

Do Not Disseminate: Request Permission

Just Ask!

Increasing Diverse Participation in Clinical Trials

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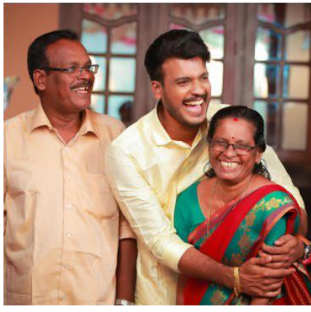
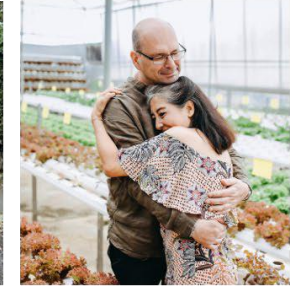
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Just Ask!

What does diversity look like?



Addressing Health Disparities

- National Geographic
- Diversity in the US 2050
- How are we going to address and talk about disparities and diversity in the future?



Implicit/Explicit Bias and Health Disparities

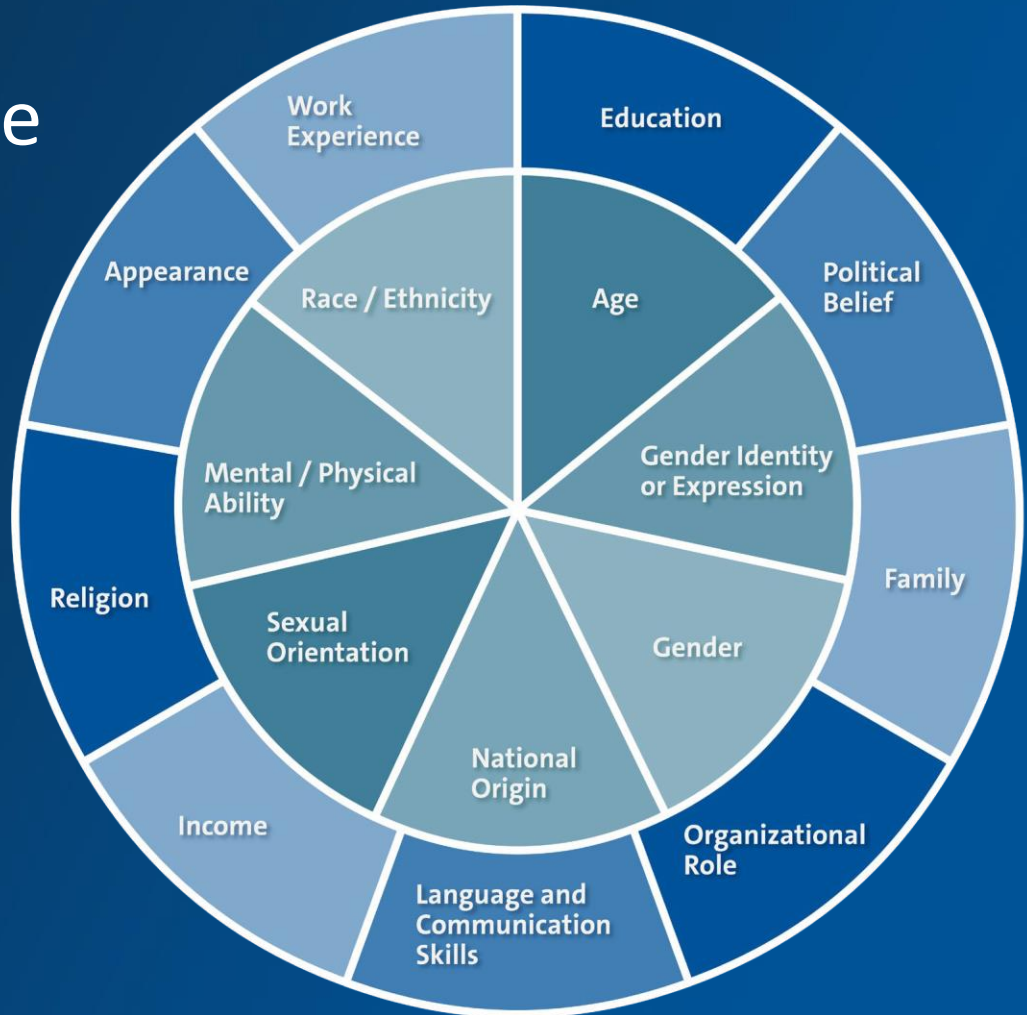
- Doctors assume their black or low-income patients are less intelligent, more likely to engage in risky behaviors, and less likely to adhere to medical advice.
- Physicians are less likely to prescribe pain medication to black patients compared to white patients.
- Pregnant women face discrimination from healthcare providers on the basis of their ethnicity and socioeconomic background.
- Women presenting with cardiac heart disease (CHD) symptoms are significantly less likely than men to receive diagnosis, referral and treatment, due to misdiagnosis of stress/anxiety.
- Research scientists are less likely to offer an oncology clinical trial to underrepresented race and ethnic groups because they are perceived to be a challenge, “non-adherent,” or lack resources to participate.

Cancer Health Disparities

- Black men have the highest cancer incidence and mortality rates compared to all race and ethnic groups.
- Where black women have a 2nd highest incidence of cancer compared to white women, the mortality rate of black women is higher than all race and ethnic groups.
- Prostate cancer incidence and mortality of black men is higher than any other race and ethnic group.
- Hispanic/Latinx communities have low rates of cancer in general but have high rates in liver, stomach, and uterine cervix cancers.
- Native American/American Indians also have high rates of liver and kidney cancer compared to any other race and ethnic group.

The Prism of Difference

- What are my assumptions about any given group that is “different” from my own?
- What influences our perceptions about other?
- Where am I located in this wheel and how does it shape my perspective, attitudes, biases?



Health Equality and Health Equity

- Race and Ethnicity
- Gender
- Rural/ Urban
- Socioeconomic
- LGBTQA

Equality



The assumption is that **everyone benefits from the same supports**. This is equal treatment.

Equity



Everyone gets the supports they need (this is the concept of “affirmative action”), this producing equity.

Justice



All 3 can see the game without supports or accommodations because **the cause(s) of the inequity was addressed**. The systemic barrier has been removed.



Current State of Diversity in Clinical Research

- Historically, women and people of color have not been included in biomedical research compared to white men.
- African-Americans represent 13% of the U.S. population but are only 5% of clinical trial participants.
- Hispanics make up 16% of the population of the U.S. but only 1% of clinical trial participants.
- Asian American, Native American, Pacific Islanders make up 5.6% of US Population and are most understudied.
- UREGs, those who live in rural areas, low income (SES), the elderly, un or underinsured, and LGBTQA communities, typically have low levels of participation.

Underrepresented Race and Ethnic Groups make up

38%

of the US population

Are expected to rise to over

56%

Current enrollment in clinical trials

<10%

Factors Impacting low Participation in Clinical Trials



Factors Impacting Lack of Diversity

- Historical and current medical and research atrocities impacting people of color.
- Broader inequities across all “systems” and sectors
- Trustworthiness/Trust
- Limited or non-existent community and patient engagement.
- System barriers
- Lack of a diverse workforce



Diverse Participation in CT/CR is Critical

- Diversity in research participation **IS** rigorous science
- Significantly enhance generalizability
- Explore differences across race/ancestry, ethnic group.
- Advance research and outcomes for all patients.
- Opportunity to receive SOC and cutting-edge treatment
- Promote equitable access to research



~ NIH Report
“The data we have is too white..”

They are not interested in participating in clinical trials...

Engaging African Americans in Research: The Recruiter's Perspective

[Nadine J. Barrett](#),¹ [Kearston L. Ingraham](#),¹ [Tracey Vann Hawkins](#),¹ and [Patricia G. Moorman](#)²

Perspectives on barriers and facilitators to minority recruitment for clinical trials among cancer center leaders, investigators, research staff, and referring clinicians: enhancing minority participation in clinical trials (EMPACT).

Raegan W. Durant, Jennifer A. Wenzel, Isabel C. Scarinci, Debora A. Paterniti, Mona N. Fouad, Thelma C. Hurd, Michelle Y. Martin

Research output: Contribution to journal > Article

Cancer



Original Article

Bias and stereotyping among research and clinical professionals: Perspectives on minority recruitment for oncology clinical trials

Soumya J. Niranjani BPharm, MS, PhD, Michelle Y. Martin PhD, Mona N. Fouad MD, MPH, Selwyn M. Vickers MD, Jennifer A. Wenzel PhD, Elise D. Cook MD, MBA, Badrinath R. Konety MD, MS, Raegan W. Durant MD, MPH ✉

Factors Associated with Medical and Clinical Research Participation within Community-Based Cohorts across three NCI-designated Cancer Center

Authors

Nadine J. Barrett¹ (First), Elisa M. Rodriguez² (First), Ronaldo Iachan³, Terry Hyslop^{4,5}, Kearston L. Ingraham¹, Gem M. Le⁶, Kelly Martin³, Rodney C. Haring², Natalie A. Rivadeneira^{6,7}, Deborah O. Erwin², Laura J. Fish⁸, Deidre Middleton³, Robert A. Hiatt^{9,10}, Steven R. Patierno^{5,11}, Urmimala Sarkar⁶ (Senior), Elizabeth A. Gage-Bouchard² (Senior)

Unexpected findings in the exploration of African American underrepresentation in biospecimen collection and biobanks.

Hagiwara N¹, Berry-Bobovski L, Francis C, Ramsey L, Chapman RA, Albrecht TL.

✚ Author information

Abstract

Racial/ethnic minorities are underrepresented in current biobanking programs. The current study utilized community-based participatory research to identify motivating factors and barriers that affect older African Americans' willingness to donate biospecimens. The standardized phone survey was administered to 78 African Americans who are 55 years old or older and live in the metropolitan Detroit area to assess their overall willingness to donate biospecimens and what factors were associated with it. The majority of the participants were willing to

Original Article

Bias and stereotyping among research and clinical professionals: Perspectives on minority recruitment for oncology clinical trials

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- 1) Recruitment interactions with potential minority participants were perceived to be challenging.
- 2) Potential minority participants were not perceived to be ideal study candidates.
- 3) A combination of clinic-level barriers and negative perceptions of minority study participants led to providers withholding clinical trial opportunities from potential minority participants.
- 4) When clinical trial recruitment practices were tailored to minority patients, addressing research misconceptions to build trust was a common strategy.
- 5) for some respondents, race was perceived as irrelevant when screening and recruiting potential minority participants for clinical trials.

Just Ask

- One primary reason people agree to participate in clinical trials and research**They were asked/informed.**
- A primary reason people do not participate in clinical trials...
They were not asked/informed



Just Ask
*engaging patients, community
and research teams*

Strategies to Increase Diversity in Clinical Research and Trials

Engagement, Recruitment, and Retention Certificate Program

Building Skills to Enhance Equitable, Diverse, and Inclusive Practices in Clinical Research Participant Interactions



Just Ask
*engaging patients, community
and research teams*



ASCO & ACCC Jointly Release
Recommendations that Address the
Lack of Equity, Diversity & Inclusion
in Cancer Clinical Trials

READ THE 6 RECOMMENDATIONS AT [ACCC-CANCER.ORG/ASCO-ACCC](https://accc-cancer.org/asco-accc)

An Assessment of the Feasibility and Utility of an ACCC-ASCO Implicit Bias Training Program to Enhance Racial and Ethnic Diversity in Cancer Clinical Trials. Barrett NJ, Boehmer L, Schrag J, Benson AB 3rd, Green S, Hamroun-Yazid L, Howson A, Matin K, Oyer RA, Pierce L, Guerra CE. JCO Oncol Pract. 2023 Apr;19(4):2023 Jan 11. PMID: 36630671.

H. Pylori Clinical Research Study

DCI OHE facilitated CCPS Co-Leader, Dr. Meira Epplein in conducting H. Pylori screening and intervention pilot in an African American church.

Partnered Event

- Hosted by The River Church.
- H. Pylori and Stomach Cancer Education followed by pilot trial enrollment, including blood draw, questionnaire and Urea breath test.

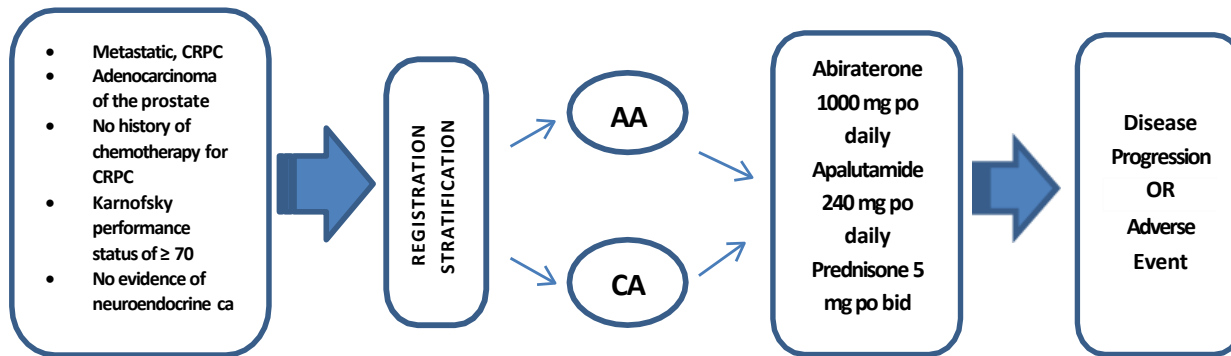
IMPACT:

- 92 participants
- 25% with H. pylori infection
- Navigation to PCPs
- Approx. 80% cure rate at 6-month follow-up



Extraordinary Early Results from Race-Stratified Clinical Trials

ABI-RACE: Abiraterone + Prednisone by race
PROCEED: Sipuleucil-T stratified by race
DOCETAXEL: Docetaxel retrospective meta-analysis by race
PANTHER: Apalutamide, Abiraterone, Pred by race (in progress)



Improved biochemical response for African-American men with advanced prostate cancer and a stronger response to both hormone and chemotherapy therapy were the centerpieces of key racial disparity studies presented by researchers from Duke's Prostate & Urologic Cancer Center at the 2018 American Society of Clinical Oncology (ASCO) Annual Meeting.





A 5-year R01-funded project (NIMHD)

Goal: To reduce the incidence of APOL1-associated kidney failure



Opeyemi Olabisi, MD,
PhD
(Principal Investigator)



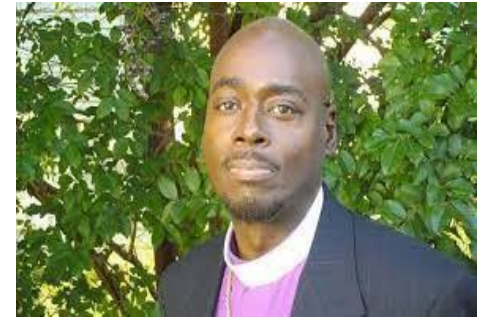
Nadine Barrett, PhD
(Co-Investigator)



Myles Wolf, MD,
MMSc
(Co-Investigator)



Chakraborty, Hrishikesh,
DrPh
(Co-Investigator)



What does this mean for our work?

- Approximately 85% of cancer patients are served in community oncology clinics
- Community clinics are more likely to serve people who are not represented in clinical research and trials
- Intentional efforts are needed for collaborations and capacity building for community cancer clinics
- Specific focus is needed to engage potential participants as partners in research
- Incorporate “why” this research is important when talking with potential participants
- Leading with a conversation vs. transaction
- Community engagement/partnerships is crucial to increasing access to quality cancer care
Advisory councils in health and research are critical colleagues that shape the quality of our programs.
- Be a listener and a learner during conversations with patients and with the community.
- Develop a strategic plan to partner and increase access to cancer research

Addressing Lack of Diversity in Research

- A recruitment and retention strategy, with a diversity plan and budget
- Address language and compensation barriers
- Monitor and slow down if not reaching goals
- Examine proximity and hours available for access
- Community engagement and partnerships
- Develop diverse Patient and Community Advisory Councils
- Implicit Bias and Anti Racism Trainings for Teams
- Develop a Diversity and Inclusion Committee/Teams
- Engage community clinics as critical partners
- Increase diversity of providers, clinicians and staff
- Incorporate quality improvement with an equity framework



Diversity and Self-Awareness

- How can my understanding of diversity, bias, power, privilege shape my interactions with patients, the community, and even my colleagues?
- How does my social status and lived experience shape my views and impact my engagement with patients?
- What steps can I take to ensure my work and actions are informed by own biases and the importance of addressing disparities?



<https://implicit.harvard.edu/implicit/takeatest.html>

Just Ask Video Link <https://vimeo.com/391994368>

Thank You!

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President: Association of Cancer Care Centers

References

1. <https://pubmed.ncbi.nlm.nih.gov/36727023/> *Inclusion of Racial and Ethnic Minorities in Cancer Clinical Trials: 30 Years After the NIH Revitalization Act, Where Are We?* (2022). Slide #11
2. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5720956/> *Engaging African Americans in Research: The Recruiter's Perspective* (2017). Slide #16
3. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4026340/> *Unexpected findings in the exploration of African American underrepresentation in biospecimen collection and biobanks* (2014). Slide #17
4. <https://doi.org/10.1002/cncr.32755> *Bias and stereotyping among research and clinical professionals: Perspectives on minority recruitment for oncology clinical trials* (2020). Slide #17
5. *Med Research "Nadine J. Barrett" slides #16 , 17 & 21*