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Research Article

Perceptions of Clinical Trial Participation in Racial and Ethnic Communities

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Abstract

Purpose: The development of pharmaceutical treatments and vaccines during the COVID 19- Pandemic brought to the forefront the importance of clinical trial participation. The purpose of this research was to assess community perceptions of clinical trials and to learn strategies to enhance participation in clinical trials among racial and ethnic communities. **Materials and Methods:** Six focus groups were conducted with 66 lay community members in three Florida cities - Jacksonville, Tallahassee, and Tampa. Data from the focus groups were transcribed verbatim. The transcripts were organized, coded, and analyzed utilizing NVivo qualitative software. **Results:** Most participants were non-Hispanic (72%), Black or African American (62%). Five of the 12 Hispanic participants identified their race as Black. There were 39 males and 21 females, most (48%) between the ages of 25-34. Many participants perceived clinical trials as research to test treatments or medications. Only two had participated in a clinical trial. Motivations to participate primarily focused on helping others and the prospect of direct benefit of participation. Barriers identified were fear of negative side effects and to a lesser degree, mistrust of research. Suggested strategies for engaging racial and ethnic communities emphasized the need for clear and detailed information about the procedures - such as blood draws, potential side effects, trial duration and the intended use of collected data during initial advertising and recruitment efforts. **Discussion:** Updated and more informative education regarding clinical trials should be made available in medical practices and community clinics to encourage more racial and ethnic populations to participate in clinical trials.

Keywords: COVID-19; Clinical trials; Minority; Community; Perceptions; Focus group

Introduction

The development of pharmaceutical treatments and vaccines during the COVID 19- Pandemic brought to the forefront the importance of clinical trial participation. Clinical trials are essential for evaluating the safety, efficacy, and tolerability of medical therapies. Participation by racial and ethnic communities is critical to ensure comprehensive clinical data that supports the assessment of new treatments across diverse populations. Clinical trials are essential for evaluating the safety, efficacy, and tolerability of medical therapies. Participation by racial and ethnic communities is critical to ensure comprehensive clinical data that supports the assessment of new treatments across diverse populations. Often, the participation of racial and ethnic population in clinical trial studies is limited [1-3]. Given the effort to decrease health disparities, the National Institute of Health encourages clinical trials to increase racial and ethnic participation [4]. However, racial and ethnic populations remain underrepresented in clinical trials [5,6]. A study examining the equitable representation also in vaccine clinical trials found that individuals from racial and ethnic minority groups, as well as older adults were underrepresented across all phases of clinical trials [7].

The underrepresentation of racial and ethnic minority populations in clinical trials reduces the applicability of study findings to these groups and limits their access to the benefits of scientific advancements. It is vital that well-designed trials can evaluate racial and ethnic differences in medical interventions to enhance their effectiveness, promote equitable uptake, and address health disparities. Previous studies investigated barriers and facilitators of racial and ethnic populations in clinical trial participation. These barriers include but are not limited to mistrust (due to past history), awareness of clinical trials, language, logistical and financial challenges, fear of negative treatment effects, lack of culturally appropriate information, lack of provider referral, and others [8-10]. The Tuskegee Syphilis study widely recognized known for its unethical treatment of participants, has significantly influenced the ethical oversight of human subject research and remains a key factor contributing to mistrust among Black or African Americans [11-13].

To develop effective strategies and educational materials to utilize in the minority community and provide appropriate information regarding clinical trial research, it is necessary gather input from the community on how to encourage racial and ethnic populations to participate in clinical trials. The purpose of this research was to assess community perceptions of clinical trials and to learn strategies to enhance participation in clinical trials among racial and ethnic communities.

Materials and Methods

Participants

Between November 2022 and March 2023, six focus groups were conducted with 66 lay community members in three Florida cities - Jacksonville, Tallahassee, and Tampa. Human Subject approval was obtained from Florida Agricultural and Mechanical University.

Data Collection

Coding and Analysis: Data from the focus groups were transcribed verbatim. The transcripts were organized, coded, and analyzed utilizing NVivo qualitative software. Two reviewers identified key themes using the *a priori* objectives from the focus group guide. The general code list of themes was further refined after the reviewers' initial coding pass. A general code list was developed based on the review of the transcripts (Table 1). The code list of themes was further refined after the reviewers' initial coding pass.

Code	Description
Clinical Trial Information	Where would you go for information regarding clinical trials?
Community Description	How would you describe your community?
Community Information Needs	What would your community need to know about clinical trials?
Knowledge of Clinical Trials	What do you know about clinical trials?
Most helpful information	What is the most important information you need to know about clinical trials?
Most Trusted Source of Information	Most trusted source to get information regarding clinical trials.
Most unhelpful information	What is the most unhelpful information to receive about clinical trials?
Motivation to Participate	What would make you decide to participate in a clinical trial?
Cons to Participate	Why a person would not participate in clinical trials
Pros of Participation	Why a person would participate in clinical trials
Often Receive Information	How often do you receive or see information about clinical trials?
Participate in clinical trial	Has ever participated in a clinical trial.

Table 1: List of Code Descriptions.

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Results

Study Population

Between November 2022 and March 2023, six focus groups were conducted with 66 lay community members in three Florida Counties - Duval County in Jacksonville, Leon County in Tallahassee, and Hillsboro County in Tampa. Table 2 shows the demographics of the focus group community participants. Most participants were non-Hispanic, Black or African American. There were 39 males and 21 females, most between the ages of 25-34.

Patient Characteristics	Number of Study Participants = 66
Race	
American Indian or Alaska Native	1
Asian	5
Black or African American	41
Native Hawaiian or Other Pacific Islander	2
White	11
Prefer not to answer	2
Unknown	4
Ethnicity	
Hispanic	12 (5 identified their race as Black)
Non-Hispanic	48
Prefer not to say	2
Unknown	4
Gender/Sexual Identity	
Male	39
Female	21
Another identity	1
Prefer not to answer	1
Unknown	4
Gender categories	
Cisgender man	-
Cisgender woman	-
Transgender man	1
Transgender woman	-
Non-binary	-
Another identity	-
Age groups	
18-24 years old	8
25-34 years old	32
35-44 years old	13
45-54 years old	3
55 to 64 years old	1

65 years or older	4
Unknown	5
Geographic locations- Florida County	
Duval	13
Leon	20
Hillsboro	33

Table 2: Community Participant Demographics.

Knowledge about Clinical Trials

Participants were asked to describe their level of knowledge about clinical trials. At least half admitted that they knew very little about clinical trials. One participant stated, "*My knowledge about clinical trials is just simple …the basic knowledge I see online or in books*." Others told what they perceived to be the purpose of clinical trials. Nine participants stated that clinical trials were research studies to test a new medical device, treatment, or drug. As explained by these participants:

> *Clinical trials are research studies performed on people that are aimed at evaluating a medical, surgical, or behavioral intervention.*
>
> *You could say it's like some kind of research study to tell how people respond to treatment, like try new methods of disease prevention.*
>
> *I think clinical trials is subjecting people to test a new drug. I mean to know the responses and the adverse effects of the drug on each person.*

A few of the participants or someone in their family had participated in a clinical trial. The trials mentioned were ADHD and multiple myeloma. As these participants stated:

> *I actually participated in a clinical trial for multiple myeloma. It lasted, I believe, about 18 months.*
>
> *I have been invited to get involved in several others since the completion of the one that I did before. But they were not things that necessarily interested me, so I passed on those.*

Information regarding Clinical Trials

When participants were asked how often they receive information about clinical trials, five spoke up to say, "rarely" or "not often." One stated, "I have never received clinical trial invitations for accessible studies." Two had received information 1-2 times per year. If participants wanted information regarding clinical trials, they looked in numerous places. Health care providers, social media, and the internet were the most mentioned (Table 3).

Place	Number
Clinic	1
Internet	6
Health Care Providers, Doctors	11
Social Media	9
Hospitals	1
Government Agency	1
Church	1
Department of Health	1
Television	1

Table 3: Places Where Participants Sought Information Regarding Clinical Trials.

Trusted Sources of Information for Clinical Trials

Participants were asked "Who would you most trust as a source of information about clinical trials?" Twenty-five concurred that they trusted information from their health care providers. At least 13 trusted social media or the internet for clinical trial information. As one stated, "I would actually go to the website, use keywords and be specific if I wanted to find something out…clinical trials on African Americans with high blood pressure, heart disease, or obesity." Other trusted sources included:

- Webinars
- Clinical trial website
- Friends, family members
- Community members
- Community schools
- Informed colleagues or doctoral researchers
- Government agencies
- Relatives in the medical field
- Mail correspondence
- Celebrities

My personal feeling is, if you utilize a celebrity, who, in fact, is either familiar with or has whatever the issue, I think that would carry a lot of credibility.

- Pastors
- Community leaders

It boils down to the infrastructure more than anything. Having the infrastructure in our communities and the leaders who look like use in those positions and carrying out these trials.”

- HBCUs
- Health Department
- Health journal
- Insurance website

Helpful Information regarding Clinical Trials

Seven of the participants preferred receiving clear “facts and figures” over information they felt was unrelated to the benefits of participating. Remarks included:

It’s helpful if I’m being educated on the outcome…People need to know what they are about to participate in and it’s not going to harm them. I don’t want to hear about having side effects.

It should also be encouraging that people know by participating in a clinical trial they are going to be indirectly solving problems of others.

I would want full disclosure of everything if I’m going to be involved in the good, bad, and the dirty as well. We need proper education on the risks and benefits of the clinical trial.

I am skeptical about some stuff, you know, these different medicines. I think the doctors are really just making us guinea pigs. But when it came down to COVID, I was like I got to get this shot.

Motivation to Participate in Clinical Trials

The participants revealed many pros and cons of participation in clinical trials. The top pro of participating was to impact the community’s health or to help their personal health. Many mentioned the fear of side effects and time needed to participate as a con of participating in clinical trials. More pros and cons are listed in Table 4.

Pros of Participation	**No.**
To Impact the Community’s Health	15
To Improve Personal Health	13
Having more information [about treatments]	11
Compensation for Participating	8
Help People/Benefit Humanity	8
Proper treatments for Health Issues	7
Cons of Participation	**No.**
Side Effects	12
Time for Participation	12
Discrimination against Race or Age	9
Stress/Anxiety/State of Mind	5
Cost	4
Mistrust of Medicine/Research	3
Unfamiliar Treatments	3
Location	3
Injections/Drawing Blood	3
Insurance	2
Transportation	2
Getting a Placebo	2
Safety	1

Table 4: Motivation to Participate in Clinical Trials.

Description of their Community

The focus group participants were asked to describe their community. Most said their community was predominately Black or African American residents. There were three that said their community consisted of Black Muslims. Others were mixed or diverse communities. As stated by these participants:

We have a mixture, but mostly we have white people in my community.

I would say that my community is both urban and suburban as well as city. I think there’s a pretty good blend…depending on what area you live in.

It’s mainly pretty diverse. There’s a combination of Whites and Blacks and Hispanics, and they’re not all in the same exact section. But at the same time, if I look at my block, I could say that I’m the only person of color that lives on my block.

Information and Messaging Needs of the Community about Clinical Trials

Questions were asked about possible information needed by the community about clinical trials and what type of messaging would be best to communicate this information. Knowing about the health benefit, possible risks and side effects was top of their list. Knowing all the facts and what types of clinical trials are available was also valuable information for the community and what compensation will be provided. Other suggestions include:

> *My community needs to understand that it is important for our population to participate in clinical trials. Most of us take high blood pressure pills. Well, the study that was done at the Framingham study, was just done on people that don't look like us. If we are not part of these studies, they will never know how we be affected.*
>
> *I think it should focus more about the type of clinical trial it is, maybe for what type of disease. Also, the information should assure them of safe health.*
>
> *We should prepare the community for understanding what clinical research is and why we do it. You want to dispel of the myths and urban messages about research and replace that with more positive messages.*
>
> *I think an explanation of how the information in the clinical trial is going to be used and how your information is going to be secured and kept confidential would probably be something to include in a message about trials.*

The participants felt the best messaging was through social media, flyers, newsletters, and radio stations. "The radio is key. Everyone listens to some African American dominated radio station, whether it's gospel or hip hop." Another recommended that the flyers should be a true representation of people of color. Other suggestions for messaging include:

> *When it comes to trying to reach other people, you know most times you tend to find yourself in a rural community and not everyone has access to the Internet. So, reaching out to businesses like the barber shop, house salon, the movie theatres, restaurants, you know. I think it helps, spread the information faster than social media.*
>
> *The communities that I am involved with are predominantly African American communities and mostly impoverished. Information that's needed sometimes come to them in more scientific terms that many of the community don't understand. Word of mouth may be the best ways, because our communities tend to rely a great deal on social media that [don't] touch the lives of many people outside of the black churches.*
>
> *The content of the message has to be such that I can explain it to you once I hear it, and then it can be disseminated very easily. If it's too technical it's not going to go very far.*

Discussion

Our lay community focus group study provides insight into racial and ethnic community participation in clinical trial studies. Our study identified that lack of knowledge and access to information, and trust are some of the barriers to clinical trial study participation. Most focus group participants viewed clinical trials as research designed to test treatments or medications, with only a few reporting prior participation in such studies. Most focus group participants viewed clinical trials as research designed to test treatments or medications, with only a few reporting prior participation in such studies. While mistrust of research was noted, the primary concern preventing most participants from joining a clinical trial was the fear of potential side effects. Participants emphasized the importance of providing accurate and realistic information about clinical trials to their community, including details on procedures like blood draws, potential side effects, trial duration, and the use of collected data. The most trusted resource for information about clinical trials was physicians or their health care providers. However, most participants had never received information from their health care providers about clinical trials.

In summary, our study highlights barriers to clinical trial participation within racial and ethnic communities, including fear of side effects, mistrust, and limited access to information. Addressing these challenges requires culturally tailored outreach, transparent communication about trial processes, and leveraging trusted sources like healthcare providers. These efforts are crucial for fostering trust, enhancing participation, and ensuring equitable representation in clinical research.

Ethical Considerations

The study is approved by Florida A&M University Institutional Review Board.

Conflict of Interest: The authors disclose no conflict of interest.

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