

African American Populations Toolkit

Table of Contents

| | |
|--|----|
| I. Historical and Current Issues Regarding Research Population | 3 |
| A. Contested Definitions..... | 3 |
| B. History of Mistreatment by Researchers, Medical Professionals, and Government Agencies..... | 3 |
| C. Underrepresentation in Research | 5 |
| D. Health Disparities..... | 5 |
| E. Multiple Sources of Identity | 5 |
| F. Engaging the Community in Research | 5 |
| II. Health and Research Practice | 8 |
| A. Best Practices and Interventions | 8 |
| B. Searchable Database:..... | 8 |
| III. National and Local Data | 9 |
| A. General Data | 9 |
| B. State and Local Data | 9 |
| IV. Ethical and Regulatory Issues..... | 11 |
| A. Applying the Belmont Report: Principle of Justice | 11 |
| B. Transparency, Privacy, & Confidentiality..... | 11 |
| V. Recruitment and Retention Best Practices | 12 |
| A. Community-Based Participatory Research in African American Communities: Principles | 12 |
| B. Engaging African American Communities in Research: Moving from Principles to Action..... | 12 |
| C. Community-Engaged Research: A Less Intensive Alternative to CBPR | 13 |
| VI. Recruitment Templates | 14 |
| VII. Community Engagement Resources | 14 |
| A. Local Organizations | 14 |
| B. National Organizations..... | 15 |
| VIII. Researchers at UIC and C3 Working on the Issue..... | 16 |
| A. UIC..... | 16 |
| B. Northwestern | 17 |
| C. University of Chicago | 18 |
| IX. Measuring Instruments | 19 |
| A. A Note on Measuring Race and Ethnicity | 19 |
| B. Other Measuring Instruments..... | 19 |
| X. Program Announcements for Grants..... | 21 |
| A. MSI Designation | 21 |

- B. Grant Programs 21
- XI. Community Stakeholder Involvement 22
 - A. African American Specific Resources 22
 - B. General Resources for Individuals 22
 - C. General Resources for Organizations 22
- XII. Team Readiness to Work with Special Populations..... 24
 - A. Cultural competency training..... 24
 - B. Team diversity representation 24
 - C. Implicit-association test (IAT) – Offers a way to probe unconscious biases..... 24
 - D. Resources to Evaluate Attitudes Necessary for Working with Black Communities 24
- Citing the CCTS’s Target Population Toolkit 25



African American Populations Toolkit

I. Historical and Current Issues Regarding Research Population

A. *Contested Definitions*

There is no clear consensus about which term is preferred for African Americans or Black Americans, and who is included in those terms. Many different words have been used to describe this group in the past. In the mid-20th century, it was not uncommon for the terms “Colored” or “Negro” to be used: signs used during segregation would often indicate which facilities were “White” and “Colored,” and Rev. Dr. Martin Luther King used “Negro” more often than “Black” in his “I Have a Dream” speech.¹ However, these terms, with their association with segregation, are no longer used.

Today, the most commonly-used terms are African American and Black. The latter has been used for a longer period. The former has risen to prominence in the last few decades, spurred on by a speech by Jesse Jackson in 1988, where he emphasized that the term links people to a shared culture and heritage.² This was formally recognized by the US government in 1997, when the Office of Management and Budget adopted a recommendation that government survey questions about race should include the option “Black or African American,” an expansion of the previous option, which was simply, “Black.”³ Which term people prefer is less clear. A Gallup poll in 2007 found that a majority (61%) of African Americans did not have a preference between the terms. Among those who did, more preferred African American (24% of all respondents) rather than Black (13% of all respondents).⁴ Thus, there is no consensus on one term that should be used over the other.

There are also distinctions to be made about who is included in the group. The Census Bureau, in an outreach plan for the 2010 Census, described three distinct groups: African Americans, or Blacks born in the United States; Black Africans, or Black immigrants from Africa; and Afro-Caribbeans, people of African descent whose ancestors passed through the Caribbean before coming to the US. The unifying feature is that members of all groups have African descent.⁵ Some writers suggest a distinction should be made between people descended from slaves, who have a unique history of disadvantage, and all others, such as Africans who voluntarily immigrated to the US.⁶ Another consideration is the intersection of race and ethnicity. The Census Bureau asks about these identities in two distinct questions.⁷ However, many reports and studies use a selective combination of these identities (non-Hispanic Black, Hispanic of any race).⁸ This can be problematic as some people could be considered African American/Black, and Hispanic, such as many Dominicans.

This section is not intended to prescribe one term or definition to the exclusion of all others. This document will use both African American and Black. What will be key for your study is being clear about the population with which you will be working. Additionally, when working with partners, it can be helpful to ask how they would like you to refer to them and their community, and then make a conscious effort to use that term.

B. *History of Mistreatment by Researchers, Medical Professionals, and Government Agencies*

African Americans have faced mistreatment from researchers and medical professionals, including those employed by government agencies, for centuries. This legacy continues to cast its shadow over current interactions, through discrimination, reluctance on the part of African Americans to participate in research and leading to or increasing health disparities.

African American Populations Toolkit

In addition to the exploitation African Americans endured through slavery and the denial of rights to free Black people, abuse came specifically from doctors and researchers as well. In 1835, a French visitor to Baltimore observed that only Black bodies were used for dissection because the African American community did not have the power to resist. Doctors also performed gruesome experiments on living people. A physician named Thomas Hamilton performed a series of experiments on a slave named Fed, forcing him to stand in a scorching pit until he collapsed due to the heat. Hamilton often injected Fed with medications to see if they would make him endure more heat, so that slaves could work longer under hot conditions. In another series of experiments, J Marion Sims performed dozens of surgeries on three slave women's genitalia, without anesthesia, which resulted in severe maiming for at least one of the women, Lucy. Sims later performed the surgery to repair vesicovaginal fistulas on White women, but with anesthesia and only after having practiced the procedure on Black women.⁹

These abuses continued after the end of slavery. Widespread grave-robbing of Black bodies was exposed in 1882 in Philadelphia, and historians have noted grave robbing happened in the South to provide bodies for Northern medical schools. Dr. Daniel Hale Williams discussed how White physicians, especially in the South, used Black patients as guinea pigs. Dr. Nathan Francis Mossell described African American patients receiving the poorest care, being placed in inferior wards, and having to undergo experimental treatments.¹⁰

The US Public Health Service Study of Syphilis in the Negro Male (PHS syphilis study) has come to represent the pattern of abuse that African Americans have suffered at the hands of medical personnel and researchers. Between 1932 and 1972, the US Public Health Service enrolled and monitored 399 African American men who had syphilis and 201 men who did not in Tuskegee, Alabama. The aim was to understand the progression of the disease, even though it was already well-understood. It is important to note that while no one was purposely infected with syphilis, those who were diagnosed with the disease were never informed of their diagnosis nor were they treated, which allowed them to unknowingly spread it to others. Even after penicillin was shown to be an effective treatment for syphilis, men in the study were prevented from accessing this medication. The aftermath of the study's revelation to the general public led to a large public inquiry and the subsequent establishment of rules for federally-funded research, such as requiring informed consent, institutional review boards, and limited use of deception. Nevertheless, the study continues to influence attitudes towards research among African-Americans, often making people skeptical and hesitant to participate.¹¹

Also in the mid-20th century, the Henrietta Lacks case illustrates many of the issues with research that make African Americans wary of participating in research. In 1951, Lacks was a young woman receiving treatment for cervical cancer at Johns Hopkins Hospital. A sample of her cells was taken without her knowledge or consent and given to the laboratory. There, researcher George Gey was able to get her cells to replicate in the lab, creating the first immortal cell line. The cells, labelled "HeLa" and thereby compromising her privacy, would eventually be used by thousands of researchers across the world. Despite the considerable amount of scientific knowledge that has been created, and the profit that researchers have enjoyed, the family has never been compensated.¹²

After the US PHS syphilis study, rules for researchers were implemented as federal law, but discrimination and mistreatment – and distrust – have continued. Focus group participants have reported bad experiences with research in the past, tarnishing the image of research in their minds. More generally, people have described research happening in their communities, but that they never saw the results of the research or any benefits from it. Others have experienced discrimination in trying to access general health care, giving them the impression the medical system does not have the same regard for their health and well-being as it does for others, especially

African American Populations Toolkit

Whites.¹³ These negative experiences create an environment where many African Americans are deeply reluctant to participate in research.

C. Underrepresentation in Research

African-Americans are underrepresented in several types of research. African American cancer patients are less likely to be enrolled in clinical trials than White cancer patients.¹⁴ Similarly, HIV disproportionately affects African Americans, but their participation rate in clinical trials related to the virus lags behind their burden of infection.¹⁵ Some reasons African Americans have given for not participating include the legacy of mistrust related to US PHS syphilis study and other historical abuses described above, concerns about the integrity of research practices, mistrust of the health care system, and concerns about the lack of choice in clinical trials. Some of these concerns can be addressed if safety assurances are put in place to protect participants, trust is developed between the researcher and participants, other racial groups are shown to be participating, and participants have choices they can exercise during the study.¹⁶ Systemic factors also play a central role. African Americans have reduced access to medical care, making them less likely to get a diagnosis that would qualify them for a study or to hear about studies. Many researchers choose not to recruit Black participants, sometimes from the belief that they are less likely to participate in studies, which becomes a self-fulfilling prophecy. The relative lack of researchers from the Black community also acts as a barrier to the building of trust between patients and researchers.¹⁷ Efforts to address the individual and systemic barriers will be needed to make research participation more equitable. Other sections in this Toolkit, such as V: Recruitment & Retention Best Practices, provide suggestions you can use to be successful in making your own research inclusive.

D. Health Disparities

African Americans face significant health disparities. Life expectancy at birth in 2015 was estimated to be 3.5 years lower for African Americans (including Black Hispanics) compared with Whites. It was especially pronounced for Black males, who were expected to live 4.4 fewer years than White males.¹⁸ African Americans who die from complications from AIDS lose 11 times the number of years of potential life as do Whites who die from complications from AIDS.¹⁹ In some important areas, rather than making progress in the last few decades, the gap has widened: the death rates for heart disease and cancer went from being lower in Blacks than Whites in the 1980s to 30% higher by 2000.²⁰ African Americans also have substantially higher prevalence of diabetes, along with increased rates of complications and diabetes-related mortality, compared with Whites.²¹ Many more disparities could be listed here, but the purpose is not to provide an exhaustive list of disparities; instead, the intent is to highlight the disproportionate disease and mortality burden that African-Americans bear.

E. Multiple Sources of Identity

An individual's racial identity should be viewed in the context of multiple identities. In addition to race, their ethnicity, sexual orientation, gender identity, citizenship status, class, and many other aspects influence how they view themselves and their risk and resilience factors for health outcomes. Recognizing these dynamics is a critical step to building relationships with research participants.

F. Engaging the Community in Research

The troubled history of research with African Americans and the resulting trust gap, described above, make it essential that researchers work closely with the community to build connections and alleviate fears. One of two

African American Populations Toolkit

approaches can be used. Community-based participatory research (CBPR) offers a promising avenue to do so. CBPR aims to equitably involve community members, organizational representatives, and researchers in all phases of research. Among many principles, a few are key, including building on community strengths and resources, facilitating collaborative partnerships, and integrating knowledge and action for the benefit of all partners.²² Using this method, community members can design projects to preemptively avoid problems and boost buy-in. Moreover, they can act as ambassadors for the project, helping recruitment and retention to be more successful. However, CBPR can be difficult and time-consuming. Community Engaged Research (CEnR) encourages engagement with the community where possible, without the requirement that community members be involved in every step of the process. CEnR may be a more approachable way for some researchers to start working with the community. See Section V, Recruitment and Retention Best Practices, for further information.

¹ King, M.L., Jr. (1963 August 28). "I Have a Dream," Address Delivered at the March on Washington for Jobs and Freedom. *The Martin Luther King, Jr. Research and Education Institute, Stanford University*. Retrieved from <https://kinginstitute.stanford.edu/king-papers/documents/i-have-dream-address-delivered-march-washington-jobs-and-freedom>.

² Martin, B.L. (1991). From Negro to Black to African American: The Power of Names and Naming. *Political Science Quarterly*, 106(1), 83-107. Retrieved from https://www.jstor.org/stable/2152175?seq=1#page_scan_tab_contents.

³ Office of Management and Budget. (1997 October 30). Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. *Federal Register*. Retrieved from <https://web.archive.org/web/20090315191301/https://www.whitehouse.gov/omb/fedreg/1997standards.html>.

⁴ Newport, F. (2007 September 28). Black or African American? *Gallup News Service*. Retrieved from <http://news.gallup.com/poll/28816/black-african-american.aspx>.

⁵ US Census Bureau. (2008 August). 2010 Census Integrated Communications Campaign Plan: The Success of the Census is in Our Hands. Retrieved from https://www2.census.gov/programs-surveys/decennial/2010/program-management/1-plan/provide-support/communication-campaign-plan/2010_icc_plan_final_edited.pdf.

⁶ Dickerson, D.J. (2007 January 22). Colorblind: Barack Obama Would Be the Great Black Hope in the Next Presidential Race – If He Were Actually Black. *Salon*. Retrieved from <https://web.archive.org/web/20100924194645/http://www.salon.com/news/opinion/feature/2007/01/22/obama/>.

⁷ Humes, K.R., Jones, N.A., & Ramirez, R.R. (2011 March). Overview of Race and Hispanic Origin: 2010. *2010 Census Briefs*. Retrieved from <https://www.census.gov/content/dam/Census/library/publications/2011/dec/c2010br-02.pdf>.

⁸ National Center for Health Statistics. (2017). Health, United States, 2016: With Chartbook on Long-Term Trends in Health. *Centers for Disease Control and Prevention*. Retrieved from <https://www.cdc.gov/nchs/data/abus/abus16.pdf#015>.

⁹ Gamble, V.N. (1997). Under the Shadow of Tuskegee: African Americans and Health Care. *American Journal of Public Health*, 87(11), 1773-1778. Retrieved from <http://ajph.aphapublications.org/doi/pdfplus/10.2105/AJPH.87.11.1773>.

¹⁰ Gamble, V.N. (1997). Under the Shadow of Tuskegee: African Americans and Health Care. *American Journal of Public Health*, 87(11), 1773-1778. Retrieved from <http://ajph.aphapublications.org/doi/pdfplus/10.2105/AJPH.87.11.1773>.

¹¹ Freimuth, V.S., Quinn, S.C., Thomas, S.B., Cole, G., Zook, E., & Duncan, T. (2001). African Americans' Views on Research and the Tuskegee Syphilis Study. *Social Science & Medicine*, 52, 797-808.

¹² Lasso, R.A. (2011). Book Review: *The Immortal Life of Henrietta Lacks* by Rebecca Skloot. *Journal of the American Medical Association*, 305(11), 1143-1144. Retrieved from https://jamanetwork.com/data/journals/JAMA/18301/jbk0316_1143_1144.pdf.

¹³ Scharff, D.P., Mathews, K.J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). More than Tuskegee: Understanding Mistrust about Research Participation. *Journal of Health Care for the Poor and Underserved*, 21(3), 879-897. <http://doi.org/10.1353/hpu.0.0323>.

¹⁴ Murthy, V.H., Krumholz, H.M., & Gross, C.P. (2004 June 9). Participation in Cancer Clinical Trials: Race-, Sex-, and Age-Based Disparities. *Journal of the American Medical Association*, 291(22), 2720-2726. DOI: 10.1001/jama.291.22.2720.

¹⁵ Gwadz, M.V., Colon, P., Ritchie, A.S., Leonard, N.R., Cleland, C.M., Riedel, M., Bowens, D., Banfield, A.D., Chang, P., Quiles, R., & Mildvan, D. (2010). Increasing and Supporting the Participation of Persons of Color Living With HIV/AIDS in AIDS Clinical Trials. *Current HIV/AIDS Reports*, 7(4), 194-200. <http://doi.org/10.1007/s11904-010-0055-3>.

¹⁶ George, S., Duran, N., & Norris, K. (2014). A Systematic Review of Barriers and Facilitators to Minority Research Participation Among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health*, 104(2), e16-e31. <http://doi.org/10.2105/AJPH.2013.301706>.

African American Populations Toolkit

¹⁷ Shavers-Hornaday, V.L., Lynch, C.F., Burmeister, L.F., & Torner, J.C. (1997). Why are African Americans Under-Represented in Medical Research Studies? Impediments to Participation. *Ethnicity & Health*, 2(1/2), 31-45.

¹⁸ National Center for Health Statistics. (2017). Health, United States, 2016: With Chartbook on Long-Term Trends in Health. *Centers for Disease Control and Prevention*. Retrieved from <https://www.cdc.gov/nchs/data/abus/abus16.pdf#015>.

¹⁹ Morbidity and Mortality Weekly Report. (2005 January 14). *Centers for Disease Control and Prevention*, 54(1). Retrieved from <https://www.cdc.gov/mmwr/pdf/wk/mm5401.pdf>.

²⁰ Airhihenbuwa, C.O., & Liburd, L. (2006 August). Eliminating Health Disparities in the African American Population: The Interface of Culture, Gender, and Power. *Health Education and Behavior*, 33(4), 488-501. DOI: 10.1177/1090198106287731.

²¹ Peek, M.E., Cargill, A., & Huang, E.S. (2007 October). Diabetes Health Disparities: A Systematic Review of Health Care Interventions. *Medical Care Research and Review*, 64(5, Supplement) 101S-156S. Retrieved from <http://journals.sagepub.com/doi/pdf/10.1177/1077558707305409>.

²² Israel, B.A., Schulz, A.J., Parker, E.A., & Becker, A.B. (1998). Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health. *Annual review of Public Health*, 19, 173-202. Retrieved from <https://www.annualreviews.org/doi/pdf/10.1146/annurev.publhealth.19.1.173>.

African American Populations Toolkit

II. Health and Research Practice

A. *Best Practices and Interventions*

- [2014 Evidence-Based Guideline for the Management of High Blood Pressure in Adults](#)
- [The Black-White disparity in pregnancy-related mortality from 5 conditions: Differences in prevalence and case-fatality rates](#)
- [Combating Persistent Cultural Incompetence in Mental Health Care Systems Serving African Americans](#)
- [Diabetes Management: Interventions Engaging Community Health Workers](#)
- [High-Impact HIV Prevention: The CDC's Approach to Reducing HIV Infections in the United States](#)
- [Improving Asthma Care for African American Children by Increasing National Asthma Guideline Adherence](#)
- [Management of High Blood Pressure in Blacks: An Update of the International Society on Hypertension in Blacks Consensus Statement](#)
- [New Recommendations for Treating Hypertension in Black Patients: Evidence and/or Consensus?](#)
- [Race, biochemical disease recurrence, and prostate-specific antigen doubling time after radical prostatectomy: Results from the SEARCH database](#)
- [Racial and ethnic differences in advanced-stage prostate cancer: The Prostate Cancer Outcomes Study](#)

B. *Searchable Database:*

- [Healthy People 2030 Best Practice Research Search](#)

III. National and Local Data

A. General Data

- Pew Research Center
 - [5 Facts about the Religious Lives of African Americans](#)
 - [For African Americans, Discrimination is Not Dead](#)
 - [On Views of Race and Inequality, Blacks and Whites Are Worlds Apart](#)
- US Census Bureau
 - [The Black Population: 2010](#)
 - [Changes in Areas with Concentrated Poverty: 2000 to 2010.](#)
 - [The Changing Economics and Demographics of Young Adulthood: 1975–2016](#)
 - [Coresident Grandparents and Their Grandchildren: 2012](#)
 - [Disparities in STEM Employment by Sex, Race, and Hispanic Origin.](#)
 - [Educational Attainment in the United States: 2015](#)
 - [Household Income: 2016](#)
 - [Poverty Rates for Selected Race & Hispanic Groups by State and Place: 2007-11](#)
 - [School Enrollment in the United States: 2011](#)
 - [Selected Population Profile in the US: Black or African American alone](#)
- [CDC Wonder](#)

B. State and Local Data

- Chicago Metropolitan Agency for Planning
 - [The Cost of Segregation](#)
 - [Economically Disconnected Area Clusters in the CMAP region](#)
 - [Race and Ethnicity in the CMAP Region](#)

African American Populations Toolkit

- [Travel Patterns in Economically Disconnected Area Clusters](#)
- US Census Bureau
 - [Chicago Quick Facts](#)
 - [Illinois Community Facts](#)
 - [Illinois Quick Facts](#)

IV. Ethical and Regulatory Issues

A. Applying the Belmont Report: Principle of Justice

The Belmont Report that emerged in the wake of the outcry over the US Public Health Service syphilis study established many of the principles that guide the ethical practice of research today. While the entire report is useful to keep in mind when conducting research with African American participants, the principle of justice merits specific attention. The report calls out several instances in which participants were selected because it was relatively easier to get their participation than others, such as poor ward patients, concentration camp inmates, and the disadvantaged Black men in the US PHS syphilis study. However, the benefits of these studies (when benefits even emerged) often went to other groups who did not participate in the research. The report therefore calls for careful consideration of the selection of participants in relation to the burdens and benefits of research. There are different formulas for thinking about burdens and benefits, but generally speaking, no group (African Americans included) should bear undue burdens of research, nor should they be excluded from likely benefits of research.²³ Typically, this will mean that participation in research should either reflect that group's proportion of the general population, or that group's proportion of the people who have the disease or condition being studied. Thus, addressing the underrepresentation of Black participants in research is an ethical and moral imperative as well as a process issue to be solved.

B. Transparency, Privacy, & Confidentiality

As mentioned in Section I, many African Americans have significant reservations about participating in research. Some of the suspicion relates to inadequate or incorrect information. Focus group participants expressed that medical professionals have not explained procedures or consent well, reinforcing the mistrust they have of the medical community.²⁴ Additionally, the story of Henrietta Lacks (described in Section I of the Toolkit) has made people wary of how their information and tissue samples will be used. As such, a thorough explanation of the study aims and procedures is essential, as is showing how you will keep their participation in the study private and protect their data and tissue samples. This in-depth conversation can help build trust. Investigators who receive funding from the National Institutes of Health can also apply for a Certificate of Confidentiality, which provides an additional layer of protection for participants' data by ensuring that researchers cannot be forced to disclose information about study participants.²⁵ After giving these assurances, it is critical to follow through and if any problems arise, to respond quickly and be honest with participants about the problems.

²³ National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1978). *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. Bethesda, MD: The Commission. Retrieved from https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf.

²⁴ Scharff, D.P., Mathews, K.J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). More than Tuskegee: Understanding Mistrust about Research Participation. *Journal of Health Care for the Poor and Underserved*, 21(3), 879–897. <http://doi.org/10.1353/hpu.0.0323>.

²⁵ See <https://humansubjects.nih.gov/coc/background> for more information.

African American Populations Toolkit

V. Recruitment and Retention Best Practices

A. Community-Based Participatory Research in African American Communities: Principles

As mentioned in Section I, Community-Based Participatory Research (CBPR) is one method for addressing the hesitance some Black people have for participating in research. A major tenet of CBPR is that community members (either on their own or through organizations) have a real voice in setting the research agenda, planning, implementing the plan, and realizing outcomes. Relatedly, the community should see real benefits from the process in addition to the generation of knowledge that benefits the researcher.²⁶

Members of the National Black Leadership Initiative on Cancer developed a set of guiding principles for CBPR tailored to the African American community. These are summarized in the following chart:²⁷

| Principle | Explanation |
|---------------------------------|---|
| 1. We are Family | Evoking community solidarity, this describes the commitment to working together to achieve shared goals. |
| 2. It Takes a Village | The village facilitates co-learning, shared decision-making, and mutual ownership, which both come from and continually develop trust and respect. |
| 3. Come as You Are | Everyone has something to offer right away, even if further learning and listening need to happen. |
| 4. Just Stand | Current research stands on the shoulders of past research and creates the environment for future interventions and research in a cyclical process. |
| 5. Health, Wholeness, & Healing | The purpose of the research should not just be to observe and describe, but to create actions or interventions that will help the community. |
| 6. Go Tell It on the Mountain | Dissemination should happen in the community through relevant channels, such as magazines, radio programs, faith groups, and word of mouth, in addition to academic journals and conferences. |
| 7. We Shall Overcome, Someday | The guiding light should be eliminating disparities in health and other aspects of life. |

B. Engaging African American Communities in Research: Moving from Principles to Action

A challenge to enacting these principles is that, in order to obtain funding to do research, much of the agenda setting and planning must be done prior to submitting most proposals. One approach is to do the initial relationship building and planning before applying for a grant. Investigators can also begin discussions with community-based organizations and volunteer to fill a need or help with existing projects before embarking on a research project. Similarly, if researchers have funding for a small, short-term study, this can be a way to build the groundwork for a more substantial partnership.²⁸ These approaches may require more hours for both the researchers and the community partners. Ultimately, though, they can result in a stronger partnership because of the shared commitment that everyone builds together.

After the initial period of relationship building, a few key considerations can help the partnership transition into a robust engagement. Creating a community advisory board (CAB) is essential to the process. Potential members should be committed to the project and be willing to work with their contacts in the community to

African American Populations Toolkit

build further support for the project. Members should come from multiple organizations or places in the community to ensure continuity if one organization reduces its support of the project. Convening a CAB helps bring accountability to the project, but it also is a signal to others in the community that buy-in from their community is already present. Beyond convening the CAB, it is important for the researcher to attend events outside the project, and to be physically present for meetings, to demonstrate their commitment.²⁹ At least some project-related meetings should be held in the community, not on a university campus. Having meetings on community partners' home turf allows more people to participate because they have a shorter distance to travel. Additionally, a setting like a school or community center can allow participants to show products from past projects of which they are proud or illustrate things that need improvement. Community involvement should continue after data collection. Community partners should be involved in member-checking qualitative data and helping shape the interpretation of quantitative data. Finally, the results should not only go into journal articles, but also into community action plans and materials that resonate with the people who contributed the data in the first place.

C. Community-Engaged Research: A Less Intensive Alternative to CBPR

Using the community-based participatory research (CBPR) approach involves significant investments of time and other resources. Moreover, it may be difficult if one's institutional setting is not designed to support CBPR. Community-engaged research (CEnR) is a less-intensive alternative that may be attractive to researchers who want to involve the community but may not be able to use the full CBPR model. Many of the principles remain the same. The first step is to learn about the community. This may seem obvious, but it involves building relationships, getting to know the history, culture, and power structures, and understanding the norms and values. The second step is for researchers to share power and show respect. Researchers should listen carefully and be open to difficult conversations about power dynamics. Additionally, small steps like providing food for meetings and offering child care can go a long way to helping community members participate. The third step is to include partners in all phases of research. While CEnR does not require completely equal decision-making power between researchers and community members, the views and goals of the latter should be incorporated into the study plan and execution where possible. The final step is for community partners to be compensated fairly. Researchers conduct studies for a living and get paid for their work; community partners should be afforded the same opportunity.³⁰ Engaging the community using these principles can help your project be more responsive to the community's needs as well as more successful in achieving your goals.

²⁶ Israel, B.A., Schulz, A.J., Parker, E.A., & Becker, A.B. (1998). Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health. *Annual Review of Public Health*, 19, 173-202. Retrieved from <https://www.annualreviews.org/doi/pdf/10.1146/annurev.publhealth.19.1.173>.

²⁷ Smith, S.A., Whitehead, M.S., Sheats, J.Q., Ansa, B.E., Coughlin, S.S., & Blumenthal, D.S. (2015). Community-based participatory research principles for the African American community. *Journal of the Georgia Public Health Association*, 5(1), 52–56.

²⁸ D'Alonzo, K.T. (2010 July 11). Getting Started in CBPR: Lessons in Building Community Partnerships for New Researchers. *Nursing Inquiry*, Vol. 17, No. 4, pp. 282-288.

²⁹ D'Alonzo, K.T. (2010 July 11). Getting Started in CBPR: Lessons in Building Community Partnerships for New Researchers. *Nursing Inquiry*, Vol. 17, No. 4, pp. 282-288.

³⁰ Michener, L., Cook, J., Ahmed, S.M., Yonas, M.A., Coyne-Beasley, T., & Aguilar-Gaxiola, S. (2012). Aligning the Goals of Community-Engaged Research: Why and How Academic Health Centers Can Successfully Engage with Communities to Improve Health. *Academic Medicine*, 87(3), 285–291. <http://doi.org/10.1097/ACM.0b013e3182441680>.

VI. Recruitment Templates

[CCTS CEC Recruitment Templates Toolbox](#)

VII. Community Engagement Resources

A. Local Organizations

[Affinity Community Services](#)

[African American Arts Alliance of Chicago](#)

[Austin Coming Together](#)

[Chicago Urban Leagu](#)

[Chicagoland Black Chamber of Commerce](#)

[DuSable Museum of African American History](#)

[Far South Community Development Corporation](#)

[Garfield Park Community Council](#)

[Greater Auburn-Gresham Development Corporation](#)

[The History Makers](#)

[Illinois African American Coalition for Prevention](#)

[Impact Family Center](#)

[Inspiration Corporation](#)

[Kenwood Oakland Community Organization](#)

[Lawndale Christian Health Center](#)

[Pan-African Association](#)

[South Side Community Art Center](#)

[Southwest Organizing Project](#)

[Teamwork Englewood](#)

African American Populations Toolkit

[United African Organization](#)

B. National Organizations

[100 Black Men of America](#)

[NAACP](#)

[National Urban League](#)

[Rainbow Push Coalition](#)

VIII. Researchers at UIC and C3 Working on the Issue

Please note: This list is intended to be illustrative rather than exhaustive. Resources to find additional researchers include <https://projectreporter.nih.gov/reporter.cfm>, <https://clinicaltrials.gov/>, <https://www.researchgate.net/>, and <https://scholar.google.com/>.

A. UIC

[Courtney Bonam, PhD](#)

Courtney Bonam, PhD, is affiliated with the University of Illinois at Chicago's Department of Psychology. Her profile showcases her research interests, publications, and expertise in the areas of racial and ethnic disparities in mental health, identity development, and multicultural counseling.

[Roderick A. Ferguson, PhD](#)

Roderick A. Ferguson, PhD, is a faculty member at the University of Illinois at Chicago's Department of Gender and Women's Studies. His profile highlights his research and teaching interests in the fields of critical race theory, queer theory, and cultural studies, focusing on the intersections of race, sexuality, and social justice.

[Tyrone Forman, PhD](#)

Tyrone Forman, PhD, is a professor at the University of Illinois at Chicago's Department of African American Studies. His profile provides an overview of his research, publications, and expertise in racial and ethnic relations, urban sociology, and social inequality, particularly focusing on issues of race and education.

[Henrika McCoy, PhD](#)

Henrika McCoy, PhD, is a faculty member at the University of Illinois at Chicago's School of Social Work. Her profile showcases her research interests, publications, and expertise in the areas of mental health, child welfare, and trauma, with a focus on addressing disparities in healthcare and social services.

[Branden McLeod, PhD](#)

Branden McLeod, PhD, is a faculty member at the University of Illinois at Chicago's School of Social Work. His profile highlights his research, publications, and expertise in the areas of racial and social justice, community organizing, and urban policy, with a focus on addressing poverty and social inequality.

[Lisa Sharp, PhD](#)

Lisa Sharp, PhD, is a faculty member at the University of Illinois at Chicago's College of Nursing. Her profile provides information about her research interests, publications, and expertise in the areas of community health, health disparities, and health promotion, with a focus on vulnerable populations.

[Karriem Watson, DHSc](#)

Karriem Watson, DHSc, is a staff member at the University of Illinois at Chicago's College of Medicine. His profile highlights his work in community engagement and health equity, with a focus on improving health outcomes in underserved communities through community-based research and interventions.

[Shannon Zenk, PhD](#)

African American Populations Toolkit

Shannon Zenk, PhD, is a faculty member at the University of Illinois at Chicago's College of Nursing. Her profile showcases her research, publications, and expertise in the areas of health disparities, social determinants of health, and healthcare access, with a focus on understanding and addressing disparities in urban environments.

B. Northwestern

[Edith Chen, PhD](#)

Edith Chen, PhD, is a faculty member at Northwestern University's Department of Psychology. Her profile provides an overview of her research interests, publications, and expertise in the field of psychobiology, with a focus on how stress and adversity influence physical health and well-being across the lifespan.

[Kiarri Kershaw, PhD](#)

Kiarri Kershaw, PhD, is a faculty member at Northwestern University's Feinberg School of Medicine. Her profile highlights her research interests, publications, and expertise in the areas of cardiovascular disease prevention, health disparities, and community-based interventions, with a focus on promoting healthy lifestyles in low-income and minority populations.

[June McKoy, MD, JD](#)

June McKoy, MD, JD, is a faculty member at Northwestern University's Feinberg School of Medicine. Her profile showcases her expertise in geriatric medicine, health services research, and healthcare policy, with a focus on improving healthcare delivery and outcomes for older adults.

[Adam Murphy, MD](#)

Adam Murphy, MD, is a faculty member at Northwestern University's Feinberg School of Medicine. His profile highlights his research and clinical work in the field of urology, with a focus on prostate cancer, health disparities, and patient-centered care.

[Mary Pattillo, PhD](#)

Mary Pattillo, PhD, is a faculty member at Northwestern University's Department of African American Studies. Her profile showcases her research and teaching interests in the areas of urban sociology, race and ethnicity, and social inequality, with a focus on understanding the dynamics of poverty and urban communities.

[Lincoln Quillian](#)

Lincoln Quillian is a faculty member in the Department of Sociology at Northwestern University. His profile highlights his research interests and publications in the areas of racial and ethnic inequality, neighborhood effects, and urban sociology, with a focus on understanding the social processes that contribute to disparities in housing, education, and employment.

[Celeste Watkins-Hayes](#)

Celeste Watkins-Hayes is a faculty member in the Department of African American Studies at Northwestern University. Her profile showcases her research and expertise in the areas of HIV/AIDS, poverty, and social policy, with a focus on understanding the experiences and resilience of individuals and communities affected by these issues.

African American Populations Toolkit

C. University of Chicago

[Alida Bouris, PhD](#)

Alida Bouris, PhD, is a faculty member at the University of Chicago's School of Social Service Administration. Her profile provides information about her research interests, publications, and expertise in the areas of adolescent health, HIV prevention, and LGBTQ+ youth, with a focus on developing interventions to improve their health outcomes.

[Waldo Johnson, Jr., PhD](#)

Waldo Johnson, Jr., PhD, is a faculty member at the University of Chicago's School of Social Service Administration. His profile highlights his research and expertise in the areas of school-based interventions, child and adolescent mental health, and the role of social support networks in promoting well-being among vulnerable populations.

[Stuart Michaels, PhD](#)

Stuart Michaels, PhD, is an expert affiliated with the National Opinion Research Center (NORC) at the University of Chicago. Stuart is a key contributor to the study of gender, sexuality, and health at NORC. He has over 30 years of experience developing, designing, and analyzing surveys and qualitative interviews with a primary substantive focus on sexual orientation and gender identity and health outcomes across the life-course. His profile highlights his expertise in survey research methods and public opinion research.

[Doriane Miller, MD](#)

Doriane Miller, MD, is a physician associated with the University of Chicago Medicine. Dr. Miller has been providing care to under-served minority populations for more than 20 years. In addition to her role as a primary care physician, she has a special interest in behavioral health. Under her leadership, physicians, educators and community members work to improve population health outcomes for residents on the South Side of Chicago through community-engaged research, demonstration and service models.

[Monica Peek, MD](#)

Monica Peek, MD, is a physician affiliated with the University of Chicago Medicine. Dr. Peek specializes in general internal medicine and preventive health for adults. She has a particular interest in reducing health care disparities and concentrates these efforts on diabetes care and breast cancer-screening education for African American patients.

[Dexter Voisin, PhD](#)

Dexter Voisin, PhD, is a scholar associated with the University of Chicago's School of Social Service Administration. His profile showcases his research interests, publications, and expertise. Dr. Voisin focuses on social issues and contributes to the field of social work through research, writing, and the development of interventions and policies aimed at addressing social problems.

IX. Measuring Instruments

A. A Note on Measuring Race and Ethnicity

The US Census Bureau recently announced that the 2020 Census will use a two-question format to ask about ethnicity and race, similar to what was used in the 2010 Census.³¹ However, the ethnic and racial categories in the Census may not provide sufficient levels of detail for some studies, and they may not match people's perceptions of ethnicity and race. The Food and Drug Administration suggests that, when appropriate, more detailed categories can be used. Researchers should take care to ensure the categories can be mapped back onto the standard choices for ethnicity and race.³² An example would be offering the following racial categories in addition to the standards of American Indian or Alaska Native, Asian, Native Hawai'ian or Other Pacific Islander, and White: African American (Black American born in the United States), Black African (Black immigrant from Africa), and Afro-Caribbean (including Haitians).³³ These additional categories would allow for more nuanced analysis but also still align with the general Census category of Black or African American.

B. Other Measuring Instruments

[Acquired Capability for Suicide Scale – Fearlessness about Death \(ACSS-FAD\)](#)

[African American Acculturation Scale – Revision \(AAAS-R\)](#)

[Child Feeding Questionnaire](#)

[Cross Racial Identity Scale \(CRIS\)](#)

[Depression Anxiety and Stress Scales \(DASS-21\)](#)

[Everyday Discrimination Scale](#)

[Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale \(FACIT-Sp\)](#)

[Group-Based Medical Mistrust Scale](#)

[Internalized AIDS-Related Stigma Scale](#)

[Liebowitz Social Anxiety Scale, <https://psychology-tools.com/liebowitz-social-anxiety-scale/>](#)

[Multidimensional Inventory of Black Identity-teen \(MIBI-t\)](#)

[Multidimensional Model of Racial Identity \(MMRI\)](#)

[Multidimensional Scale of Perceived Social Support](#)

[Neighborhood Scales](#)

African American Populations Toolkit

[Pain Intensity Measurement Tools for Children: African-American Oucher Scale, Wong-Baker FACES Scale, and the Visual Analog Scale](#)

[Penn Interactive Peer Play Scale](#)

[Perceived Diabetes Self-Management Scale \(PDSMS\)](#)

[Racial Respect Scale](#)

[Rosenberg Self Esteem Scale](#)

Strengths and Difficulties Questionnaire

- <https://doi.org/10.1097/01.chi.0000159157.57075.c8>
- [http://www.sdqinfo.com/py/sdqinfo/b3.py?language=Englishqz\(USA\)](http://www.sdqinfo.com/py/sdqinfo/b3.py?language=Englishqz(USA))

[Vanderbilt ADHD Diagnostic Parent Rating Scale](#)

³¹ Census Bureau Statement on 2020 Census Race and Ethnicity Questions. (2018 January 26). *US Census Bureau*. Retrieved from <https://www.census.gov/newsroom/press-releases/2018/2020-race-questions.html>.

³² Collection of Race and Ethnicity Data in Clinical Trials: Guidance for Industry and Food and Drug Administration Staff. (2016 October 26). *FDA Office of Minority Health*. Retrieved from <https://www.fda.gov/downloads/regulatoryinformation/guidances/ucm126396.pdf>.

³³ US Census Bureau. (2008 August). 2010 Census Integrated Communications Campaign Plan: The Success of the Census is in Our Hands. Retrieved from https://www.census.gov/2010census/partners/pdf/2010_ICC_Plan_Final_Edited.pdf.

X. Program Announcements for Grants

A. MSI Designation

UIC has been designated as a Minority Serving Institution (MSI) based on its full-time undergraduate enrollment. UIC researchers focusing on Black populations may qualify for special grants and opportunities. See <https://research.uic.edu/research-development-2/resources-diversity-in-research/> for more information.

B. Grant Programs

[The Commonwealth Fund](#)

National Institutes of Health: R21s are listed; links to related R01s can be found on each page. Additional NIH funding opportunities can be found at https://www.nimhd.nih.gov/funding/nimhd-funding/active_foa.html.

[Dissemination and Implementation Research in Health \(R21 Clinical Trial Optional\)](#)

[Health Promotion Among Racial and Ethnic Minority Males](#)

[Health Services Research on Minority Health and Health Disparities](#)

[Reducing Health Disparities Among Minority and Underserved Children](#)

[Patient-Centered Outcomes Research Institute](#)

[William T Grant Foundation: Reducing Inequality Grants](#)

XI. Community Stakeholder Involvement

A. African American Specific Resources

[UIC African American Academic Network](#)

[UIC African American Cultural Center](#)

[UIC Department of African American Studies](#)

B. General Resources for Individuals

[National Institutes of Health – Clinical Research Trials & You](#)

[Research Fundamentals for Activists](#)

[Research Match \(search for clinical trials to join\)](#)

C. General Resources for Organizations

[Assessing your Organization’s Research Environment and Capacity](#)

[Community-Based Participatory Research 101](#)

[Community-Engaged Research Funding & Grantwriting Tips and Strategies](#)

[Community Partner Resources](#)

[Considering and Developing Your Organization’s Research Purpose](#)

[Introduction to Qualitative Research Methods](#)

[Introduction to Research Design](#)

[NIH Biosketch for Community Partner](#)

[Patient and Stakeholder Engagement \(PCORI\)](#)

[University 101](#)

[Center for Clinical and Translational Sciences](#)

- [Recruitment, Retention, and Community Engagement Program](#)

[Clinical Trials Database](#)

African American Populations Toolkit

[A Quick Start Guide to Conducting Community-Engaged Research Southern California Clinical and Translational Science Institute, Office of Community Engagement](#)

[UIC Office of Community Engaged Research and Implementation Science](#)

[UIC Office of Community Engagement and Neighborhood Health Partnerships](#)

African American Populations Toolkit

XII. Team Readiness to Work with Special Populations

A. Cultural competency training

[Cultural Competence Assessment Instrument \(CCAI\)](#)

[National Research and Training Center \(NRTC\) Training and Education: Toolkit and Training on Assessing Cultural Competency in Peer-Run Mental Health Programs](#)

B. Team diversity representation

Making sure that the research team has some representation of the target special population group helps establish trust, understanding, and credibility. For example, when conducting research related to cervical cancer in Roseland, having African American women as team members can help to build trust and understanding between the research team and community members. This step, however, is not sufficient by itself: other efforts described elsewhere in this toolkit should also be used to garner community support and involvement.

C. Implicit-association test (IAT) – Offers a way to probe unconscious biases

[Implicit Association Test \(IAT\)](#)

[Look Different's Implicit Association Tests](#)

[Project Implicit](#)

D. Resources to Evaluate Attitudes Necessary for Working with Black Communities

[Implicit and explicit prejudice](#)

[Multidimensional Racial Attitudes \(CSNP\) Scale](#)

African American Populations Toolkit

Citing the CCTS's Target Population Toolkit

The African American Target Population Toolkit was developed by the UIC Center for Clinical and Translational Science's Recruitment, Retention and Community Engagement Program.

The National Institutes of Health requires that investigators cite the CTSA grant if they used any CCTS services or resources to support their research. The CCTS relies on these citations as a critical performance measure when reporting annual productivity to NIH.

To cite the CCTS, the following text is recommended:

“The University of Illinois at Chicago Center for Clinical and Translational Science is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR002003. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.”

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