methods (e.g., community meetings, workshops and patient-doctor appointments) may be the most effective way to initiate the recruitment process. Select convenient meeting times (e.g., weekends) and locations (e.g., the institutions or organizations with community champions such as churches, senior centers, and medical facilities) for these events. • Mediated methods (e.g., emails, phone calls, texts) may be appropriate if they come from a trusted source. This method is particularly suitable for young people. • Newsletters, flyers, and posters providing information about the study can serve as effective secondary recruitment tools. Distribute these materials at various locations, including churches, community centers, senior centers, grocery stores, schools, libraries, etc. • Provide the research team's phone number and website for participants to verify research information.
2.2. Information provided during recruitment	• Highlight the positive impact of research on participants themselves and their community. • Provide information on research transparency and clarity regarding the study's purpose, research process, how participants' information will be used, potential adverse events, etc. while recruiting. • Emphasize confidentiality and anonymity regarding participants' information, particularly for immigrant and undocumented individuals regarding their residency situation. • Emphasize an appreciative and dignifying communication tone to demonstrate a respect for and understanding of different perspectives • Use a culturally competent approach when interacting with community members.
2.3. Compensation	• Offer sufficient compensation and benefits to ensure participants feel valued and appreciated for their contribution. This could include monetary compensation, food, gift cards, event-related passes (movie tickets, etc.), and even educational materials.
3. Data collection	

3.1. Measurement	• If the study involves surveys, online methods could be suitable once trust has been established with the community.
	• For non-invasive procedures such as measuring blood pressure, height, weight, body fat, etc.:
	  ◦ Most participants are willing to undergo these measurements provided they are clearly described.
	  ◦ Sensitive or taboo questions must be approached through a culturally appropriate lens.
	• For invasive procedures (e.g., taking blood, collecting DNA):
	  ◦ Due to historical medical maltreatment and mistrust, African Americans may be less likely to provide samples. Researchers should:
	  ▪ Explicitly acknowledge historical mistreatments and explain the process for data collection, retention, and disposal to potential participants.
	  ▪ Keep participants abreast of the data process.
	  ▪ Incentivizing participation through medical care information and transparency benefits, e.g., providing participants with the test results of their given samples.
	  ◦ Only trained medical staff should conduct invasive measurements.
	• Female participants might feel comfortable with female staff members during measurements or interviews.
	• Reiterate confidentiality and anonymity.

3.2. Intervention/ trial	• Participants may have concerns about potential adverse events in intervention or trial research, so researchers should:
	  ◦ Explain to participants what adverse events could potentially occur during the study.
	  ◦ Clarify the procedures in place to assist participants should any adverse events occur

3.3. Retention	• Reminders sent via diverse methods such as email, text messages, and phone calls are helpful for retention in longitudinal studies. • Ensure to include the names of both the participant and the researcher when sending out reminders. • Consider an appropriate study duration.
4. Outcome dissemination	

Topic	Items
	• Return to the same locations where recruitment occurred to disseminate study outcomes through in-person meetings or workshops. • For intermediate outcomes: ◦ Do not wait until the end of the study to share results. Measure and inform participants on intermediate outcomes. ◦ Be honest and keep participants updated on any changes in research procedures, including negative events. • For final outcomes: ◦ Provide updates on final outcomes to all participants. ◦ Highlight how the study they participated in contributes to their community. ◦ Disseminate newsletters or flyers summarizing research outcomes.
5. Other	
Language	• Use plain language for research materials/presentations/surveys explicitly stating the details of the study. • Incorporate non-English languages in research materials if the study focuses on immigrant or refugee populations.
Discrimination	• Ensure that research do not contain discriminatory undertones.

> *"What I think is, why a lot of people do not want to do research because of what happens in Tuskegee."*- African American participant

Insufficient information about research and the utilization of data

One of the reasons participants reported that they (or individuals from their communities) might not engage in a research project was a lack of information within research recruitment materials. Participants across all groups expressed concerns about insufficient communication of research-related information; e.g., the research duration, potential complications, safety measures, and the utilization of their data by researchers. They emphasized that this lack of clarity could hinder their willingness to participate in the study: *"Sometimes you don't know what you going to get by doing the survey or what they trying to put in you, what they're trying to take out of you." (African American participant)*

Due to insufficient information, numerous African American and older adult participants voiced concerns about the potential risks associated with medical studies involving medications or placebos. They were *"scared to take some medications"* and worried about potential side effects, such as *"that could possibly have a bad impact"*, *"if I'm in the control group?" or "if you have any complications, will they follow up or will they take care of it?".*

> *"I had never dealt with placebos or anything like that. I don't do that part. We not going to take nothing. This brother's not going to take nothing. [...] I'm not going to participate with it when I have to go and actually go do some medicine or something like this and see how it's going to work. It might make me go bald or something." – African American participant*

Participants across focus groups raised concerns regarding the privacy and confidentiality of their data, spanning from survey responses to blood samples. A participant from the RIM group emphasized the importance

of anonymity, stating *"your data or opinion should be anonymous and your name should not be mentioned in everything".* Moreover, some individuals expressed distrust, even when that data was collected for a particular purpose. They lacked trust that the data would not be repurposed without their consent, with one participant remarking, *"They can tell you one thing and it doesn't have to be that. That's the whole point."* Additionally, participants had numerous inquiries about data usage and protection from non-research entities. An African American participant raised questions about the handling of DNA samples, asking "W*hat happens with the material with our DNA afterwards? Because that's the other question. How do you destroy the DNA once you've taken it from you? Where does it go?"*

Discomfort with data collection procedures

The willingness to participate among many African American and older adult participants also depended on the types of research and data collection methods implemented, as they could involve different measurements ranging from surveys to physiological tests such as body measurement to more invasive actions such as blood draws,

> *"I think there's a big difference too in what the study or the research is about. Because it's one thing if it's following you or having you take a little test or something and then it's something else if they want you to take a pill or get a shot. So I think the level of hesitancy really reflects what it is that you're being asked to do or to participate in or to whatever." – older adult participant*

Some participants in the African American focus groups emphasized limiting data collection to non-invasive measurements or other procedures that did not collect DNA: *"My blood has to stay with me"* and *"I'm just not going to let you take no blood".* While participants in the older adult group were most agreeable to all forms of data collection asked during the session, they disliked the idea of 'cold calls' for recruitment purposes or submitting personal, critical information via online surveys as that was viewed as impersonal, invasive, and the beginning of a scam. For example, they stated they would not want to give their zip code or other information that could be linked to their financial status or other personal information.

> *"With people calling you on the phone all the time 'Hi [name of participant]'. How do you know my name? [...] they called me and asked me: 'I see you've got Medicaid, Medicare' They want that Medicaid, Medicare number." – older adult participant*

Legal risks

The RIM group was particularly concerned about how information collected during studies could be used in ways that would harm their legal status in the US. Participants from groups stigmatized due to their citizenship status brought up valid concerns of anonymity and fear of deportation

because of their involvement in research. *"...it should be explained to the audience, or to the participant, that your data or opinion should be anonymous." "Even Latinos, as many as we are, there's a bunch of us that won't come out. They think they're going to get picked up."*

Language barriers

Language barriers were a significant challenge for the RIM group, with some members expressing reluctance to participate due to these barriers: *"some of them have language barriers that they don't want to come here,"* and *"we can't speak English, how can we participate there?"* Therefore, researchers focusing on the communities which speak languages other than English as their primary language may face a significant challenge because *"they're refugees or immigrants, they don't have full communication skills."* Additionally, other participants in the African American group emphasized challenges related to the use of medical terminology that may be difficult for everyone to understand. One participant suggested, *"The way you've delivered the information to them, coming down to their level, using simple terms would definitely encourage and enhance that research as well."*

Discrimination

Those in the RIM group raised a concern regarding discrimination while participating in research or medical treatment. They highlighted that if survey questions have a discriminatory undertone, they are less likely to participate. As one participant stated, *"Discrimination is the first thing that should be avoided. The researchers should not expect the response that you would like to get it."*

An African American focus group participant explained a situation in which she felt that the medical professional disregarded her pain as if she was delusional, *"Because when we go to the doctor, a lot of times they do not look like us. And even when they do, there's still a stigma or an attitude about like she said about, 'Are you really feeling the pain that you are feeling?'"* She continued and alluded to the presence of structural biases as she emphasized, *"And two of those [three] doctors were of my same color."*

Other issues

Other barriers included inconvenient timing, long duration, and lack of compensation or benefits for participating in research.

2. Research facilitators

Participants brought up various factors that can facilitate their engagement in research; these factors can be grouped into extrinsic and intrinsic rewards. Extrinsic rewards related to outcomes based on one's motivation to engage in behaviors "because they represent a means to an end" while intrinsic rewards related to outcomes based on people engaging "in behaviors that they find inherently interesting and appealing" (Radel et al., 2017).

Extrinsic rewards

Among all groups, extrinsic rewards of being a research participant included pragmatic compensation like *"money", "gift cards", "tickets", "food",* or *"bingo and scratches"* because they *"let me know that you [researchers] appreciate my time" (African American participant)*. It could be services or *"opportunities",* such as *"a free resume writing class, a career coach or something that can be impactful to the group that you're trying to get information from" (African American participant).*

Additionally, participants from various groups indicated that their willingness to participate in research studies was often influenced by their interest in the topic or the potential health benefits to them from the research:

> *"If it's something I don't want to hear, then I'm not going to participate.... But it's something I want to hear and I'll participate." – African American participant*
>
> *"Familiarization with the subject matter. If we were more familiar we could probably be more involved." – older adult participant*
>
> *"I'm not afraid to do research because that's telling me where I'm at. Because normally there's some days they'll do the physical. They do a complete physical from head to toe and everything in between" – African American participant*

Another reason that encouraged RIM group members to engage in research was the opportunity to *"find new friends."* Additionally, these RIM individuals often felt voiceless or unheard, and participation in research provided them with an opportunity to share their concerns with the world: *"So we try to reach our voice or other recommendation to any responsible person that please pay attention, or just to bring their mind for this issue or this point."*

Intrinsic rewards

While extrinsic rewards could be beneficial for recruiting participants, intrinsic ones provide a greater sense of purpose and buy-in for research engagement. Many participants across the groups were adamant about participating in research if it offered the potential to contribute to positive change for their family and community.

> *"My family had a history of kidney failure, so dialysis and kidney transplants is a big one. So yes, I will participate in kidney research." – African American participant*
>
> *"I was aware of something that there is a research study go there and focus group is discussion is going on, I will ask myself, "What's my benefit? Why should I go there?" That is very*

> *important, so that we can tell them, "That your benefit would be that you will have a better life. You will have a better service, health service. You will have this. You will have this." So that will motivate the people to participate. Otherwise...why should I go to the research?" – RIM participant*
>
> *"I think the subjects is important. What's it about? Does it affect the people life and how it will affect the people life, in short-term, long-term? ...Then, it will persuade you to encourage some other people as well, that, "Okay, let's do it. It's not for nothing. It's for something that you will change, at least if not your life, your children life." – RIM participant*

3. Building trust with the community for conducting medical research

Based on barriers and facilitators, participants suggested four main ways to build trust with the community for conducting research, including 1) establishing close relationships with *"community champions"*, 2) building a research team with shared demographic characteristics of the community, 3) enhancing research transparency and clarity, and 4) using effective modes of recruitment, data collection, and dissemination.

Establishing close relationships with community champions

Participants across groups emphasized rapport-building with the community to enhance the research team's perceived trustworthiness, especially for recruitment. To build trust with the community, participants recommended researchers should establish close relationships with *"community champions"*, because *"community champions will help you [researchers] build trust because this is a trusted face in the community" (African American participant).* Another African American participant spoke plainly on the impact of rapport building, *"[...] telling people: 'Hey, come here,' people will listen to them because they've built trust with the community."* Herein, community champions could be individuals with formal leadership roles or community-connected persons such as *"city councils", "commissioners"*, *"ministers"*, senior citizen leaders, leaders of the church, *"professional people",* and *"doctors"*. However, some participants lamented that too often formal leaders are the only ones included in researchers' outreach regarding community engagement. Community champions could go beyond the formal leaders of neighborhood associations. The informal and untitled leaders could be great facilitators of recruitment along with formal leaders, such as *"church members"* or *"local grocery store person that you see every day or somebody that do all the lawn care in the neighborhood" (African American participant).* Including community champions on the research team will allow for potential participants to be recruited and introduced to a study through a trusted source, rather than an unknown researcher they are meeting for the first time.

> *"If there's somebody doing it with a familiar hospital or somebody or some name, some reputable name or something, somebody unknown, I'm not going to give my information to somebody I'm never going to see again. And that was my first time seeing or hearing them. I'm not going to be willing to participate in your survey. So if it is somebody known, like I say, and some reputable points where you are collecting it at, I'm going to have to participate." – older adult participant*

Build a research team demographically similar to the community

This theme came up primarily for African American groups. African American participants indicated that a researcher's demographic congruency with the community (i.e., the similarity of demographic characteristics between researchers and the community) could play a role in the initial trust-building with potential participants:

> *"I was able to see in my community in New York, I saw Latino doctors, Latino nurses. So I had no fear of them...That's what I'm saying. They look like you."*
>
> *"I hear louder when it's from people of the same religion as me."*

Including researchers of shared demographics on the research team can also demonstrate to community members the researchers' dedication to equity and allow them to be more comfortable with being part of the research.

> *"And if you just want to get into a community, Latin community, North African community, just hire somebody who's from there. Send a North African because they're...afraid anyway. They're not going to come out anyway. People come knock on your door and they're not one of them, they're not even opening the door"*

However, this is not to be interpreted as a researcher's appearance being the most crucial factor in gaining the community's trust. African American group members highlighted how a lack of consideration and respect can come from people within one's ethnic group with, occupational status playing a more significant role:

> *"I totally agree as far as having somebody who looks like you. And that would be the challenge I think we run into."*
>
> *"You can't just assume everybody in this community is white, everybody in this community is black, everybody is poor, everybody is rich, middle class, that's offensive. So most of the time you have to go where they are. And I'm not talking about physically, I'm talking about mentally you have to go where they are. So,*

> *you welcome everybody, poor, rich or whatever, black, white or whatever, and try to be culturally competent as it relates to getting these surveys out or getting this study out or what have you."*

Enhancing research transparency and clarity

Researcher transparency and clarity were described as key concerns influencing willingness to participate in medical studies. An African American participant brought up transparency of information as a form of rapport-building because community members would become more comfortable participating in research studies: *"because a lot of times that is what you're battling. It's not that people don't [know] how it benefits them and what the odds are that they may impact change. So, just give them understanding that will help with them after" (African American participant).* The idea of a study having "clear purpose" and comprehensible procedures and benefits was highlighted multiple times, from research recruitment (i.e., *"explain what you're looking for and how many you're looking for and then just give us synopsis of what the tests do, what the research is about" – older adult participant),* data collection (i.e., *"So we're going to do A, B, C, and D. And this is what's going to happen" – African American participant*), to outcome dissemination (i.e., *"make the results available").*

Participants also indicated research transparency about sharing research outcomes and its impact on their community was crucial to build their trust.

> *"Be efficient. So when you get the surveys, make sure that you are going to share the results of what you did. What the organization, the company, wherever who holds the survey made the change, made the actual change, and share through the public and send the results to the ones who participated. So it gives them a trust and it made them sure and that they did something great. They made an action, so they made the change" – RIM participant*

The need for clarity on privacy, confidentiality, protection, and anonymity was highlighted. It needs to be made clear that participants' identities are kept anonymous, and no names or personal identifiers should be mentioned when reporting results: *"The third is the secrecy, that it should be explained to the audience, or to the participant, that your data or opinion should be anonymous" (RIM participant).*

Research transparency and clarity could be achieved by making all information about the research team and study easily accessible to participants. For example, an African American participant mentioned, *"You all already have a website with all the information there, where I can see the advisor board...I know them to be good workers. So then, I'm trusting the work that you all are doing. So if it's just open for everyone to see, like, 'Hey, this is what we're doing, this is where we are at. We need you all once more to help build the capacity.' I'll buy into that".*

For longitudinal studies, researchers should maintain research transparency and clarity with participants over time by providing updates on progress and any changes. Researchers should also be transparent about both potential benefits and outcomes that may not occur: *"Don't wait until the end of the survey to say, 'Oh, we found this out month one, we found this out year one'. Tell me what's happening as you go along. So I can be kind of enlightened as to what's happening. Otherwise, I don't want to be in the dark at the end of the tunnel" (older adult participant).*

Using effective modes of recruitment, data collection and dissemination

Additionally, participants gave suggestions for effective modes of recruitment, data collection and dissemination.

Recruitment methods

In-person approaches

Many participants highlighted that in-person communication strategies were the most effective approach to building trust within the community. If researchers are not from the community or share marginalized identity with community members, trust can still be built through visibility and genuine interactions. As one African American focus group member affirmed, *"So if you look like me and I hang with you, then I'll tend to believe what you tell me."*

Older adults discussed how in-person recruitment strategies could make potential participants more connected to the study and emphasized how information about a research study should come from trusted sources:

> *"Just them having that trusted face to be like, 'Hey, I've spoken to this organization, this is what they're trying to do. This is the why, this is how it would benefit. Because they're going to listen to that trusted person and they're going to be able to get them on board." – African American participant*

Participants also emphasized how researchers being physically present and conversing with community members about the purpose, procedures, and context of the study could significantly impact rapport.

> *"But in-person, face-to-face, I think that if you're looking at a person you will get the exact information that you need because that person will have time to explain things better to you than talking on the telephone or going online. That's why I just like person-to-person." – older adult participant*

Furthermore, they discussed how they wanted to see and feel researchers' passion and care for the research subject matter through their time and engagement with the community: *"[...] but also knowing that you guys love what you're doing. It is for a good cause as well. And you enjoy it. You have personal buy-in" (African American participant).*

Mediated approaches

If mediated communication methods such as telephone calls, emails, text messages, or social media advertising were the initial approach, participants expressed a willingness to engage in the study only if it came from a trusted source. Otherwise, they hesitated because they *"don't know if it's something to trust"* or *"suspect of any ads on TV"*. Therefore, it was essential to include the research team's phone number on these platforms so participants could verify the authenticity. Furthermore, older adults suggested that while this online approach might work for younger participants, it may not be suitable for older adults.

Participants suggested that online communication would be more appropriate after building trust. They expressed feeling comfortable with it, stating, *"since we've already made contact I would feel comfortable with that, that it wasn't a scam or that it was somebody because we don't know you but we've met you and we've done this study" (older adult participant).*

Furthermore, using multiple approaches including email, text messages, and phone calls would be helpful for retention in longitudinal studies. However, researchers must ensure to include the names of both the participant and the researcher when sending out reminders as to reassure to participants the legitimacy of the communication.

Other indirect approaches

Newsletters or flyers providing information about the study could serve as an effective means of recruitment and dissemination. These materials could be distributed at various locations, including grocery stores, schools (passing out information to parents through kids), parks *("because they're free"),* libraries (with community rooms), seniors centers, churches *("you guys wanted a bunch of old folks, you got them.")*

> *"if that [research information] is included in your flyer. And if whoever reads it, if that's what catches their eye or they're interested in, you may get them to come out to that." - older adult participant*

Location

Participants emphasized that the research team should conduct recruitment in familiar locations serving as trusted sources of information, such as community centers, senior centers, medical facilities, or churches: *"The people will be more likely to come here to a space as opposed to going to an unfamiliar place such as a hospital or a doctor's office or even a university that can be intimidating to folks, but they would believe their trusted sources" (African American participant)*. Choosing locations that were easily accessible with amenities such as *"free parking"* was a crucial factor. Additionally, researchers should return to these same locations for future study activities, ensuring consistency and convenience for participants: *"wherever you recruited, going back to that same place" (older adult participant).*

Time

Weekends were described as the most convenient time for African American and RIM focus group participants to engage in research: *"if you could do it on the weekend days, that will be more people can attend" (RIM participant).* Several older adult focus group participants expressed a preference for weekdays and mornings with one of them clarifying, *"definitely weekdays. Not night."* In longitudinal studies, the study duration should be appropriate to avoid a feeling of *"time waiting"*.

> *"After I got halfway through it. 'Well, this is going to take two or three more months. Two or three more years'. I don't even know that after I done got started into something that I thought was just going to be a day, a week, a month." – older adult participant*

Compensation

To encourage participation through extrinsic motivation, researchers should always offer sufficient compensation and benefits to ensure participants feel valued and appreciated for their efforts: *"If you feel that our time was valued, then that means a lot" (African American participant).*

Language

Using appropriate and inoffensive language, as well as employing simple terms while speaking, conducting interviews, and designing surveys, was crucial:

> *"Knowing the language to use on the surveys, making sure you're using the sensitive language, the culturally appropriate language in the surveys. [...] So just making sure that the language that you use is appropriate." – African American participant*

> *"The way you've delivered the information to them, coming down to their level, using simple terms would definitely encourage and enhance that research as well" – African American participant*

If the researchers focus on RIM groups, their native language should be used in all modes of recruitment, data collection, and dissemination.

DISCUSSION

Our study explored community members' views on barriers and facilitators for research participation. Based their insights, we proposed recommendations for researchers working with underserved populations, covering all phases of the research process, from selecting research topics and forming teams to recruitment, data collection, and dissemination of results. This study underscored the importance of intensive community engagement throughout the research process. Researchers often focus on their own scientific goals, but community needs may differ. To create truly collaborative research that builds on community strengths, researchers should

incorporate Isreal, Eng, Schulz, and Parker's (2012) basic principles of community-based participatory research; e.g., "to the extent possible, all partners participate in and share decision making and control over all stages of the research process" (p. 9) (Israel et al., 2012).

Community-engaged research allows us to expand the scope of research from specific projects to addressing broader community needs (National Institute of Environmental Health Sciences & National Institutes of Health, 2000). Our study highlighted the importance of research topics aligning with specific community health needs and interests. Community members may engage in research because of its intrinsic rewards (such as gaining knowledge about the topic) and extrinsic rewards (such as material benefits). It behooves researchers to discuss with community members, during the piloting phase, the types of rewards, compensations, and reinforcements which would be most effective to garner research participation especially for cohort and longitudinal studies. Carrera, Brown, Brody, and Morello-Frosch (2018) developed the concepts of research altruism within banal altruism; specifically, "engaging in ordinary, bureaucratic processes to contribute positively to society as banal altruism, and the specific type of banal altruism expressed within research as research altruism" (p. 180) (Carrera et al., 2018). Intrinsic motivations can fuel community members to engage in research even if there are no immediate personal benefits. Overall, researchers should consider the community's input on the value of both intrinsic and extrinsic rewards.

Contributing to research that improves community's health was viewed as critical for continued long-term engagement. Collaborating with communities helps refine research questions (National Institute of Environmental Health Sciences & National Institutes of Health, 2000), develop new hypotheses, and foster a deeper understanding of community health needs (National Institute of Environmental Health Sciences & National Institutes of Health, 2000).

Previous studies have highlighted the importance of collaborating with community stakeholders to improve recruitment and retention by building trust, developing access strategies, and engaging in shared decision-making (Fortune et al., 2010; Harvey et al., 2009; Ibrahim & Sidani, 2014; Pakhale et al., 2016; Savage et al., 2006; Tanjasiri et al., 2011, 2015). For example, the involvement of community leaders or advisors has been emphasized in some studies (Bonevski et al., 2014; Swanson & Ward, 1995). However, our study further emphasized the role of informal community champions, such as trusted church members or grocery store owners, who may be more accessible than formal leaders. Leveraging relationships with trusted community champions could facilitate recruitment.

Another factor to consider when establishing a research team was ensuring demographic congruency with the population of interest. It is imperative to establish a diverse research team that values and respects ethnic, racial, and cultural diversity within the community. Community-based participatory

researchers must acknowledge the ways in which their identity and positionality can influence their relationships with community members and initial access to community information. One's "insider" status could lead to research participants being more transparent and afford one the ability to empathize with shared experiences; but may also bring greater accountability demands from the community (Muhammad et al., 2015). Research team members who are ethnically diverse can offer valuable insights into their communities, particularly in leading recruitment efforts (Vangeepuram et al., 2023). This aspect has been largely overlooked in previous studies, with only brief mentions of training staff in cultural issues and employing community residents as part of the research team (Swanson & Ward, 1995). Furthermore, the intersecting identities of research team members, no matter certain demographic congruencies, should be considered when boasting a diverse research team. For instance, having a racially diverse research team with the same training background could provide aesthetic, multiethnic photo ops while also entitling groupthink perspectives. Guishard, Heyward, Brown, and Stoddard-Pennant (2021) emphasized the lesson "We Finna Check Ourselves Before We Wreck Ourselves" (p. 20) (Guishard et al., 2021). Along with their reflexive statements on their multiple identities, several of which akin to community members' identities, and championing of Black feminist participatory research, Guishard, Heyward, Brown, and Stoddard-Pennant (2021) still accentuated the need for "professional humility" by "embracing critical race praxis" and being comfortable with getting checked by others (p. 4) (Guishard et al., 2021).

Lack of trust in research or research team members has also been previously highlighted (Bonevski et al., 2014; Howerton et al., 2007), leading to concerns about mistreatment and exploitation. In addition to building trust with community champions, it is important to provide clear and transparent information about the study's purpose, research process, use of participants' information, and potential adverse events during recruitment. The historic and contemporary context for African American participants in medical/academic research informs the duty for researchers to engage in non-exploitative, transparent practices (Warren et al., 2020). Emphasizing and ensuring confidentiality and anonymity regarding participants' information, especially for immigrant and undocumented individuals regarding their residency status, is essential (UyBico et al., 2007). Our findings align with previous studies (Couzos et al., 2005; Fox et al., 2010; Shedlin et al., 2011), suggesting that community members preferred in-person recruitment methods community meetings or events and patient-doctor appointments, over methods such as telephone calls or emails (Bonevski et al., 2014; Shavers-Hornaday et al., 1997; Wallace & Bartlett, 2013). However, online methods might be suitable if they originated from trusted sources. To enhance retention rates, our participants suggested the implementation of various communication methods, including phone calls, mail, and emails (Bonevski et al., 2014).

Our study yielded novel results by identifying participants' willingness to participate in research based on the invasiveness of procedures. Non-invasive methods, like surveys, were widely accepted, though sensitive topics required culturally trained interviewers. Conversely, discussion of studies with invasive procedures often invoked historical abuses like the Tuskegee study and participants expressed hesitation to provide biological samples. For invasive procedures, participants stressed the need for trained staff proficient in executing these techniques. Therefore, transparent communication about research purpose, methods, privacy, confidentiality, and adverse events is vital to mitigate hesitancy in participation. Gender also influenced participation, with female participants preferring gender-congruent researchers to ensure comfort and honesty, highlighting an important consideration for study design. Several studies previously underscored the importance of providing project feedback to participants (Bonevski et al., 2014; Couzos et al., 2005; Hing et al., 2010; Neville Isaacs et al., 2011; Webb et al., 2010), yet there was a lack of attention to how and when this feedback should be delivered. One of the core components of community-based participatory research is sharing research findings with the community in appropriate and requested ways (Israel et al., 2012). Our community members emphasized that outcome dissemination was one of the most crucial strategies contributing to the success of research with underserved communities. They shared that it is not only the final outcomes but also the intermediate outcomes that should be reported to the community. This served as evidence of how their participation contributes to the broader community (i.e., intrinsic reward). For instance, for the SURGE project, we hosted three townhalls (one in each community) after the conclusion of data collection, in which we provided light snacks, drinks, treats (e.g., ice cream); presented preliminary findings and encouraged community members to provide feedback; and offered some additional programming based on interests noted by focus group members (e.g., a brief mindfulness meditation practice and discussion of stress management). It is salient to community-academic partnership formation and maintenance to conceptualize "power as a social determinant of health that must be distributed equitably across groups of different social status" (p. 6) (Andress et al., 2020).

Limitations

The identified themes are the perspectives shared by the focus group participants and should not be broadly generalized, as our study only focused on small subsamples of participants from the Atlanta metropolitan area. The findings may not be transferable to individuals with different cultural or experiential backgrounds than our participants. Nonetheless, though there was substantial diversity among participants in the RIM focus group, there were more experiences *in common* than there were differences, underscoring that there did seem to be consensus around most of the specific topics/questions posed. All the participants agreed to participate in this research study; therefore, we might not have included perspectives on participation

barriers among people who chose not to be part of this study. Those who did participate in the study may have been motivated to present themselves/their community in a more positive light and/or in a more socially acceptable manner (social desirability bias). However, the likelihood of this having a major impact on our findings is minimal, as we employed common strategies for minimizing social desirability bias in qualitative research (Bergen & Labonté, 2020) including: (1) including assurances that no opinions are "wrong", that we wanted them to speak freely, and explaining the confidentiality and anonymity procedures at the beginning of the discussion and (2) posing questions indirectly (e.g., "why do you think *some* people might not want to participate in studies that involve collecting saliva or blood?"). Additionally, the focus groups only included participants with English language proficiency, which introduced bias by potentially excluding other health issues faced by RIM communities who are not fluent in English. Furthermore, due to word count limitation, the participant quotes used primarily reflect Black American participants, which might not fully represent the diversity of perspectives within the study.

CONCLUSION

Our sample representing urban older adults, African Americans, and RIM populations validated that greater efforts are still needed to promote and facilitate their engagement in research. Overall, successful community engagement in research studies requires a holistic approach that prioritizes relationship-building through community champions, transparency in research methods and dissemination of findings back to the community, and cultural sensitivity. This approach to research emphasizes research "with community" versus "on community." Furthermore, community engagement provides opportunities for crafting relevant health research, recruitment and retention sustainability, a more nuanced contextualization of analyzed data, and a diverse range of audiences invested in the dissemination of the research findings. Understanding community members' diverse motivations and preferences in recruitment/retention and data collection is key for researchers to successfully engage underserved populations in research.

List of abbreviations

RIM: refugee/immigrant/migrant

Ethics approval and consent to participate

This study was approved by the Georgia State University Institutional Review Board (IRB number: H23220) and all participants provided written informed consent.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

All authors conceptualized and planned the study. LP supervised the study. TPTT and IS coded the data. TPTT, JCC, CAH, JF, FL, KAD, CAS, CES, LP read the coded transcripts, wrote memos, and discussed the findings. TPTT and JCC wrote the first draft. All authors contributing to writing, revising, and approved the final manuscript.

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