

Addressing the Lack of Diversity in Clinical Trials: Overcoming Barriers and the Role of Social Media

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Abstract

The underrepresentation of African Americans and other minority groups in United States clinical trials is a critical issue that limits the development of equitable, patient-centered interventions and sustains existing healthcare disparities. This article examines the persistent lack of diversity in clinical research, highlighting how low participation rates, particularly in diseases with high prevalence among minority populations (e.g., sickle cell and metabolic disorders), create significant information gaps. Key barriers discussed include the lingering impact of historical injustices, such as the Tuskegee experiment, which generated deep community distrust; stringent structural issues like eligibility criteria; and socio-economic challenges, including poverty and geographical inaccessibility. We propose actionable strategies to overcome these barriers, focusing on building community engagement, establishing trust through partnerships with local faith-based institutions, and leveraging the reach of social media platforms (e.g., Facebook and YouTube). Utilizing social media can facilitate targeted health awareness, advocacy, and convenient participant recruitment, thereby improving access for underserved populations and promoting the fairness and justice required to resolve healthcare disparities.

Keywords: historical injustices, community engagement, health equity, health justice, social media, underrepresented.

Introduction

Clinical studies are scientific processes that entail investigations on the effectiveness of different clinical processes directed toward patients to improve approaches to human health. The United States (US) records the highest number of clinical trials on different chronic and genetic conditions each year with a total of 186,000 clinical trials conducted between 2000 and 2024. 15% of the clinical trials are directed towards cancers, 6.3% on mental health, 1.7% on blood disorders, and 5.7% on metabolic conditions (Unger et al., 2024). 90% of patients with sickle cell disease are from the African American race indicating the highest prevalence of the condition. Despite the high rate of sickle cell among African Americans, only 8% of participants in sickle cell studies are recruited from the African American population [1].

Studies on metabolic disorders such as hypercholesterolemia, diabetes, and hypertension have the highest prevalence among African Americans, clinical studies on average recruit 6-10% of participants and a minimum of 75% for the White majority race indicating a low rate of recruitment [2]. There is an underrepresentation of African Americans and other underrepresented communities in clinical trials indicating the lack of diversity and this is a factor that limits the resolution of the disparities experienced in the healthcare sector.

A study conducted in 2020 in the USA revealed that the clinical trials of that year included 8% of participants as African Americans, 11% as Hispanic 6% as Asian, and more than 75% from the white majority group [2]. This illustrates that there is an insufficient application of clinical studies in underrepresented populations and this contributes to the sustenance of the status quo in regards to healthcare disparities.

Some barriers prevent conducting clinical studies in underrepresented populations and overcoming these barriers will be critical in improving clinical studies and access to care [3]. Social media also presents an opportunity to improve access to clinical studies and the participation of underrepresented populations [4]. The purpose of this article is to address the lack of diversity in clinical trials and to examine how to overcome the barriers to clinical trial diversity and the role of social media in improving access to clinical trials for underrepresented populations.

Benefits of Clinical Studies in Underrepresented Populations

Clinical studies are also crucial in understanding the uniqueness of different groups about clinical processes and can provide a platform for providing targeted interventions for some communities [5]. It is important to include underrepresented communities in clinical trials as clinical trials provide opportunities to understand the communities and the uniqueness of community-centered and patient-centered treatments and interventions. The limited application of clinical studies in underrepresented populations creates challenges in gaps of information and healthcare misconceptions that can misdirect the interventions, treatment, and policies that would be otherwise implemented in these communities [6]. A study conducted in 2020 in the USA revealed that the clinical trials of that year included 8% of participants as African Americans, 11% as Hispanic, 6% as Asian, and more than 75% from the white majority group [2]. This illustrates that there is an insufficient application of clinical studies in underrepresented populations and this contributes to the sustenance of the status quo in regards to healthcare disparities.

The benefit of including underrepresented populations in clinical trials is avoiding the generalization of treatments and healthcare interventions and a focus on a patient-centered or community-focused approach [6]. This means that clinical trials would provide a diversity of treatment approaches and interventions that can be used on different populations to improve healthcare access and healthcare quality. Different social groups and populations can have different responses to a treatment module and conducting human trials will help understand these differences before the treatment or intervention is approved as standard protocol. Clinical trials can provide perspectives and ideas for innovation in healthcare to address population-specific healthcare problems [7].

Through understanding the needs and healthcare dynamics of underrepresented populations, it is possible to invent technology, medication, and even policies that will directly address the needs of the underrepresented population and improve access to services and information. There is also an aspect of ethical responsibility in ensuring clinical studies are conducted in underrepresented populations [8]. The concept of fairness and equal responsibility to different social groups can be influential in rebuilding the trust between underrepresented communities and the healthcare system. Improving trust through engaging in clinical trials with properly informed consent and transparency can help to encourage healthcare-seeking behavior from underrepresented communities hence improving access to care.

Barriers to achieving clinical trial diversity

Some barriers impact the efforts to clinical trial diversity, especially in the inclusion of underrepresented groups in the trials. One of the barriers to achieving clinical trial diversity is historical injustices towards underrepresented groups that have resulted in lack of trust, suspicion, and paranoia among the communities. The Tuskegee experiment is one event in history whose revelations led to a breakdown of trust between the African American community, the healthcare system, and clinical trials in general (Ford et al., 2024). Between 1932 and 1970, a clinical study on syphilis was conducted on the African American population (Ford et al., 2024). A total of 600 participants were recruited and 399 went without treatment as the study sought to examine the complications of syphilis on human beings (Ford et al., 2024).

The participants were generally selected from impoverished and poorly educated or uneducated African American communities. More than 130 participants died from devastating effects and complications of syphilis without treatment even though health professionals in the trial were aware of their illness and taking advantage of their socio-economic disadvantage. The details of this experiment resulted in many African Americans and individuals from other underrepresented populations avoiding interactions with healthcare workers and the healthcare system (Barrett et al., 2019). This historical injustice is a primary barrier to the inclusion of underrepresented communities in clinical trials due to their unwillingness to participate due to suspicion of Government manipulation and discrimination.

Cross-sectional studies conducted among the African American population revealed that the Tuskegee experiment had significant social consequences in the erosion of trust between African Americans and the healthcare system and government programs in general (Barrett et al., 2019). The fear of

victimization due to the revelations of the Tuskegee experiment increased suspicion among African Americans (Ford et al., 2024). The suspicion and fear due to the revelations of the Tuskegee experiment have contributed to the increasing rate of disparities experienced in the healthcare sector as African Americans avoid situations that expose them to similar manipulation. Studies conducted in the US reveal that the African American population has the lowest rate of healthcare-seeking behavior due to socioeconomic factors and distrust of the healthcare system taking a central role in their healthcare avoidance behavior (Ford et al., 2024).

Structural issues are another barrier that limits the ability to achieve clinical trial diversity. One structural issue is the application of stringent eligibility criteria for clinical trials which tend to lock out individuals from underrepresented populations. Studies indicate that clinical trials targeting minorities and underrepresented populations have the highest rates of rejection and exclusion when compared to trials targeting the White majority population (Ford et al., 2024). The clinical trials are based on inclusion and exclusion criteria that determine the participation of individuals. The purpose of the eligibility criteria in clinical trials is to enhance the safety of the patient and to promote the reliability and validity of the study results. The effect on limitation of diverse groups is an unfortunate side effect of the stringent measures in the clinical trial selection and exclusion. The criteria for clinical trial participation have been affected by issues of systematic discrimination and assumptions about minority groups that lead to the exclusion of minority participants (Ford et al., 2024). A good example of a situation that can lead to the exclusion of underrepresented minorities is in clinical trials targeting specific genetic markers that may not be inclusive of diverse genetic backgrounds.

Socio-economic factors affecting underrepresented populations are part of the barriers that contribute to the lack of diversity in clinical trials [9]. The common socio-economic factors affecting the minority groups in healthcare in the US are poverty, lack of healthcare information, the lack of healthcare insurance and this contributes to a lack of access to healthcare services and opportunities. High rates of poverty can limit the ability of individuals to access information about clinical trials as they lack healthcare-seeking behavior. African Americans suffer the highest rates of poverty and lack of health insurance and this means they have the highest potential of missing out on information about clinical trials. The lack of incentives for participation is also a limiting factor for underrepresented populations facing different socio-economic challenges.

Clinical trials are usually time-consuming and sometimes have financial and time limitations in aspects such as movement. The lack of incentives or payment to compensate the participants has played a role in turning away underrepresented populations who might not see the benefit of participation without an incentive. Socio-economic issues can also bring about the issue of access to the underrepresented populations especially for those in rural areas (Vuong et al., 2020). Clinical studies are conducted in urban areas where there are major facilities with resources and opportunities to actualize the clinical trials. This means the underrepresented communities who majorly live in rural areas will miss out on the clinical trials due to their remote location. Rural areas lack the infrastructure required to be able to host

clinical trials and this have limited the number of clinical trials in geographically remote areas.

The underrepresentation of professionals from minority populations and cultural distrust is another barrier to limiting diversity in clinical trials. There is a small percentage of people from underrepresented populations working in the healthcare sector and clinical trials. Having clinical trials conducted by people of similar ethnic identity with the participants tends to raise the trust levels of the participants. There is also an aspect of cultural sensitivity and cultural safety in conducting clinical trials using professionals with a proper understanding of the culture of the underrepresented population can be useful in bridging the gap that exists.

Strategies to promote diversity in clinical trials and overcome barriers

The engagement of the community is a strategy that can be applied to promote diversity in clinical trials [10]. Engagement of the community in this case means targeting specific populations with information and awareness programs about clinical trials or specific diseases. The underrepresented populations have limited access to healthcare information and services and targeted engagements can help to bring information to the communities. The engagement of the community while providing proper health education to support clinical studies can improve the trust and participation of underrepresented communities in clinical studies (Bibbins-Domingo et al., 2022).

The African American community suffers high rates of diseases such as cancer while they remain underrepresented during clinical trials. Engaging the community to create awareness of cancer, its etiology, and the purpose of the clinical trials can be useful in improving rates of participation within the community. The aspect of informed consent which is a legal and ethical standard in clinical trials is easy to achieve with the process of community engagement. Informed consent means that the participants in the clinical trials are well versed in their condition and are aware of the details of the clinical trials including the side effects of the trial.

Partnering with local faith-based institutions can be useful in building trust and improving local participation in clinical trials. Applying strategies that are considerate of culture will promote cultural sensitivity and cultural safety and this will encourage the individuals from the underrepresented communities to participate in clinical studies. Partnering with local faith-based institutions can help build trust and improve local participation in clinical trials. Americans from minority groups such as African Americans, Hispanics, and Pacific Islanders have a strong sense of religion and faith (Public Religion Research Institute, 2021). This means that within the underrepresented community, religion is a unifying communal factor.

Studies conducted among the African American population reveal that more than 1/3 attend religious activities regularly while 2/3 are in contact with their spirituality through the practice of values and beliefs of their respective religion (Public Religion Research Institute, 2021). Including faith-based institutions in the solutions to improve clinical trial diversity can help to build trust due to the close relationship between underrepresented communities. The inclusion of a person of faith in the process of clinical studies is useful in encouraging those who believe in the faith to be part of the clinical trials.

Faith-based institutions can also serve as a platform for information dissemination and creating health awareness and awareness about clinical trials. 1/3 of the African American population attend to their religious beliefs and practices and more than 40% of the Hispanic population attend church regularly (Public Religion Research Institute, 2021). The large population of religious and church-attending individuals in underrepresented communities provides a platform to engage the community while providing awareness of the importance of clinical studies (Crocker et al., 2018). Partnerships with the local community and religious leaders can help to engage the conversation on clinical trials. The outlook of leadership from religious leaders will reduce the fear and negative attitude toward clinical studies as a result of the Tuskegee experiment. The presence of religious leaders helps to improve the moral standpoint of the clinical studies lowering the perceived risk of manipulation by the underrepresented communities.

Partnerships with religious institutions in underrepresented communities can help improve clinical trial diversity by promoting cultural safety and sensitivity [5]. Religious leaders and religious centers have a bearing on cultural standards which is a major barrier to the implementation of clinical trials. The lack of cultural diversity can lead to the violation of the culture and beliefs of the participants and this can discourage individuals from underrepresented communities from participating in the clinical trials (Tan et al., 2025). Faith-based institutions can help provide a bearing on the cultural requirements of every community to ensure the clinical trial respects culture and does not discourage participation due to a lack of cultural sensitivity. Applying strategies that are considerate of culture will promote cultural sensitivity and cultural safety and this will encourage the individuals from the underrepresented communities to participate in the clinical studies.

Social media can be applied as a tool to support clinical studies in underrepresented communities and also improve their healthcare awareness [11]. This means that social media can be used as a tool to overcome the barriers that cause the lack of diversity in clinical trials. Social media is a tool that provides a platform for general and targeted health campaigns. In the US, 75% of the population has access to at least one social media platform such as Facebook or Instagram (Pew Research Centre, 2024). Studies conducted among African American populations reveal that 7 in 10 African Americans are engaging the internet using at least one social media platform (Pew Research Centre, 2024). YouTube and Facebook are the most used social media applications in the US by African American individuals.

Social media can be used to target specific populations with different healthcare needs and can be used to create awareness or play an advocacy role on diseases, clinical trials, and other healthcare issues [12]. The role of social media as a tool for mobilization and raising awareness became evident during the COVID-19 pandemic. Government and different organizations use social media to raise awareness about the COVID-19 virus, how it spreads, and its prevention and treatment [13]. Furthermore, the need for social isolation also improved the value of social media as a tool for the dissemination of information while avoiding physical meet-ups that would worsen the spread of disease.

The underrepresented communities can have the experience of packaged information on the diseases that mostly affect their population the different clinical trials available and the importance of these trials. The impact of social media as a tool for information, creating awareness, and mobilization in healthcare is demonstrated by a study conducted by Bui et al., (2023) [14]. Bui et al., (2023) [14], used social media as a data extraction site when comparing emotional health and climate-change-related stressors. The application of social media by Bui et al., (2023) [14], indicates the critical role social media can play as a source of information and data. In clinical trials, social media can be used as a source of information and recruitment for potential participants. Social media provides a wide base of study participants that can provide cultural diversity and can provide access to underrepresented populations. Clinical studies can employ social media to plan and implement processes while reaching information and populations that would be traditionally out of reach.

Social media also provides the convenience of simplicity of the recruitment process and this is a factor that promotes diversity in clinical trials. One barrier that has contributed to the lack of diversity in clinical trials is the inaccessibility of the underrepresented population [15]. The underrepresented population is inaccessible due to their geographical location and other socio-economic factors and social media presents a solution to improving access. While using social media as a recruitment platform, it would be easy to reach out to the underrepresented communities and this can improve the average number of underrepresented communities in this trial [16]. While cancer has the highest rates of occurrence among African Americans, less than 8% of African Americans are represented in clinical trials and the use of social media can help to improve the recruitment drive [1]. It is also important to note that clinical trials are more commonly conducted in urban centers than in rural areas. The use of social media can make it possible to recruit willing participants from underrepresented populations in rural and marginalized areas hence improving clinical trial diversity.

Conclusion

Clinical trial diversity is an important issue as it has the potential to impact the quality of healthcare services and the level of healthcare disparities experienced by the population. Clinical trials are needed to be able to provide treatments that are disease-specific and address the specific qualities and characteristics. The lack of diversity in clinical trials while locking out underrepresented populations has a negative influence on the care of these populations and the risk of sustained healthcare disparities. Barriers such as loss of trust due to the Tuskegee experiment, and socio-economic and cultural barriers have prevented the potential to achieve diversity in clinical trials. The respective solutions are the use of faith-based organizations to restore trust and provide platforms for the engagement of underrepresented communities. Engagement of the community and using social media as a tool for creating awareness, advocacy, and recruitment for clinical trials. The advantage of social media is its ability to reach large populations of people conveniently and can apply a targeted or general approach to educate the public. The use of YouTube, Facebook, and other social media platforms can positively influence awareness and recruitment strategies for participants in clinical trials. Promoting diversity in clinical trials is important as it is a tool that can be used to not only improve the quality of care of

patients and underrepresented communities but also to promote fairness and justice in the healthcare system. The issue of healthcare disparities can also be resolved through the use of clinical trials to address population-specific needs which is a communal aspect of the patient-centered approach to care.

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