

# “Black Lives Matter and Black Research Matters”: the African Society of Human Genetics’ call to halt racism in science

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**ABSTRACT** The African Society of Human Genetics (AfSHG) was formed to provide a forum for human genetics and genomics scientists in Africa to interact, network, and collaborate. This is critical to facilitate development of solutions to the public health burden of many rare and common diseases across the continent. AfSHG fully supports the Black Lives Matter movement, which is dedicated to fighting racism and ensuring that society values the lives and humanity of Black people. The AfSHG would like to add its “voice” to the public outcry against racism sparked by George Floyd’s death and to declare its commitment to ensuring that injustice and systematic racism, as well as abuse and exploitation of Africans and their biological material, are no longer tolerated. This is particularly relevant now as African genomic variation is poised to make significant contributions across several disciplines including ancestry, personalized medicine, and novel drug discovery. “Black Lives Matter and Black Research Matters” is AfSHG’s call for the global community to support halting, and reversing, the perpetuation of exploitation of African people through neocolonial malpractices in genomic research. We also propose five key ways to curb racism in science, so that we can move forward together, with a common humanity, collectively embracing scientific endeavors.

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Abbreviations used: AfSHG, The African Society of Human Genetics; GWAS, Genome-Wide Association Study; H3Africa, Human Heredity and Health in Africa Consortium; NIH, National Institutes of Health; WHO, World Health Organization.

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The African Society of Human Genetics (AfSHG; <https://www.afshg.org/>) was established in 2003 after consultation with African and international researchers (Rotimi, 2004). AfSHG's goals are focused on education, networking, collaborations, and building capacity to undertake human genetics research in Africa. In addition to individual members from Africa and the diaspora, as well as non-African scientists with an interest in African genomic research, AfSHG is made up of member societies from Cameroon, the Democratic Republic of Congo, Egypt, Mali, Morocco, Rwanda, Senegal, South Africa, and Tanzania. The members meet annually and host conferences to promote career development of young investigators and support African-led research in genomics and related fields. While AfSHG has influenced the research agenda in Africa, by and for Africans, the society acknowledges that its endeavor does not occur in a vacuum and thus it affirms the recent global outcry against racism sparked by George Floyd's May 2020 death in the United States (Medicine and medical science, 2020). Therefore, AfSHG is committed to addressing injustice and systematic racism affecting people of African ancestry, and minority groups globally, in science and society at large.

Modern apologists for colonialism and imperialism, despite their perpetuation of racism, tend to find justification in the moral duty to distribute "the gracious gift of Science" from the West. Also, sadly, the African continent has a long-standing legacy of "helicopter research" and exploitation where overseas researchers collect and ship African biological samples out of the continent with no direct benefit to the study participants or to African researchers. As an example, in 2011 most published research using DNA samples collected in Cameroon from Cameroonians included no African institutions or authors and largely lacked approvals from African ethics review boards (Wonkam *et al.*, 2011). Such activities perpetuate scientific imperialism, sometimes in the guise of tackling global public health emergencies including the collection and removal of Ebola samples from the continent (Schroeder *et al.*, 2018). Furthermore, current genomic research on the African continent is largely defined by external funding and research agendas that may not reflect the current needs of the continent (Hedt-Gauthier *et al.*, 2019). Additionally, the lack of local opportunities, funding, mentorship, and investment in research has led to a "brain drain" when African researchers are enticed out of the continent to pursue careers in more affluent parts of the world. "I can't breathe..." is a sentiment shared by numerous young Africans who, stifled by a lack of prospects, are forced to leave the continent. Those who remain are subjected to prejudices, such as limited access to external funding sources (Ginther *et al.*, 2011) and limited opportunities to publish in major international journals due to "editorial and reviewer racism" (where manuscripts could be rejected based on the affiliation of the authors and not always on the quality of the science).

AfSHG strongly condemns these practices and supports the need to dismantle colonial behaviors that have plagued the African continent for too long, resulting in exploitation of African peoples and their biological material. We recognize that, following the murder of George Floyd in 2020, waves of anti-racism statements have been published by funding agencies, publishers, scientific journals, and academic institutions in support of eliminating racism in science. However, this has not often been followed by measurable actions. Therefore, some solutions are put forward here as a way to start these discussions in the broader research community. First and foremost, what is urgently needed is an equitable and ethical inter-continental collaboration framework. This is, of course, possible only with appropriate support from national and international funders, African governments, private charities, and industry. In fact, a mutu-

**BOX 1: Five key points toward addressing, racism and exploitation in science/genomics in Africa.**

- Framework for equitable access to opportunities for African and all researchers, including editorial and publishing guidelines, adopted by national and international funding agencies, publishers, African governments, and international organizations such as the WHO, private charities, and industry.
- Promotion and implementation through the African Union of African-led and African-funded research in human genetics to:
  - Defeat helicopter/imperialistic research
  - Halt unethical research practices
  - Promotion of community engagement and benefit sharing
- Fostering pan-African academic mobility and research networking through supporting young investigators for professional societies such as AfSHG and establishing diplomatic passports for scientists.
- Developing processes for deconstructing and debating the decolonization of science, for example, with the inclusion in academic curricula the contributions of African and all civilizations in science.
- Developing paths for recognition of malpractices of the past and present by global institutions and processes for repairing the harm caused, including returning scientific artifacts "stolen" from Africa during colonial times.

ally beneficial partnership between the AfSHG, the National Institutes of Health (NIH), and Wellcome led to the establishment of the Human Heredity and Health in Africa Consortium (H3Africa) (Rotimi *et al.*, 2014). H3Africa and other similar initiatives prove that creating opportunities reveals talents and could potentially contribute to decreasing the stigma and prejudice endured by both Africans on the continent and those in the diaspora largely as a consequence of Africa's colonial and slavery legacy. Currently, H3Africa supports more than 50 African-led projects that are addressing diseases relevant to Africa but that are often disregarded by the global research community (Rotimi *et al.*, 2014). Importantly, such initiatives have a high likelihood of reversing the limited representation of African genomic data in public databases, which is a travesty because it is widely acknowledged that public availability of large-scale African data will accelerate understanding of African genomes and potentially contribute to better health not only for Africans but for all global populations (Choudhury *et al.*, 2020). Such data sharing should go hand in hand with plans to promote benefits to participating communities (Ramsay, 2022).

Moreover, commercialization of genomic research products needs appropriate regulation now more than ever as African genomes are likely to become central to major health-related discoveries (Wonkam *et al.*, 2022). Hastiness to once more exploit this unique resource has contributed to legal challenges for an "African" Genome-Wide Association Studies (GWAS) DNA chip that was developed by a company that lacked sufficient engagement with key stakeholders (Stokstad, 2019). Africans are not leading the selection of Africa's research agendas. Therefore, neoimperialism and racism in science, which could divide an already fragile African scientific community, should be prevented as they could derail African-led research efforts (Nordling, 2014). We acknowledge that

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Ambrose Wonkam is a professor of genetic medicine and the director of the McKusick-Nathans Institute and the Department of Genetic Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland. He is also director of GeneMAP (Genetic Medicine of African Populations) at the Faculty of Health Sciences, University of Cape Town, South Africa.

After Medical Doctor training from the Faculty of Medicine and Biomedical Sciences, University of Yaoundé (Cameroon), he completed a thesis in medicine/medical sciences at the University of Geneva (Switzerland) and a PhD in human genetics (University of Cape Town, South Africa). He also trained as a specialist medical geneticist at the University of Geneva (Switzerland). He subsequently has practiced medical genetics in both European and African contexts.

His research interests are reflected in more than 190 peer-reviewed publications. His research focuses on 1) Genomics modifiers of sickle cell disease (SCD); 2) Genetics of hearing loss, and 3) Ethical and educational issues in human genetics in Africa. Over the past 10 years, Prof. Wonkam has successfully led numerous NIH- and Wellcome Trust-funded projects, accounting for about 20 million USD. His research projects span several countries across Africa (Tanzania, Cameroon, Nigeria, Zimbabwe, Zambia, Uganda, Mali, Sudan, Rwanda, and Ghana).

Prof. Wonkam is the president of the African Society of Human Genetics, the chair of the steering committee of H3 Africa, a board member of the International Federation of Human Genetics Societies, a steering committee member of the Global Genetic Medicine Collaborative (G2MC), and a faculty scholar of the Human Genome Organization (HUGO). Furthermore, he is associate editor of the *American Journal of Human Genetics*, the *American Journal of Medical Genetics*, and the *Journal of Community Genetics*, academic editor of *PLoS One*, and a member of the editorial board of *Human Genetics*.

He was awarded the 2003 Denber-Pinard Prize for the best thesis from the Faculty of Medicine, University of Geneva, Switzerland, won the very competitive Clinical Genetics Society International Award for 2014 from the British Society of Genetic Medicine, the 2021 Alan Pifer Award from University of Cape Town, and the 2021 MRC South Africa Gold Scientific Merit Award for the excellence of his research.

scientific exploitations not only are specific to the African continent but are experienced by other marginalized populations such as the American Indigenous community (Tsoie *et al.*, 2021). Additionally, another important factor is decolonization of the academic curricula as highlighted by recent students' protests in South Africa (Nordling, 2019). To reduce stigma and bias, contributions of Africans to science need acknowledgment; for example, Imhotep, the "real father

of medicine," was from ancient Egypt, but this fact as well as numerous others is not included in academic curricula. Indeed, >2000 years before Hippocrates, Africans from Egypt were the first civilization known to have an extensive study of medicine and to have left behind written records of its practices and procedures. For instance, the Ebers Papyrus, 1550 B.C., among the oldest preserved medical documents, describes the treatment of diabetes mellitus in this way: "to eliminate urine which is too plentiful," the following mixture was prescribed: "A measuring glass filled with water from the bird pond, elderberry, fibres of the asit plant, fresh milk, beer-swill, flower of the cucumber and green dates."

In conclusion, AfSHG fully supports the Black Lives Matter movement and cannot remain silent to injustices toward people of color and other marginalized communities. We can all either continue to "bury our heads in the sand" and ignore these practices or we can acknowledge the systemic and deeply ingrained racism that is entrenched in the way we practice science. AfSHG is contributing to turning the "brain drain" to "brain gain," with the involvement of numerous scientists from the African diaspora and support from several non-African scientists who have an aligned vision to strengthen research capacity in Africa. AfSHG calls upon the global community to support its call toward halting, and reversing, the perpetuation of exploitation of African people through neocolonial malpractices in genomic research and proposes key ways to curb racism in science and society, so that our common humanity prevails, enabling us to move forward, hope, breed, and live together (Box 1). Notably, Black Research Matters as much as Black Lives Matter.

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