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Mayowa Adegboyega
Duke University

Xinjun Zhang
University of Michigan

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Ethics and Best practices of studying contemporary human populations

Mayowa Adegboyega^{1*\$}, Xinjun Zhang^{2,3\$}

1. Department of Biological Anthropology, Duke University
2. Department of Human Genetics, University of Michigan Medical School
3. Department of Ecology and Evolutionary Biology, University of Michigan

*Address correspondence to: mayowa.adegboyega@duke.edu

\$These authors contributed equally to this manuscript

October 04, 1951, Johns Hopkins Hospital in Baltimore, Maryland: On this day, a young female patient named Henrietta Lacks was succumbing to a ravaging cervical cancer. Unbeknownst to the 31-year-old mother of five, a sample of her cancer cells were involuntarily taken from her. These cells grew and multiplied *in vitro*, and later got distributed worldwide in cancer biology laboratories where they continue to be used. Henrietta's cells—better known as the *HeLa* cells—have enabled numerous biomedical research and drug developments to date. However, most troublingly, neither Henrietta nor the Lacks family were informed about the cell line until decades later, meaning that consent was never obtained to take parts of her body nor to use it in countless procedures and scientific undertakings (2018).

The story of *HeLa* cells revealed just the tip of the iceberg of the ethical quandaries revolving around studies using contemporary human peoples and populations. Despite our reliance on living participants to pursue important scientific research, formal regulations and legal efforts with obtaining consent and informing effectively remained underdeveloped and underdiscussed. Lately, since the outbreak of COVID pandemics, a rapid increase in studies have been carried out using biological data collected from people of various age groups, genders, country of origin, and infection status. In contrast to the excitement of the prospect of a vaccine and drug, far much less was opined about the ethical complexities involved in studying living humans or about the development and implementation of best practices when people are the subjects of research. This disparity in research priorities was not born of this era. In fact, over the last two decades, with the advent of the genomics era in modern biology research and the

advance in our abilities to process and analyze large datasets of information, the proliferation of research involving contemporary human populations did not lead to a commensurate commitment to addressing the moral and ethical quandaries that presented themselves as a result.

The American Association of Physical/Biological Anthropologists (the former AAPA, now known as the AABA) virtual meeting 2021 in the middle of the COVID pandemic (originally scheduled in-person in Baltimore) enabled an opportunity to restart a conversation regarding the equity and ethics concerns surrounding fieldworks and data analysis that directly involves living human beings and populations around the world. The conversation was led by scholars, scientists, and trainees from the broad biological anthropology research field, who often directly or indirectly engage their studies with the living population. In the *Ethics and Best practices of studying contemporary human populations* symposium, we brought together an interdisciplinary panel composed of thoughtful and forward-thinking experts representing every stage of a scientific career to share with us their insights on the whole field while also drawing specific questions and solutions from genomics, archaeology, biomedical informatics, legal policy, and biocultural studies. Each participant brought their own perspectives and moral considerations about how to handle issues of consent, communication, honor/respect customs, science follow-ups, controversies/complications and more. In this introduction, we summarize the articles and discussions from the symposium. And within this special edition, we present a selection of those articles that demonstrate how biological anthropologists contribute to these important discussions.

George Perry (2021) raised how important it is for biological anthropologists to be upfront and honest with ourselves and with the public about the historical misuses and abuses of our studies of human populations around the world. For centuries, our scientific discoveries have been purposefully or been repurposed to reinforce harmful and prejudiced social practices and attitudes and we must not shy away from this terrible truth. In fact, it is our duty and responsibility to shift the public away from these ideas that have permeated our perceptions of each other, our systems, and our communities for too long. To achieve this ideal, we must first recognize the deep-seated roots of racism, colonialism and sexism within our field and think deeply about the scientific systems under which we formulate our research hypothesis. Then we must take concrete steps to actively avoid introducing those ideas into our work and finally with a new outlook, we must revise and restructure the present training, theories, methodologies and

praxes in Biological Anthropology and science at large.

We are duty bound to respectfully engage with the people and communities in which we base our studies whether they be living or deceased. Unlike many other researchers, our study subjects are our fellow human beings and all the data we collect and analyze can directly impact people's lives. For example, Ripan Mahli (2021) raised the issues with uploading paleogenomic data belonging to Indigenous peoples to open access sites where they can be linked to living people without their knowledge or consent. He and Rick Smith (2021) noted how practices such as these continue the long practice of stripping people of their sovereignty under the guise of scientific advancement. As a solution, Mahli advocated for collaboration with indigenously run Biobanks that are familiar with concerns of people within those communities and are therefore better prepared to facilitate mutually beneficial partnerships between them and the researchers interested in working with them. He also promoted the practice of Biocultural Labels that identify where the data come from along with how it can be used as defined by Indigenous peoples linked to that data.

Michael Edge (2021) and Jennifer Wagner (2021) also emphasized the need to preserve genetic privacy by creating systems to protect not only the individuals who consent to the use of their genetic data in scientific research, but also those with whom they share that data. Most members of the public are not aware about the vulnerabilities they and their families are exposed to when they submit their DNA to researchers or even consumer genetic testing companies therefore, we need to better educate people and think about how we can more responsibly engage with these databases. Edge suggested that scientists adopt collective decision-making approaches to consent, and Wagner reminded us that the redesign of our methods must also address the disproportionate impacts of the loss of privacy on marginalized communities who often have less means of recourse if their data is misused. Wagner and Katrina Claw (2021) further emphasized the need for Biological Anthropologists to engage in the fight for data justice in healthcare. They highlighted the key role we can play in shaping data protocols and research to be more patient or individual centered and to address issues surrounding the underrepresentation of marginalized communities in medical research. Scientific justice is not just in sharing the benefits of research, but in the conduct and determination of what research questions get asked. To this point, Claw and Tina Lasisi (2021) stressed the need for representation not just in the rank-and-file members of research teams, but in the leadership designing and directing those projects. When the

leadership can relate to the lived experience of research participants, they will ultimately be better able to interpret the results they observe in a more authentic and empathetic way. Furthermore, the promotion of diversity and inclusion in our field will push us to reconsider traditional approaches and open us to new and innovative ideas.

Smith noted how public and science discourse has falsely characterized the intersection between the coronavirus pandemic and racial violence as unprecedented whereas marginalized people have long been operating within a historical framework of scientific abuse that continues to inform their decisions in the present. Furthermore, he noted that our conceptions of bioethics are developed within scientific communities, oftentimes ignoring the knowledge of people who experience the abuse. Consequently, we are unable to deal with ideas outside of our frameworks. This has been very noticeable in the development of the concept of informed consent. While many strides have been made in how we obtain permissions to utilize people's data, these systems are ill equipped to deal with refusals. Smith implored us to think about how Black and Indigenous people's refusal to engage with medical and scientific communities are often framed as anti-science, ignoring the histories of abuse that have necessitated that these communities assert their autonomy. Smith further implored us to look at refusals as their own form of knowledge production and to think about how they can help to shape how we propose, formulate, and practice research. Taiye Winful (2021) also asked us to think more deeply about how we construct our bioethical praxis. Using her study of the Institutional Review Board (IRB) processes of two nations—the United States and Nigeria—with quite different histories and relationships with scientific institutions she directed us to think about how ethical research frameworks are developed and how they can evolve. She highlighted how a country like Nigeria whose history with bioethical malpractice has mostly from international medical organizations now focuses on clinical protocols that allow them to reduce their reliance on external organizations while the United States whose history of malpractice has largely been internal has developed a more inwardly facing perspective.

The entire panel and the audience agreed that whatever new ideas and practices we develop must not reside solely within the ivory tower. Disseminating our discoveries to the public must be an integral part of our work. Maria Avila-Arcos (2021) and Robin Nelson (2021) presented studies that highlighted the need to engage with our research participants consistently and continuously. This involves restructuring the relationship between researcher and participant

to be more collaborative, and reporting results and finding back to the participants in a way that considers the specifics of the group, social, political etc. Furthermore, these innovations need to be supported and encouraged with funding, resources, and training by our institutions. Agustin Fuentes, who served as our discussant rounded up the discussion by highlighting the work that has already been done, and the work that is left to do to move our field into a more ethical and just future.

In this special edition, we highlight recent advancement and opinions from biological anthropologists, with the goal to raise awareness in the entire biomedical research field. We hope that by initiating this conversation, we see a long-term discussion and collaborative effort put in practical actions to continuously improve the best practice and ethics of studying contemporary human populations.

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