ISP | Integrating Special Populations

NYU Langone Health
Office of Science and Research
Clinical and Translational Science Institute
Integrating Special Populations Core
Engaging Special Populations Best Practice Brief
Black, African American Population
12 May 2024

CTSI

NYU Langone Health

Overview

Demographic Profile

New York has the fourth largest population of Black (i.e. African, African American, Afro-Caribbean, or any ethnicity of African descent) persons among all 50 states.[1] In NYC, the Black community represents the third largest racial ethnic group, comprising of 23.1% of the population (~1.8 million) (see Figure 1 & 2).[2,3] One quarter of the Black population is comprised of African and Afro-Caribbean, non-Hispanic foreign-born immigrants.[4] The foreign-born Black population is 5% of the overall immigrant population in NYC, but despite its small percentage the Black immigrant population faces its own set of health disparities.[4] For example, immigrant families comprise a large majority of the uninsured and low-income populations in NYC and experience challenges related to access to care, health literacy levels, limited English proficiency). [5]

	Selected Area		New York City	
	Number	Percent	Number	Percent
Total population	8,804,190	100.0%	8,804,190	100.0%
Hispanic	2,490,350	28.3%	2,490,350	28.3%
White non–Hispanic	2,719,856	30.9%	2,719,856	30.9%
Black non–Hispanic	1,776,891	20.2%	1,776,891	20.2%
Asian non–Hispanic	1,373,502	15.6%	1,373,502	15.6%
Some other race non–Hispanic	143,632	1.6%	143,632	1.6%
Non-Hispanic of two or more races	299,959	3.4%	299,959	3.4%

Figure 1: Race and Ethnicity in NYC from 2020 census data.[3]
The "Selected Area" is New York City (referring to the five boroughs that constitutes New York City), which is why the data below the columns "Selected Area" and "New York City" are the same.

Largest Detailed Black or African American Alone and Alone or in Any Combination Groups: 2020

Group	Alone		Alone or in any combination	
	Number	Percent	Number	Percent
African American	22,091,770	53.7	24,569,479	52.3
Sub-Saharan African	2,285,543	5.6	2,818,785	6.0
Nigerian	493,188	1.2	604,077	1.3
Ethiopian	300,108	0.7	325,214	0.7
Somali	209,896	0.5	221,043	0.5
Ghanaian	150,442	0.4	172,558	0.4
Caribbean	2,147,086	5.2	2,615,988	5.6
Jamaican	811,245	2.0	1,047,117	2.2
Haitian	916,277	2.2	1,032,737	2.2
Trinidadian and Tobagonian	131,109	0.3	194,364	0.4
West Indian	74,964	0.2	119,806	0.3
Other Black or African American	14,417,192	35.1	17,167,725	36.6
Other Black or African American, not specified	14,334,854	34.9	17,017,541	36.3

Note: Groups shown are in order of the largest Black or African alone or in any combination groups. The category African American refers to those who reported a response of "African American." The category West Indian refers to those who reported a response of "West Indian." "Other Black or African American, not specified" includes respondents who only marked the Black or African American checkbox or provided write-in responses of "Black." Data may not sum to totals due to rounding and the noise applied for privacy protection. Information on suppression, confidentiality protection, nonsampling error, definitions, and guidance on using the data is available at <https://www2.census.gov/programs-surveys/decennial/2020/technical-documentation/complete-tech-docs/detailed-demographic-and-housing-characteristics-file-a/2020census-detailed-dhc-a-techdoc.pdf>.
Source: U.S. Census Bureau, 2020 Census Detailed Demographic and Housing Characteristics File A; 2020 Census Redistricting Data (Public Law 94-171) Summary File.

Figure 2: Disaggregated data table from U.S. Census Bureau 2020 data. https://www.census.gov/library/stories/2023/10/2020-census-dhc-a-black-population.html.

Black Population in NYC

- Black people make up 23.1% of the NYC population and 17.7% of New York state's population
- 60% of Black people live in either Brooklyn or Bronx
- 17.2% of Black people in NYC live below the poverty line
- 36.3% of NYC's population are foreign born, with 47.8% speaking a language other than English at home

Figure 3. The Black Population is comprised of different diverse groups.[3]

Health Profile

The Black community has some of the poorest health outcomes and lower overall life expectancy (highest years of life lost) compared to non-Hispanic Whites across NYC and the US.[1,6] Black people have the highest prevalence rates and mortality rates for obesity, high blood pressure, heart disease, cancer, stroke and diabetes.[6] Black, non-Hispanic patients have the highest mortality rates, hospitalization rates, premature birth rates, low birthweights births, infant mortality rates, maternal mortality rates, and asthma and chronic lower respiratory hospitalization rates across all demographics in NYC.[6] Additionally, Black people have higher disease prevalence compared to White and overall NYC residents.[6] According to the US Department of Health and Human Service's Office of Minority Health, the national death rate for Black persons is generally higher than White persons for heart diseases, stroke, cancer, asthma, influenza and pneumonia, diabetes, HIV/AIDS, and homicide.[1]

Black/AA Engagement in Research

Community engaged research is the process of addressing issues affecting the target populations of a study by collaborating and involving those directly impacted by studies in the research process.[7] The extent to which a research study requires community involvement will vary depending on the needs of the study. Thus, community engaged research exists on a spectrum (as seen in Figure 3). For a community-engaged study that moves further to the right on the spectrum, there is greater community involvement with a stronger bidirectional relationship and shared leadership between researchers and the community.[8] Community-based participatory research (CBPR) studies are research studies formatted to incorporate community members into the research process.[6] The CBPR approach has shown much success in conducting research within disenfranchised communities since community engaged research facilitates trust and effective communication, which can later lead to community buy-in and future study sustainability.[6]
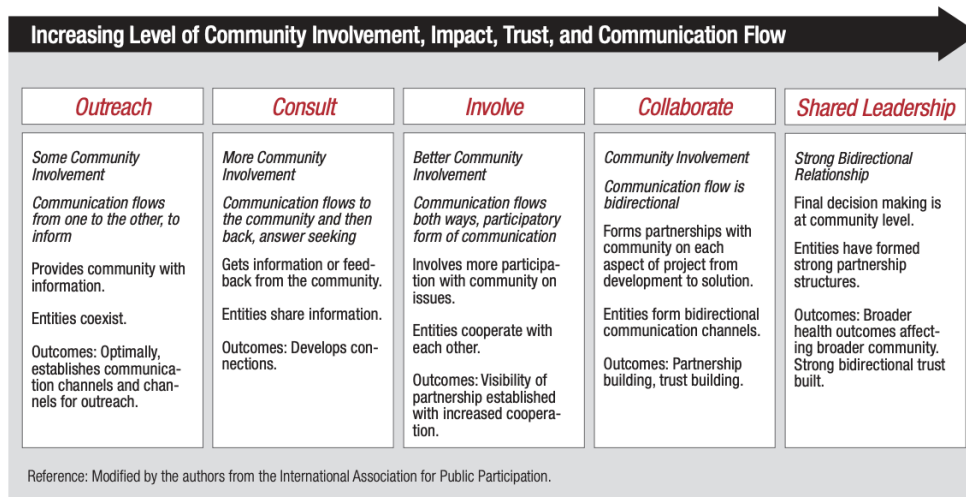
Community Engagement Continuum

Figure 4. As study moves further to the right on the spectrum, the greater bidirectional relationship and shared leadership between researchers and the community.[9] Source: Principles of Community Engagement Report (2nd Ed.), Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee Task Force on the Principles of Community Engagement.[9]

Best Practices in Engaging the Black/AA Community

When specifically addressing the Black community, there are several considerations researchers must take to successfully develop long-term, amiable relationships:

- Warm, interpersonal relationships with the community helps combat stigma and distrust of academic institutions[8]
- Emphasis on affiliation and cooperation of the community is a pertinent cultural value that has been shown to help increase engagement of the Black community[9]
- Researchers must acknowledge the fact that implicit bias, uninformed/unconsented experimentation, and systemic racism have all played a large role in mistrust between the medical/research and Black communities.[10,11]

Recruitment Best Practices

Outreach
- Promote and advertise the research study in a culturally and linguistically appropriate way[12]
- Utilize Black research coordinators and/or other BIPOC research staff members who can help ensure better communication with community members[12]
- Disaggregate Black data from national data, then use localized data, community needs assessments and community surveys to determine needs and areas of investigation[12]
- Establish community relationships with community leaders or stakeholders (e.g., partner with community healthcare providers, faith-based leaders, community health workers, patient navigators, social & community service agency directors)[12]
- Create a community advisory board or panel to get direct study/project feedback, outreach ideas, and dissemination assistance[12]
- Attend and participate in neighborhood events to engage with and establish a strong relationship with families and encourage families to recruit their family members[12]
- Emphasize the importance of the work and the need for community involvement so families feel invested in the project and sustain research practices after study completion[12]
- Consider how the social determinants of health (i.e. physical and social barriers to health equity) affect participation, such as taking time away from work, traveling to a university or hospital setting for data collection, etc. [12]

Scheduling and Costs
- Incorporate flexible data collection schedules in your protocol[12]
- Provide support services that would help offset participant costs (e.g., childcare, food, public transportation or rideshare vouchers, parking validation)[12]
- Conduct data collection in flexible locations (e.g., faith-based centers, community centers, recreation centers, local clinics, schools)[12]
- Provide fair and culturally appropriate compensation for participation (consult community members or advisory board and use recommended form of compensation)[12]

Education and Language
- Provide community workshops or trainings about adverse effects and participant liability in clinical trials[13]
- Be aware of health literacy levels when communicating by using plain language (7th grade reading level) or using jargon-free language[13]
- Provide options for participants to complete study measures independently or with the help of a research assistant[13]
- Provide options for study measures to be administered verbally[13]

Cultural Sensitivity and Values
- Critically examine questions and assess whether certain questions may be alienating and only include necessary demographic questions (e.g., sensitivity to questions about education levels, addiction, housing, or income)[15,16,17]
- Consider cultural norms and values (e.g., mistrust of medical system and personnel) and be conscious of any implicit bias or stereotypes when designing the study protocol[15,16,17]
- Address participants with appropriate and culturally relevant language to indicate mutual respect[15,16,17]
- Be mindful of differences in social and cultural practices (e.g., individualism versus collectivism framing) and communication styles in developing recruitment materials and messages. [15,16,17]

References

Works Cited

1. OMH (2019). Profile: Black/African Americans. Minority Population Profiles. US Department of Health and Human Services Office of Minority Health. https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=61
2. NYC Department of Health and Mental Hygiene. (2021). 2019-2021 Community Health Assessment and Community Health Improvement Plan: Take Care New York 2024. NYC Health. https://www1.nyc.gov/assets/doh/downloads/pdf/tcny/community-health-assessment-plan.pdf
3. United States Census Bureau. (2023). Black or African American alone, percent. U.S. Census Bureau QuickFacts. https://www.census.gov/quickfacts/fact/table/newyorkcitynewyork,US/RHI225222
4. NYC Planning Department of City Planning, City of New York. (2015). Info Brief. NYC's Foreign-born, 2000 to 2015. https://www1.nyc.gov/assets/planning/download/pdf/planning-level/housing-economy/nyc-foreign-born-info-brief.pdf?r=1
5. NYC Mayor's Office of Immigrant Affairs. (2018). State of Our Immigrant City: Annual Report, March 2018. https://www.nyc.gov/assets/immigrants/downloads/pdf/moia_annual_report_2018_final.pdf
6. New York State Department of Health. (2020). New York City Health Indicators by Race/Ethnicity, 2015-2017. https://www.health.ny.gov/statistics/community/minority/county/newyorkcity.htm
7. NIH (2021). Inclusion of Women and Minorities as Participants in Research Involving Human Subjects. U.S. Department of Health and Human Services National Institutes of Health. https://grants.nih.gov/policy/inclusion/women-and-minorities.htm
8. Barrett, N.J., Ingraham, K.L., Hawkins, T.V., & Moorman, P.G. (2017). Engaging African Americans in Research: The Recruiter's Perspective. *Ethnicity & Disease*. 2017 Autumn; 27(4): 453–462.
9. CTSA Community Engagement Key Function Committee. (2011). Principles of Community Engagement. https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf
10. Hagiwara, N., Kron, F.W., Scerbo, M.W., Watson, G.S. (2020). A call for grounding implicit bias training in clinical and translational frameworks. *Lancet*. 395(10234):1457-1460. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7265967/
11. Romano, M.J. (2018). White Privilege in a White Coat: How Racism Shaped my Medical Education. *Ann Fam Med*. 16(3):261-263. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5951257/
12. Otado, J., Kwagyan, J., Edwards, D., Ukaegbu, A., Rockcliffe, F., Osafo, N. (2015). Culturally Competent Strategies for Recruitment and Retention of African American Populations into Clinical Trials. *Clin Trans Sci*; 8: 460–466. https://ascpt.onlinelibrary.wiley.com/doi/pdf/10.1111/cts.12285
13. Chung, A., Seixas, A., Williams, N., Senathirajah, Y., Robbins, R., Newsome Garcia, V., Ravenell, J., & Jean-Louis, G. (2020). Development of "Advancing People of Color in Clinical Trials Now!": Web-Based Randomized Controlled Trial Protocol. *JMIR Research Protocols*, 9(7), e17589. https://doi.org/10.2196/17589
14. Nápoles, A.S., & Stewart, A.L. (2018). Transcreation: an implementation science framework for community-engaged behavioral interventions to reduce health disparities. *BMC Health Serv Res*. 2018; 18: 710. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6134771/
15. Tchouankam, T., Estabrooks, P., Cloyd, A., Notice, M., Teel-Williams, M., Smolsky, A., Burnett, P., Alexis, G., Conley, T., Partridge, Ej., Hogan, P., Thorpe, R., & King, K. M. (2021). Recruiting Low-Income African American Men in Mental Health Research: A Community-Based Participatory Research Feasibility Study. *American Journal of Men's Health*. https://doi.org/10.1177/15579883211018418
16. Dueñas, H.R., Seah, C., Johnson, J.S., & Huckins, L.M. (2020). Implicit bias of encoded variables: frameworks for addressing structured bias in EHR–GWAS data. *Human Molecular Genetics*; 29(R1), R33–R41. https://doi.org/10.1093/hmg/ddaa192
17. Frederick, J.K. (2020). Four Strategies for Crafting Inclusive and Effective Demographic Questions. Ithaka S+R. https://sr.ithaka.org/blog/four-strategies-for-crafting-inclusive-and-effective-demographic-questions/

Internal & External Resources

Research and Recruitment Resources	NYULH Trainings & Resources*	Health Profiles	National Organizations
Lessons learned for recruitment and retention of low-income African Americans (ePub journal article)	CDC Plain Language	Black/African American Population Profile (US Office of Minority Health report)	Black Mama's Matter Alliance (Black Maternal Health Organization)
Strategies Addressing Barriers to Clinical Trial Enrollment of Underrepresented Populations (ePub journal article)	CDC Health Literacy	NYC Health Indicators by Race (NY State Dept. of Health report)	Society for the Analysis of African American Public Health Issues (SAAPHI)
Recruitment of Black Identifying Young Adults into Clinical Trials: COVID-19 (ePub journal article)	CDC Select Terms for Populations	African American Health Vital Signs Report (CDC report)	Black Women for Wellness (BWWLA)
A Model to Translate Evidence-Based Interventions Into Community Practice (ePub journal article)	FOCUS Inclusive Mindset Training	Health Disparities by Race and Ethnicity (Center for American Progress report)	Black Women's Health Imperative (BWHI)
Development of "Advancing People of Color in Clinical Trials Now!": Web-Based Randomized Controlled Trial Protocol (ePub journal article)	FOCUS Driving Change and Anti-Racism Training	Health Disparities Among African-Americans (Pfizer report)	Mamatoto Village (Healthy Mamas + Babies + Communities Initiative)
Top Black Health Resources List (Black News resource)	FOCUS Supporting Allyship and Anti-Racism at Work Training	Race and health profiles in the US: CHIS adult survey (ePub journal article)	The Love Land Foundation (Support for Black women and girls)
List of U.S. Minority Organizations (US Office of Minority Health resource)	FOCUS Discussing Racism Training	Improving the health of African Americans in the USA: an overdue opportunity for social justice (ePub journal article)	National Institute on Minority Health and Health Disparities (NIMHD)
Accrual of Black participants to cancer clinical trials following community outreach and engagement (ePub journal article)	FOCUS How to Speak Up Against Racism at Work Training	Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement (Agency for Healthcare Research and Quality report)	African American Community Health Advisory Committee (AACHAC)
Minority Recruitment Websites (U of Tex San Ant, Long School of Med resource)	FOCUS Design Thinking, Social Innovation, and Complex Systems Training	Health Disparities Experienced by Black or African Americans (CDC report)	African American Health Program (Montgomery County Dept. of HHS)
Engaging African Americans in Research: The Recruiter's Perspective (ePub journal article)	FOCUS Just Ask: Discussing Race Training	Black and African American Health (Medline Plus report)	Cross Cultural Health Care Program (XCulture)
Michigan Center for Urban African American Aging Research Participant Resource Pool (MCUAAAR resource)	FOCUS Building Inclusive Work Communities Training	Racism, Inequality, and Health Care for African Americans Report (The Century Foundation report)	The Center for African American Health (CAAH)
Recruitment of Black Adults into Cardiovascular Disease Trials (ePub journal article)	FOCUS Strategies to Foster Inclusive Language Training		Association of Clinicians for the Underserved (ACU - Clinicians)

Research and Recruitment Resources	NYULH Trainings & Resources*	Health Profiles	National Organizations
https://www.joinallofus.org/ Best strategies to recruit and enroll elderly Blacks into clinical and biomedical research (ePub journal article)	FOCUS Strategic Resources and Support Services for Investigators & Study Teams	https://www.cancer.org/research/cancer-facts-statistics/hispanics-latinos-facts-figures.html	https://latinocenterforhealth.org/
	FOCUS Talking About Race at Work Training		
	FOCUS Marketing to Diverse Audiences Training		
	FOCUS Creating a Culture of Collaboration Training		
	FOCUS Communicating Across Cultures Training		
	FOCUS Best Practices for Managing Projects Across Cultures Training		
	FOCUS Cultural Competency at NYULH Training		
	FOCUS Interpersonal Communication Training		
	FOCUS Managing a Diverse Team Training		
	FOCUS Diversity, Inclusion and Belonging Training		
	FOCUS Inclusivity in Committed Allies Training		
	FOCUS Leading Inclusive Teams Training		
	FOCUS Confronting Bias: Thriving Across Our Differences Training		
	FOCUS Addressing Unconscious Bias in Medicine Training		

*FOCUS only accessible with Kerberos ID.