

Ethics of research at the intersection of COVID-19 and black lives matter: a call to action

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ABSTRACT

This paper describes how to ethically conduct research with Black populations at the intersection of COVID-19 and the Black Lives Matter movement. We highlight the issues of historical mistrust in the USA and how this may impact Black populations' participation in COVID-19 vaccination trials. We provide recommendations for researchers to ethically engage Black populations in research considering the current context. Our recommendations include understanding the impact of ongoing trauma, acknowledging historical context, ensuring diverse research teams and engaging in open and honest conversations with Black populations to better address their needs. The core of our recommendation is recognising the impact of trauma in our research and health care practices.

The USA has exceeded 400,000 COVID-19-related deaths, 16.8% of which were among Black Americans.^{1,2} While vaccine trials are ongoing, Blacks only account for 3% of enrollees, which may threaten the validity and generalisability of the vaccine trial results.³ Although scientific research is one of the most important ways to advance public health, its success is contingent on the participation of key populations. Vaccine trials with diverse participants are essential to find a medicine that works for all people. Yet fewer than half of Black Americans say they would get a COVID-19 vaccine, compared with 63% of Hispanic people and 61% of white people, according to a December report from the Pew Research Center.⁴ Many Black people say they do not trust the medical establishment because of glaring inequities in modern-day care and historical examples of mistreatment. The spread of misinformation about the vaccine development process has not helped either. Low participation of Blacks in COVID-19 vaccine trials and uptake may have dire consequences for their future health and well-being. Blacks have been disproportionately and negatively impacted by the coronavirus with higher rates of infection, hospitalisation and death in Black communities.¹ In Chicago alone, Black people represent almost 70% of all COVID-19 deaths—more than three times higher than any other racial/ethnic demographic.¹ The factors driving COVID-19 health disparities are complex and include increased vulnerabilities associated with the social determinants of health (ie, discrimination, criminalisation, healthcare access, socioeconomic status, work and housing),⁵ delays in access to testing and treatment in Black communities and structural racism, which has been increasingly linked to morbidity and mortality outcomes among Blacks. These same factors may increase the likelihood that

Black communities will not participate in vaccine trials or agree to be vaccinated, thus, exacerbating existing COVID-19 disparities.

Efforts to diversify participants in COVID-19 vaccine trials and uptake will likely be difficult due to historical mistrust of research among communities of colour, growing scepticism regarding the objectivity of scientific research and weakened trust in institutions of higher education, where most scientific research takes place in the USA. The Black Lives Matter (BLM) movement is demanding a societal reckoning with the racist foundations of this country and the ongoing structural violence that limits the life chances of people of colour. The mission of the BLM global network founded in 2013 is to 'eradicate white supremacy and build local power to intervene in violence inflicted on Black communities by the state and vigilantes'.⁶ Efforts based on the civil unrest and killings of unarmed Black people (eg, George Floyd, Breonna Taylor and Ahmaud Arbery) are the foundation of the current worldwide uprising demanding an end to police brutality and equity for all. Indeed, scientific research is being implicated along with other institutions and structures, such as the police, in failing in their role to 'protect/serve/help' all people. Numerous accounts of historical mistrust underscore the urgency of work needed to encourage Black people to feel confident in the medical establishment.^{7–10} Understandably so—unethical research practices over many years, combined with persistent health disparities and lack of access to effective treatments for Black people, discourage the very groups most in need of new innovations from receiving them.

A historical mistrust of research by Black communities stems from the heinous abuse of Black bodies in clinical trials in the USA. Furthermore, Black communities have endured the burden of excess deaths from health disparities for generations.⁷ Several examples underscore this reality. In the 19th century, the 'father' of modern gynaecology, James Marion Sims, developed surgical techniques to improve women's reproductive health, but these were derived from research conducted on enslaved Black women without their consent or the use of anaesthesia.⁸ The Tuskegee Syphilis study that began in 1932 lasted until 1972 after it was leaked to the press that impoverished Black men enrolled in the clinical study were allowed to needlessly suffer and die long after a cure was found.⁹ It is now widely recognised that the Tuskegee experiment was highly unethical. Finally, in 1951, Henrietta Lacks' trust was betrayed by the medical system when her cervical cells were removed from her body and stored without her knowledge or permission and



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used to develop the polio vaccine due to their ‘immortality’.¹⁰ The Tuskegee study and the story of Henrietta Lacks reveal the depths of structural racism in this country and its foundation in the US healthcare system. Institutional Review Boards were formed partially in response to the Tuskegee study. While formal abuses in research have been significantly reduced, maltreatment in the healthcare setting persists.

Importantly, racist policies and modern-day medical practices continue to harm Black communities. In 2020, Black mothers in the USA had the highest mortality rates postpartum, three times higher than white women.¹¹ Maternal mortality has been attributed to institutional racism in that healthcare professionals fail to listen or believe mothers when they report a problem during childbirth.¹² Similarly, grave disparities in how doctors treat pain in Blacks exist, including Black children.^{13–15} Racist and stereotypical beliefs by healthcare providers are implicated in these disparities and can be traced back to slavery, whereby violence against Black people was justified by a false belief that Blacks had a greater pain tolerance due to thicker skin.¹⁴ The persistence of these false beliefs was documented as recently as 2016 in a study of white medical students.¹⁵

Ongoing structural racism and mistrust of the USA medical establishment, particularly in the face of COVID-19 disparities and BLM, continue to traumatise and retraumatise Black individuals.^{6,7} COVID-19 has produced disproportionate rates of unemployment, mental health issues and death in Black communities, and while the BLM movement has reignited a desire to fight for Black human rights, it has also ‘reopened psychosocial wounds’ reminding people that Black lives are devalued and expendable.¹⁶ The media’s constant bombardment of images of Black people being killed reinforces a sense of vulnerability, lack of protection and safety, which triggers fears of the future. The BLM movement has brought to light the blatant racism, discrimination and prejudice Blacks face and the ways in which these circumstances create roadblocks to education, impede healthcare and economic opportunities and contribute to mental health problems. We must ask ourselves, why should Black people trust that involvement in scientific research will benefit them?

As scientists who are committed to bettering the lives of Black people and reducing health disparities, our job is to conduct research that drives effective interventions and prevention programmes. Yet, as academics, we must also acknowledge the tensions between the power of research to improve health inequalities and mistrust among Black populations and ourselves in the ‘institution of science’. Currently, the National Institutes of Health funding to study COVID-19, including community engagement, is being given to those who already have proven track records with funding, a predominately white contingent; reducing the likelihood of Blacks receiving federal funding for their research.^{17,18} This means that researchers with the most experience and knowledge of disparities and sociocultural factors related to research participation will again be absent from the table. Funding whites to conduct research with Black populations may further perpetuate misunderstanding of why Blacks would not participate in research trials and take the vaccine. We have been asking ourselves whether it is ethical to engage vulnerable populations in research? Is it ethical to recruit those who are disproportionately impacted by COVID-19 and continuously devalued and victimised by science and other socially sanctioned institutions (ie, government, police, hospitals)? And yet, what are the public health costs of not pursuing research with Black communities with whom we are deeply invested?

Clearly, it is important to continue research with Black communities, but with new standards. Fully understanding

the intersection of BLM, COVID-19 and historical trauma, researchers must be explicit in strategies to avoid retraumatizing or perpetuating violence of Black lives as disposable at every point of the research process. Furthermore, it will also require research institutions to change how we engage Black populations, commit resources to diversify our workforce and enact antiracist programmes/policies, to foster greater sensitivity to these issues. Against this backdrop and in the context of a global health pandemic and civil unrest, academics of colour are also experiencing heightened levels of mistrust. The intersections of COVID-19 and BLM have triggered a critical self-examination among academics of colour who engage vulnerable populations in research and begs the question: How do we implement research with care and minimise retraumatization of Black people?

We have three recommendations for researchers to ethically engage Black populations in research. First, researchers must acknowledge and understand the ongoing impact of current and historical trauma, enacted by the medical establishment and research, on Black lives. The Tuskegee study was a clinical trial that enrolled vulnerable Black men and led to many unwarranted deaths because a cure, penicillin, was withheld by ‘trusted’ medical professionals. By asking Black communities to once again participate in clinical trials, we risk retraumatizing individuals if we fail to address them properly. Traumatic life events (ie, racism, discrimination, death) can be triggered by healthcare experiences as well as education, corrections, child welfare and government systems.¹⁹ Trauma may limit participation in research, but it may also be a point of connection for Black people. As researchers, we must acknowledge sources of ongoing harm and excess deaths, and that trauma compounds the emotional pain, physical illness, economic hardship and injustice Black communities continue to endure.⁷ Using a trauma-informed lens (ie, recognising the impact and symptoms of trauma and understanding potential paths to recovery) and culturally safe, research methods that respect Black peoples’ lived experiences can provide the confidence and trust needed to engage in research. In addition to understanding trauma, we must be explicit about addressing it in our research. For example, we must ensure that our research settings are both emotionally and physically safe (ie, by asking questions regarding safety, listening and centring participant experience). We must be transparent about our research by ensuring that the informed consent process is clear and understood by various literacy levels. Mixed method approaches (ie, open-ended questions and interviews) can capture the voices and lived experiences of Black people, providing much needed context of findings based on quantitative data. Offering a safe space for participants to discuss their trauma can empower Black people, as their narratives have often been silenced, ignored or delegitimised. In response to participants sharing their trauma, researchers should be prepared to provide mental health resources and to assist with linkages to care. Researchers must collaborate with mental health professionals to aid in providing trauma-informed care as needed. We must also be intentional about who is on our research teams by ensuring they are representative of the population and properly trained in antiracist thinking, cultural safety and/or implicit bias. If we truly aspire to create a physically safe environment, we need to have diverse teams of clinical researchers representing the patients they treat.

Second, research interventions should acknowledge the historical context of Black participants’ experiences and address it directly where possible. Researchers must understand that racism is embedded in our country’s structures and systems and

contributes to health disparities. A parallel between historical USA events (World War I, Red Summer and Civil Rights Movement) and present-day circumstances (COVID-19, BLM movement) is evident; in both, Black people are disproportionately impacted and have been left traumatised.⁶ This historical perspective should trigger explicit reflection of researchers regarding sampling. We must take intentional steps to avoid repeating historical atrocities, and instead, use our unique platform to help support, protect and empower Black communities. Research should challenge and counter stereotypical narratives that criminalise Black communities and highlight strengths, contributions and voices of Black people. Finally, sharing research findings with communities will facilitate trust and encourage input and insight into interpreting the results. For example, now that COVID-19 vaccines have been approved, it will be important to ensure equitable access and prioritise communities most at need.³ While healthcare providers were among the first to be vaccinated, more vulnerable populations of health workers (ie, home health aides), who do not have access to PPE, may not be considered to be 'essential'.²⁰ Blacks are more likely to be concentrated in lower status positions, such as home health aides, in the healthcare work force and maybe systematically left out of the equation for the first round of vaccines.

Finally, researchers must engage in open and honest conversations with Black participants about how they feel participating in research during the COVID-19 pandemic, including the risks, strengths and barriers. Then, researchers must listen, adjust timelines, protocols and objectives based on the information provided. We must reconsider how to implement our research to minimise the risks and maximise the benefits. For example, concerns already exist regarding vaccine uptake among individuals from racial and ethnic minority groups. While it is critical to evaluate vaccine efficacy across populations, Blacks will be understandably dubious to enrol. Programmes that promote vaccines must build on pre-existing researcher/community-based partnerships, engage trusted community leaders to message their importance and employ Black researchers and staff from the communities where people live and work. Studies show that individuals are more likely to adopt behaviours promoted by people indigenous to their community.²¹ Hence, vaccine success will depend on whether members of Black communities deem them safe and effective, and if they believe the institution (ie, colleges, hospital and clinics) delivering the vaccines are trustworthy and care about their needs.³

Racial disparities and structural racism exist in the healthcare system, and academic researchers must take action now to avoid previous mistakes, ensure safety and change the future trajectory of scientific engagement by Black populations. The core of our recommendations is the recognition of the impact of trauma in our research, care and practices. In order to protect Black populations engaging in research, we must acknowledge our history of maltreatment and racism, incorporate Black voices, experiences and perspectives and be intentional about the purpose of our research. Now is the time to regain Black Americans' trust in research and the healthcare system.

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REFERENCES

- 1 APM RESEARCH LAB STAFF. The color of coronavirus: COVID-19 deaths by race and ethnicity in the U.S. Available: <https://www.apmresearchlab.org/covid/deaths-by-race> [Accessed 16 Sep 2020].
- 2 New York Times. U.S. coronavirus cases top 6 million. Available: <https://www.nytimes.com/2020/08/30/world/coronavirus-covid.html> [Accessed 08 Sep 2020].
- 3 Warren RC, Forrow L, Hodge DA, et al. Trustworthiness before Trust - Covid-19 Vaccine Trials and the Black Community. *N Engl J Med* 2020;383(22):e121.
- 4 Funk C, Tyson A. Intent to Get a COVID-19 Vaccine Rises to 60% as Confidence in Research and Development Process Increases. Available: <https://www.pewresearch.org/science/2020/12/03/intent-to-get-a-covid-19-vaccine-rises-to-60-as-confidence-in-research-and-development-process-increases/> [Accessed 03 Dec 2020].
- 5 Centers for Disease Control and Prevention. Health Equity Considerations & Racial & Ethnic Minority Groups, 2020. Available: https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/race-ethnicity.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fneed-extra-precautions%2Fracial-ethnic-minorities.html
- 6 McCoy H. Black lives matter, and Yes, you are racist: the parallelism of the twentieth and twenty-first centuries. *Child Adolesc Social Work J* 2020;37(5):463–75.
- 7 Cooper L, Williams D. Excess deaths from COVID-19, community bereavement, and restorative justice for communities of color. Available: https://jamanetwork.com/journals/jama/fullarticle/2771762?guestAccessKey=9ed4105b-d5f0-4566-9311-dfabfa638394&utm_source=silverchair&utm_medium=email&utm_campaign=article_alert-jama&utm_content=ol&utm_term=101220 [Accessed 12 Oct 2020].
- 8 Wall LL. The medical ethics of Dr J Marion Sims: a fresh look at the historical record. *J Med Ethics* 2006;32(6):346–50.
- 9 Frakt A. Bad medicine: the harm that comes from racism, 2020. Available: <https://www.nytimes.com/2020/01/13/upshot/bad-medicine-the-harm-that-comes-from-racism.html>
- 10 Stump JL. Henrietta lacks and the HeLa cell: rights of patients and responsibilities of medical researchers. *Hist Teach* 2014;48(1):127–80.
- 11 Melillo G. Racial disparities persist in maternal morbidity, mortality and infant health. Available: <https://www.ajmc.com/view/racial-disparities-persist-in-maternal-morbidity-mortality-and-infant-health> [Accessed 13 Sep 2020].
- 12 Chuck E. The U.S. finally has better maternal mortality data. Black mothers still fare the worst. Available: <https://www.nbcnews.com/health/womens-health/u-s-finally-has-better-maternal-mortality-data-black-mothers-n1125896> [Accessed 29 Jan 2020].
- 13 Tamayo-Sarver JH, Hinze SW, Cydulka RK, et al. Racial and ethnic disparities in emergency department analgesic prescription. *Am J Public Health* 2003;93(12):2067–73.
- 14 Warraich H. Racial disparities seen in how doctors treat pain, even among children. Available: https://www.washingtonpost.com/health/racial-disparities-seen-in-how-doctors-treat-pain-even-among-children/2020/07/10/265e77d6-b626-11ea-aca5-ebb63d27e1ff_story.html [Accessed 11 Jul 2020].
- 15 Hoffman KM, Trawalter S, Axt JR, et al. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proc Natl Acad Sci U S A* 2016;113(16):4296–301.
- 16 Jaye L. Why race matters when it comes to mental health. Available: <https://www.bbc.com/future/article/20200804-black-lives-matter-protests-race-mental-health-therapy> [Accessed 11 Aug 2020].
- 17 National Institutes of Health. Nih funds community engagement research efforts in areas hardest hit by COVID-19. Available: <https://www.nih.gov/news-events/news-releases/nih-funds-community-engagement-research-efforts-areas-hardest-hit-covid-19> [Accessed 16 Sep 2020].
- 18 National Institutes of Health. Research topic contributes to persistent gap in NIH research grants to black scientists. Available: <https://www.nih.gov/news-events/news-releases/research-topic-contributes-persistent-gap-nih-research-grants-black-scientists> [Accessed 09 Oct 2019].
- 19 Shimmin C, Wittmeier KDM, Lavoie JG, et al. Moving towards a more inclusive patient and public involvement in health research paradigm: the incorporation of a trauma-informed intersectional analysis. *BMC Health Serv Res* 2017;17(1):539.
- 20 Cahan E. Most Home Health Aides 'Can't Afford Not to Work' — Even When Lacking PPE. Available: <https://khn.org/news/mostly-poor-minority-home-health-aides-lacking-ppe-share-plight-of-vulnerable-covid-patients/> [Accessed 16 Oct 2020].
- 21 Sankaré IC, Bross R, Brown AF, et al. Strategies to build trust and recruit African American and Latino community residents for health research: a cohort study. *Clin Transl Sci* 2015;8(5):412–20.