

Strategies to Combat Structural Racism: Improving Diversity in Pediatric Clinical Trials

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Objectives

1. Understand how structural racism can impede families' ability to enroll and stay in clinical trials
2. Potential solutions to combat structural racism as a barrier for optimized clinical trials



Why is Racial and Ethnic Diversity Important in Clinical Research?



Health Equity: Different demographic groups can have variations in health outcomes, disease prevalence, and response to treatments. By increasing diversity, scientists can better understand these variations and develop healthcare interventions that are more effective and equitable for patient groups.



Generalizability: Clinical research aims to generate findings that can be applied to the broader population. If research participants are predominantly from one racial or ethnic group, the results may not be applicable or safe for other groups. A lack of diversity can lead to limited generalizability of study findings.



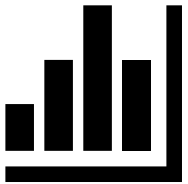
Identification of Disparities: Clinical research that includes diverse populations can help identify and address health disparities that disproportionately affect certain racial or ethnic groups. Understanding the root causes of these disparities is crucial for developing targeted interventions to reduce them.



Why is Racial and Ethnic Diversity Important in Clinical Research?



Safety and Efficacy: Drug metabolism, side effects, and treatment responses can vary among different racial and ethnic groups. Without diverse representation in clinical trials, potential safety issues or less effective treatments for specific populations may go unnoticed.



Scientific Rigor: A diverse study population can enhance the robustness and reliability of research findings by accounting for potential confounding factors related to race and ethnicity.



Public Trust: Ensuring diversity in clinical research can foster greater trust and engagement among communities that have historically been marginalized or mistreated in medical research. Building trust is crucial for recruiting participants and conducting ethical research.



Structural Racism: Implications for Research



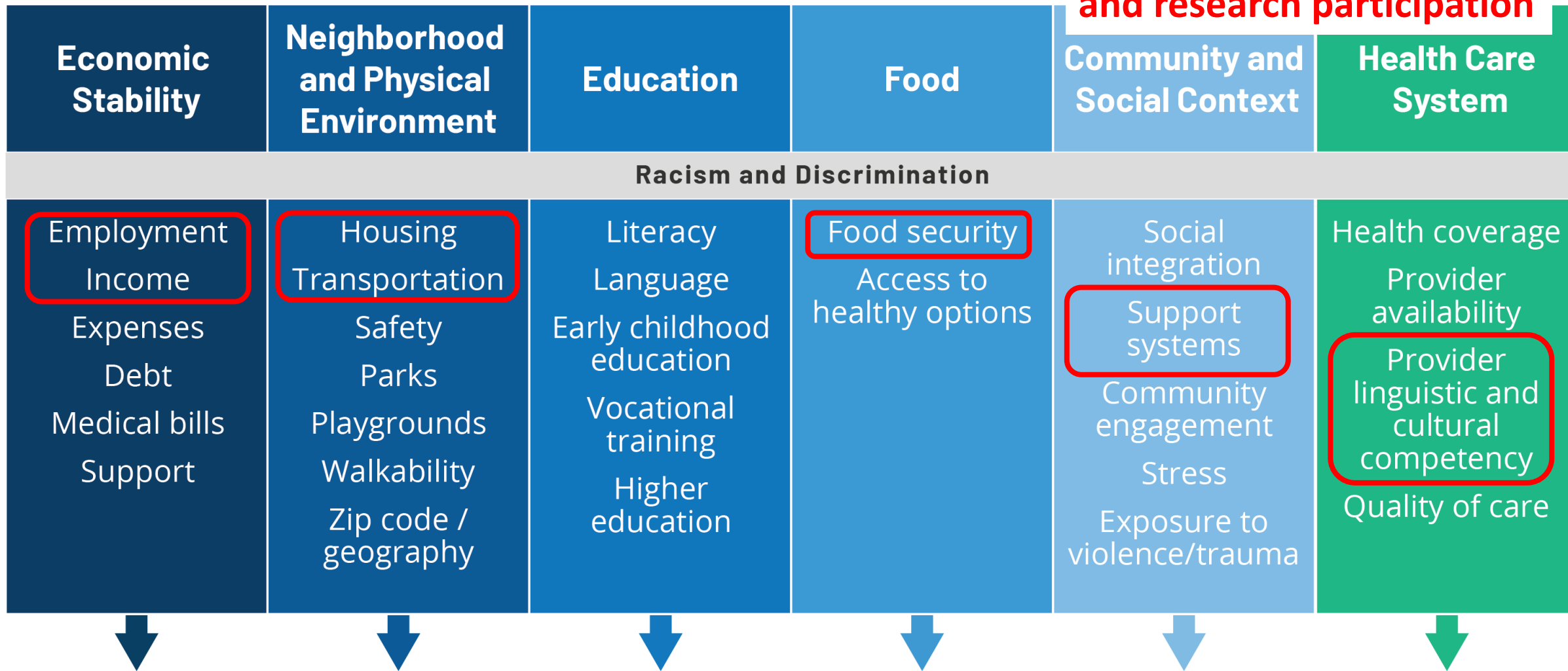
Structural Racism = Structural Disadvantage

- Structural disadvantage is **the disadvantage experienced by some individuals or families or groups or communities as a result of the way society functions.**
 - how resources are distributed
 - how people relate to each other
 - who has power
 - how institutions are organized



Social and Economic Factors Drive Health Outcomes

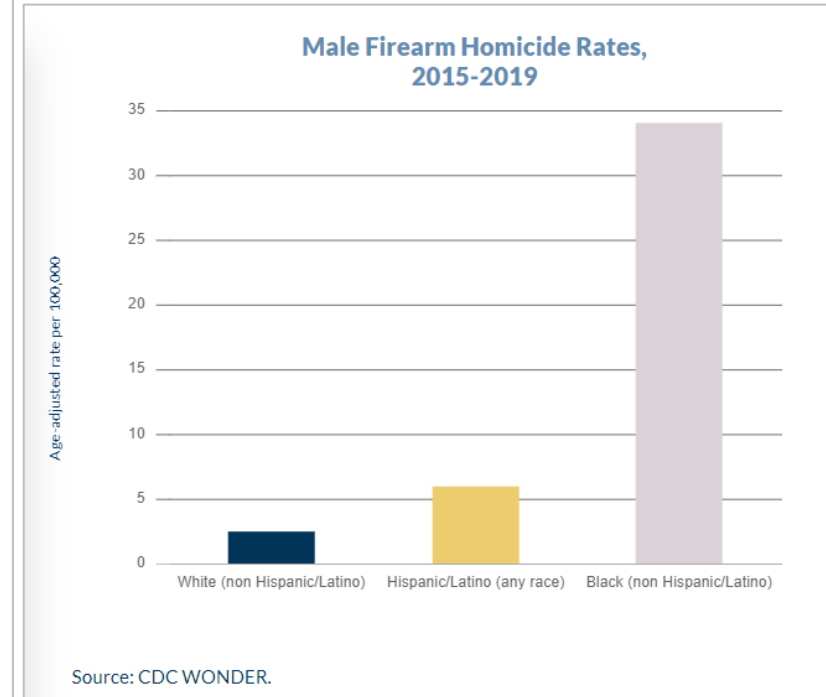
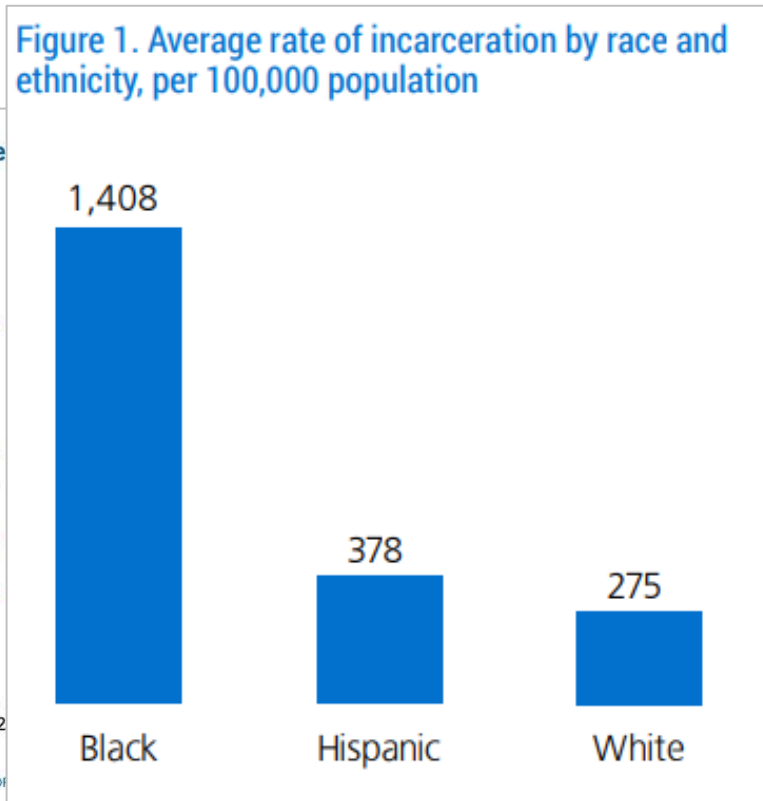
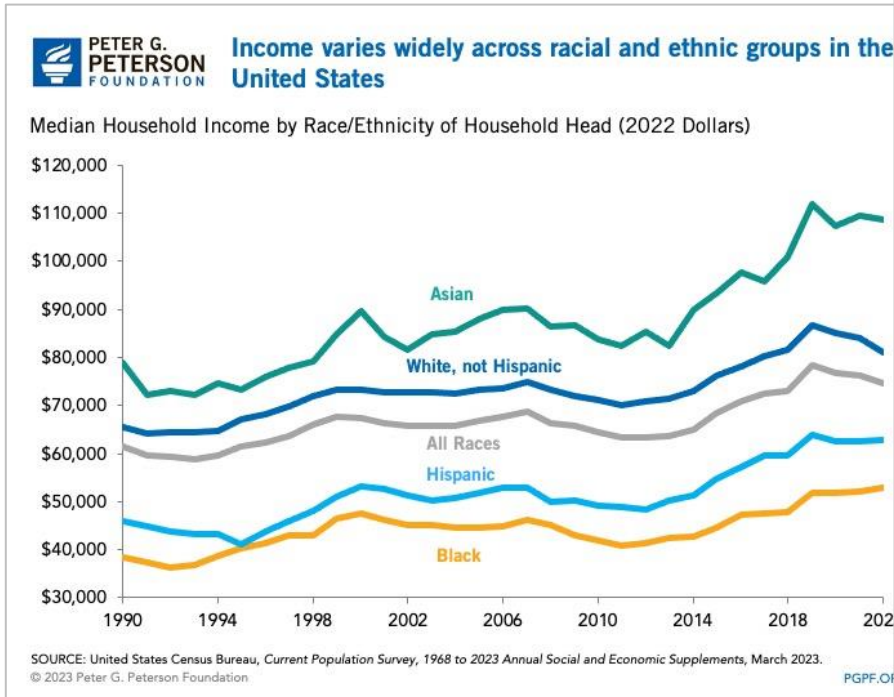
and research participation



Health Outcomes: Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

Societal disadvantages affects families in many ways

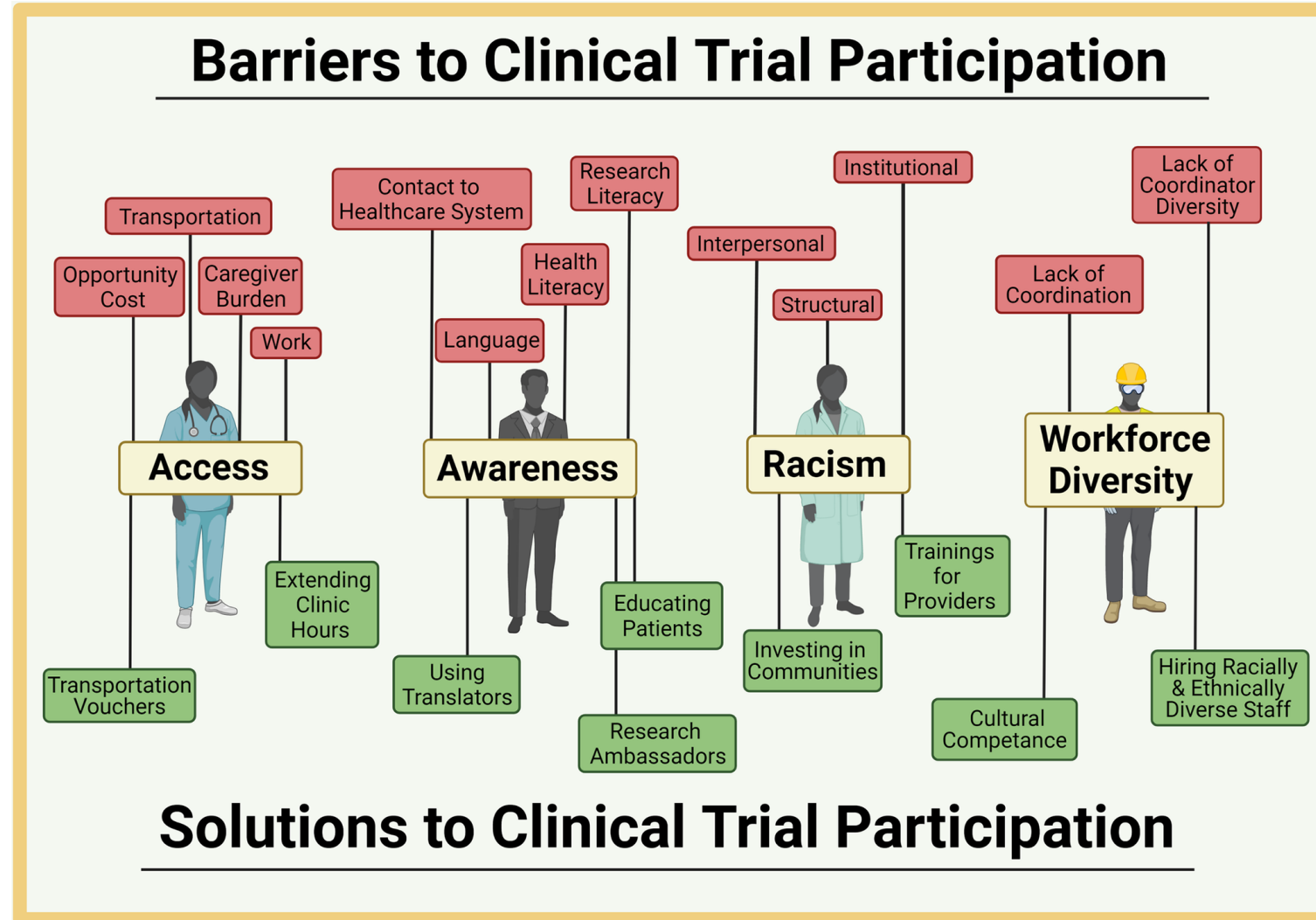
Do all families have equal opportunity to show up with emotional and cognitive bandwidth, ready to engage in research-related discussions?



Barriers and Solution for Clinical Research Diversity and Equity



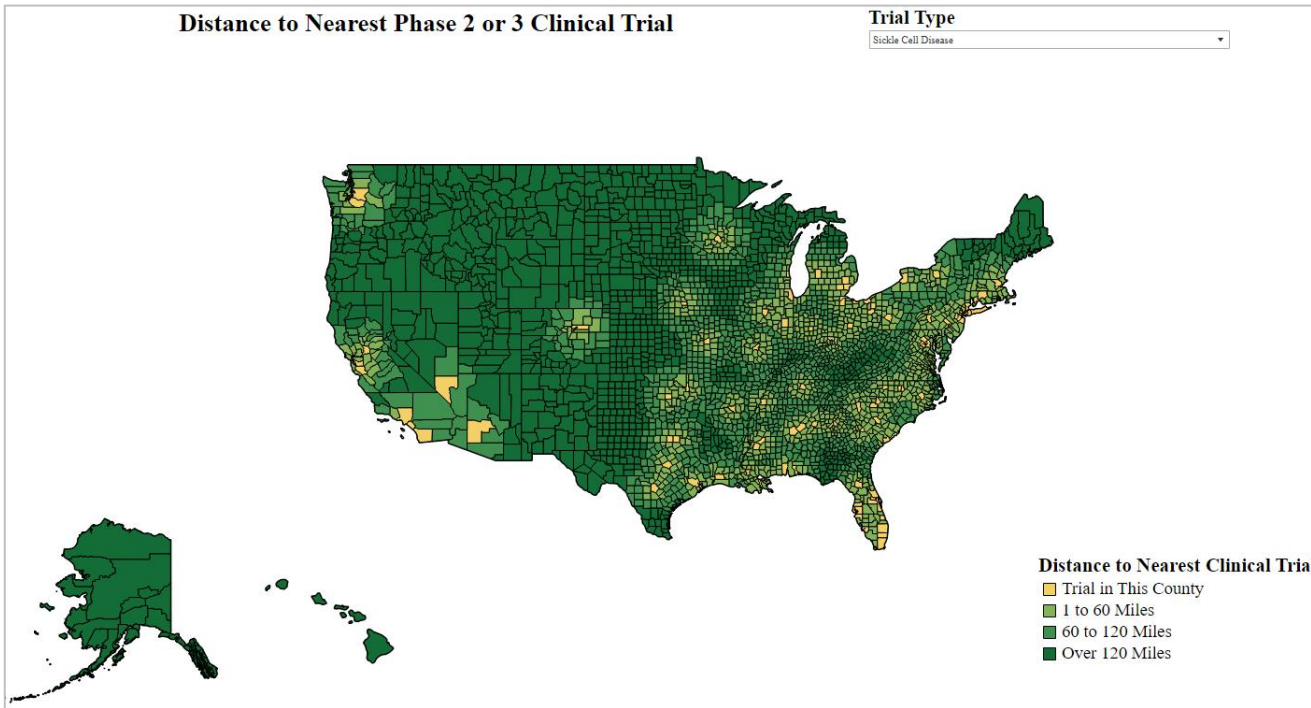
Community engagement and clinical trial diversity: Navigating barriers and co-designing solutions— A report from the “Health Equity through Diversity” seminar series



Barrier #1:

Limited access to healthcare is a major barrier to clinical trial recruitment that disproportionately impacts racial/ethnic minorities.

Access as a Barrier to Diversity in Clinical Trials



- **Limited Healthcare Access:** Limited access to healthcare disproportionately affects racial/ethnic minorities, hindering their participation in clinical trials.
- **Geographic Barriers:** Research sites are often distant from minority communities, making participation difficult due to transportation challenges and unfamiliar locations.
- **Caregiver Burden:** Caregivers from racial/ethnic minority groups face additional challenges in participating, as they may have less time to spare due to caregiving responsibilities.
- **Occupational Constraints:** Racialized / rural individuals may be in service or labor-intensive occupations with limited paid time off, making it hard to attend research visits during traditional working hours.

Solutions to Access Barriers

Incentives and Compensation

Including incentives and compensation in research budgets at the institutional level. Financial remuneration & reimbursement for study-related costs can increase diversity

Transportation Support

Providing transportation vouchers helps address transportation-related barriers

Childcare and Eldercare Support

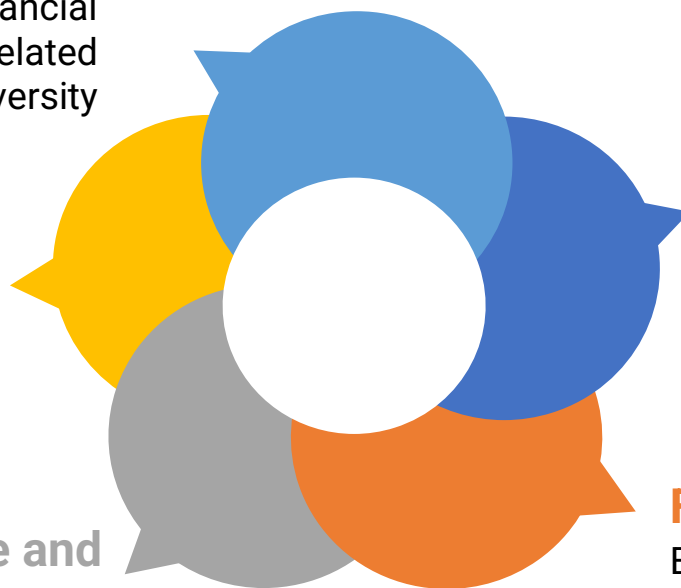
Providing financial support for childcare and eldercare and compensating for missed work time can incentivize participation

Community-Based Clinics

Placing research clinics in community-based ambulatory primary care offices can enhance accessibility

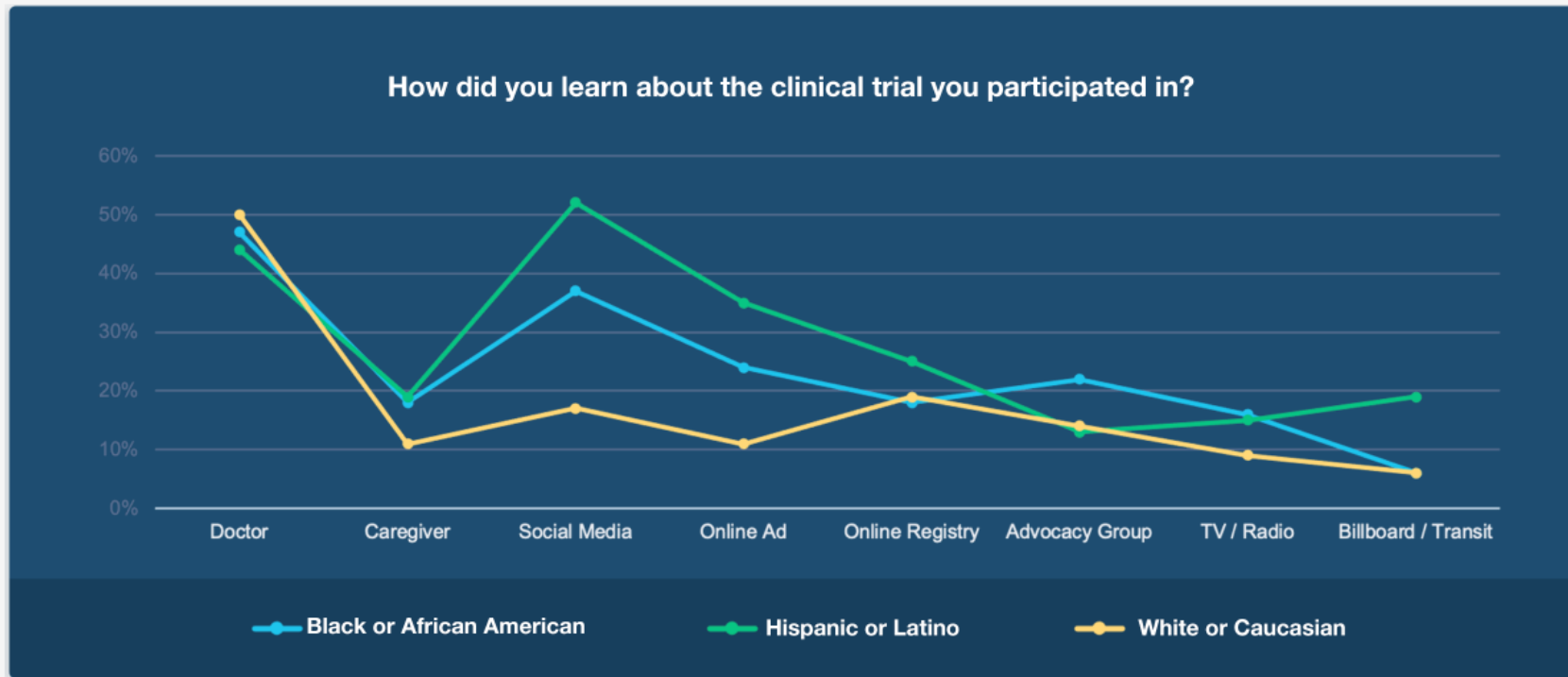
Flexible Timing

Early morning, evening, and weekend research-related activities can improve accessibility and retention in clinical trials, especially for those with daytime work commitments



Advertisement outside of traditional routes

A Diversified Outreach Strategy Is Key to Improving Diversity, Equity and Inclusivity (DEI)



<https://www.bbkworldwide.com/>

Inclusivity - Best Practices

- **Take extra caution when developing the eligibility criteria for a study or trial**
 - Are certain groups inadvertently excluded?
 - Must attend multiple follow-up visits (excludes most financially disadvantaged)
 - Expected to independently complete complex questionnaires (excludes families with limited medical literacy)
 - Study teams must discuss bias in recruitment before enrollment begins
- **Decentralized trials – away from the “Ivory Tower”**
 - What study procedures can be performed remotely?
 - Are there easy-to-reach community sites where study procedures can take place?



Barrier #2:

Racism in its many forms is a critical factor inhibiting clinical trial diversity.

Complex issues surrounding perceived, interpersonal, institutional, and structural racism serve as major obstacles to recruitment of racialized groups in research.



Racism as a Barrier to Diversity in Clinical Trials

- **Lack of Trust:** Lack of trust in the medical and scientific communities affect racialized patients. Mistrust is directly linked to racism, including structural racism, which has contributed to health disparities and created medical mistrust
- **Historical Abuses:** Historical abuses and unethical practices in medical research, such as the nutritional research in residential schools, leads to deep-seated mistrust among minority populations
- **Fear of Experimentation:** Minority groups may fear that participating in clinical trials will involve unethical experimentation or exploitation
- **Present-Day Discrimination:** Overt racism in healthcare interactions and racial disparities in healthcare quality contribute to mistrust
- **Worse Health Outcomes:** Racial and ethnic minority populations, especially Black and Indigenous populations, experience worse health outcomes due in part to receiving lower quality of care



Well-earned medical mistrust from racialized communities

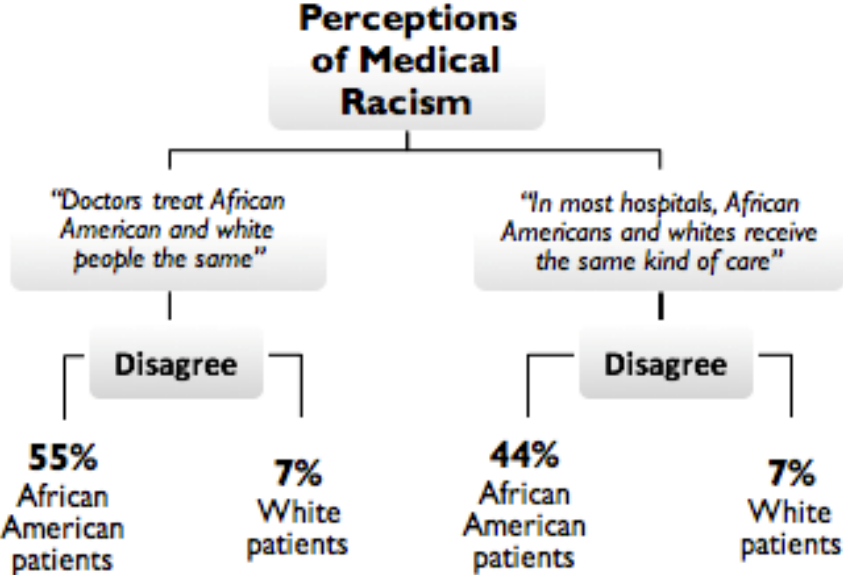


Figure 1: Select statements in the Medical Mistrust Index and Perceptions of Racism in the Healthcare System validated scales. African American transplant patients reported higher levels of perceived medical racism and medical mistrust as compared to white patients.

Solutions to Racism Barriers

Addressing Racism

It is OK to mention potential community mistrust due to past research misdeeds. Create a safe space for families to mention experiences of racism

Intentional Use of Race

When designing research, the inclusion of race should be intentional, clearly defined, and accompanied by discussions on how racism affects health outcomes

Dissemination of Results

Sharing study results directly with participating communities and those impacted by the conditions being studied fosters engagement & trust

Discussions about increasing trust should focus on eliminating the causes of mistrust, rather than blaming minority populations

Framing the Discussion

Educating the research team about trauma faced by minority populations can promote engagement from a place of understanding and humility

Historical Trauma Education



Conclusions

- Structural racism and structural disadvantage can impede research entry and participation for the many racialized families
- Study team intentional focus on addressing barriers can improve trial diversity
- Subsequent two talks in this session:
 - Inclusivity best practices from the non-profit research lens
 - Improving diversity in oncology clinical trials

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