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

Natasha Crooks, Geri Donenberg, Alicia Matthews

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.5 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),6 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’.4 Efforts based on the civil unrest and killings of unarmed Black people (eg, George Floyd, Breonna Taylor and Ahmaud Arbrey) 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...
used to develop the polio vaccine due to their ‘immortality’.

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. 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. Similarly, grave disparities in how doctors
treat pain in Blacks exist, including Black children. 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. The
persistence of these false beliefs was documented as recently as
2016 in a study of white medical students.

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 indivi-
duals. COVID-19 has produced disproportionate rates of
unemployment, mental health issues and death in Black commu-
nities, and while the BLM movement has reignited a desire to
fight for Black human rights, it has also ‘reopened psychoso-
cial wounds’ reminding people that Black lives are devalued and
expendable. 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, discrim-
ination 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. 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 popu-
lations 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 vulner-
able 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 retraumatising
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 popula-
tions, 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 popu-
lations in research and begs the question: How do we imple-
ment research with care and minimise retraumatisation 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 retraumatising
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. Trauma may limit participa-
tion 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. 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 trans-
parent 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 quantita-
tive 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 partic-
ipants 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 profes-
sionals 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


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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. This historical perspective should trigger explicit reflection of researchers regarding the communities where people live and work. Studies show that individuals are more likely to adopt behaviours promoted by social and ethnic minority groups. While it is critical to understand and address these disparities, it is equally important to ensure equitable access and prioritise communities most in need. 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’. Blacks are more likely to be concentrated in lower status positions, such as home health aides, in the healthcare workforce and may systemically left out of 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. 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.

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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**ORCID iD** Natasha Crooks http://orcid.org/0000-0003-0178-2844