Dismantling unethical acts of a few neo-colonial bullies in global biomedical research

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On July 29, 2024 – an American collaborator of mine on an intramural NHGRI-funded 'nutrigenomics project' notified me of the decision by NIH not to fund the project if I was part of it.

Supposedly, I had been blacklisted by the Uganda CDC team for my scientific advisory role during the 2022 outbreak of Sudan Ebola virus disease (SUDV). During this outbreak, the Uganda Ministry of Health kicked out CDC and DOD partners from the field – for inappropriate behaviour.

Specifically, through their Ugandan proxies – these teams were entering the Ebola treatment units (ETUs) and bleeding patients without due authorisation or even accountability for where the specimens were headed.

This Safari practice – that happened to an explainable extent during the outbreak of Ebola virus disease (EVD) in West Africa, was not welcome to us. Instead, we preferred an open collaborative framework led by Ugandan scientists collaborating with their American counterparts.

To the bully in the bureaucratic of CDC-Uganda, however, this was not a welcome proposal for two reasons (a) American taxpayers' money was funding the work and (b) American scientists involved were top notch compared to the Ugandan amateurs.

This superiority and self-entitled mentality overlooked the fact that the Ugandan authorities had the ethical, social and legal custody of the biospecimens from these patients.

In this article, I open the lid on the can of worms that has since times immemorial characterised the history of collaborative research between the West and Africa.

In 1984, Nobel Laureate Luc Montagnier described the concept of a 'Safari' kind of research, where researchers from the developed world came to Africa, stayed in fancy hotels, got themselves African puppets to do the dirty job of bleeding their sick colleagues, only for the researchers of the developed world to pack and ship all the biospecimens back to their laboratories in the North.

From these biospecimens, millions of papers would be subsequently published that claim originality and do not acknowledge the contribution of the African puppets.

Further still, discoveries of medicines and diagnostics would be made, that did not factor in the contribution of the research participants who gave the samples for the research. Access to these countermeasures was more or less restricted to the populations of the wealthy countries of the North by exorbitant costs.

On August 1, 2023, the *Conversation* – a US based daily carried an article titled "Settlement with family of Henrietta Lacks is an opportunity to reflect on inequalities in genetic research" wherein the case of the legal battle of the descendants of Henrietta Lacks – an American tobacco farmer who suffered from cervical cancer in 1951 and whose immortalised cells were harvested for research without her consent at John Hopkins in Baltimore, was settled.

ThermoFisher – the company that held rights to the cells was tasked with paying compensation to the surviving relatives of the late Ms Lacks. This story must give us hope. To quote Aileen Editha from Queens University Ontario, "Lacks' story – though seemingly a tale of the past, is well known since it has been popularised in novels and film. Nonetheless, the inequalities suffered by Lacks remain problems of the present. As a legal researcher and woman of colour, I have found that these problems are still alive and kicking today.

Genetic research (and medical practice more generally) is filled with systemic racism, racial discrimination and unconscious biases. For many Black, Indigenous and Peoples of Colour (BIPOCs), the battle for an equitable framework is not over yet."

In the same article above, another case of the Havasupai tribe's lawsuit against the Arizona Board of Regents is narrated.

"Blood samples from the tribe were obtained for research on inherited diabetes. The samples were later unlawfully used for other research, including studies on inbreeding and schizophrenia. This violated the Havasupai's consent agreement and had deeper repercussions, as these topics were considered taboo by the tribe."

This story is very close to what we witness some rogue elements in the friendly partnerships with the American people want to legalise by attacking those who chose to stand up against the unethical practices.

This is probably what the authors of the 'Magnitsky' on my person aimed to do, hoping to intimidate me to coil my tail between my legs. What they did not factor in in their calculations is that I am a free spirited and self-actualised independent academic. During the World Health Summit 2022 held in Berlin Germany between October 16 to 18, Uganda's Minister of Health (perhaps counting on my maturity to address the impasse) appointed me to represent her in discussions with the then sitting overall CDC director Dr Rochelle P. Walensky, where we discussed the unbecoming and unfortunate unethical behaviour of a few actors – bad apples I call them – in the Ugandan CDC directorship then. This must have spiralled a targeted hate campaign against me.

What is not told by the perpetrators of this act, is that as chair of the scientific advisory committee then and interim chair of the research pillar, I had spearheaded a series of meetings during which, we (Ugandan scientists) had met with partners to harmonise how to approach research during the SUDV epidemic. That meeting has since birthed what we have labelled, the Interdisciplinary Consortium for Epidemic Research (ICER) led by Ugandan researchers in collaboration with their global partners.

I write this article as part of my scientific obligation to dismantle neo-colonial mentalities in scientific research. It is a common philosophical adage that 'he who pays the piper decides the tune'.

However, Uganda's and many African countries' biomedical research capabilities and capacities have come of age, and anyone that insists on setting the research agenda for us is rather being short sighted and a bully. Instead, we want to see truly collaborative research that respects not only our autonomy as Ugandan scientists, but that of the patients whose interests we are charged to take care. We are tired of the exploitative, Safari type of research as Prof. Montagnier labelled it.

This does not mean we do not respect or value the contribution of our American colleagues on the other side. However, it is important moving forward, that the few bad apples are who unethically stirred the waters and the villagers wrongly accused all American scientists of being unethical, are duly weeded out. We are not isolated in this fight for autonomy, much as we may be too poor to fully fund our research agenda.

In 2007, the government of Indonesia represented by Health Minister Siti Fadilah Supari refused to share its isolates of H5N1 influenza (bird flu) viruses with WHO, unless WHO guaranteed that they would not share the same with commercial entities without due permission.

The idea was not to halt the sharing of these isolates, but rather set the stage for the upfront negotiation of benefit sharing. And once WHO agreed to the terms, the impasse was resolved.

This must remain a key issue for the deliberation of the pandemic treaty and revised international health regulations (IHR, 2015) to avoid undue exploitation of communities constantly affected by epidemics of dangerous pathogens, by commercial entities.

For example, its unethical when a single vial of a monoclonal antibody cocktail isolated from a Ugandan patient during the 2000 Gulu-Masindi outbreak, is sold back to us for over $10,000; particularly considering that a patient will require about 3-4 vails a day for seven days to be cured of EVD. Where is the contribution of the Ugandan patient from whom this treatment was isolated and how do we account for it moving forward? Benefit sharing negotiations are an indispensable part of the negotiations for open access to data; pathogen isolates and biospecimens. Otherwise, why would America now be imposing data-sharing restrictions on China? Aren't these double standards applied to similar situations?

I pray that the authorities at the US Senate and Congress take this act of unethical behaviour seriously, investigate and resolve the personalised impasse.

The writer is chairperson of Ministry of Health's ministerial scientific advisory committee on epidemics and dangerous pathogens and interim chair of the SUDV epidemic research pillar 2022

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