

## Statement of the African Academy of Sciences' Biospecimens and Data Governance Committee On COVID-19: Ethics, Governance and Community engagement in times of crises

### Introduction

The world is currently facing a novel global pandemic, which has led to an urgent search for solutions, proliferation of research and development activities and ongoing surveillance. Managing emergencies can raise challenging ethical and governance issues for organisations and stakeholders at the forefront of decision-making.

The biospecimens and data governance committee as an advisory committee established by the African Academy of Sciences (AAS) appreciates the need for proper engagement with the relevant stakeholders and communities in these times of emergency. It appeals for a consideration of the following factors to ensure respect for human dignity of the affected community members and citizens of affected countries.

### 1. Community engagement during times of epidemic crises

- 1.1 During epidemic crises, the highest priority must be placed on saving human lives and local communities must be involved in shaping the research agenda and empowered to differentiate between research and treatment, the relative value of research and the importance of free and voluntary participation in research. **Governments and research institutions must invest in building the capacity of organized/existing groups, opinion and religious leaders and the community at large by sensitizing/educating them and identifying issues of concern and effective strategies for addressing any misconceptions, in order to build mutual trust and respect.** Building mutual trust and respect during a crisis such as the COVID-19 pandemic allows citizens to follow guidelines and directives from their governments. Likewise, community engagement allows national governments to listen, reflect on and take appropriate action on the concerns raised by their citizens. This facilitates seamless coordination of activities during the crisis, without which there would be resistance from affected communities ultimately provoking unnecessary force from the state as witnessed in some countries in Africa.
- 1.2 Where urgent decisions that directly affect vulnerable communities are made, organized/existing groups should be engaged in shaping the strategies that inform decision-

#### **Examples of modes of Community Engagement for COVID19:**

*In situations of lockdown traditional face-to face engagement may not be feasible. Community members can be engaged through online survey monkeys and phone interviews about their perceptions and concerns of COVID 19, setting up a freely downloadable and data free phone application for sharing facts from trusted sources to counter myths and misinformation about COVID19, setting up WhatsApp discussion fora, SMSs and recorded messages*

making. In the context of the COVID-19 pandemic, governments and other authorities may decide to relocate the homeless or those living in informal settlements in a bid to curb the spread of the virus. Proper engagement with the communities and organised groups can reassure vulnerable community members that their fears and concerns are addressed.

## 2. Ethics and informed consent in times of crisis

2.1 Times of crisis are challenging, and a lot can go wrong: Important standard operating procedures can be overlooked, resources are usually constrained and there is a lot of anxiety. During such times, the lines between healthcare and research tend to become more blurred. Moreover, populations that were hitherto considered resilient, may be vulnerable. Within the context of provision of care and carrying out research, potential research participants may become desperate for any product brought their way, that provides any kind of hope, oblivious of the products' potential harm or unproven efficaciousness. Furthermore, researchers may be under pressure from donors and influential pharmaceutical companies, to test trial products before the pandemic weans off. While researchers and health providers are expected to always act in the best interest of their patients, pressure to get a scientifically significant sample size may cloud their desire for responsible research practice, and the temptation to bypass standard ethics review procedures and cut corners may just be as overwhelming. In this context, it may be argued that ethics review slows and can be a bottleneck to the process of conducting emergency research.

2.2 We underscore here that ethics review during a crisis like the COVID-19 pandemic is critical to protect highly vulnerable populations from potential harm. On the other hand, **we urge national governments to sufficiently equip and enhance the capacity of their Ethics Review Committees to enable them to conduct rapid ethics review for emergency research to facilitate timely conduct of ethically sound research. We emphasize that the passion and vigour national governments use to promptly establish emergency response teams to guide national and regional response to COVID-19 should be replicated in establishing emergency research ethics committees in every country and in**

### **Examples of Informed Consent models for COVID 19:**

*Given that patients presenting at hospitals and in isolation may be quite ill and not able to give truly informed consent to participate in research context specific models of consent should be used. For example, preliminary consent/ "consent for recontact" can be used. This entails asking patients who are not well enough to consent to provide their contact details, researchers can hold their samples and contact them again in a prudent number of days to discuss whether they would like to participate (at which point: yes=> full informed consent and samples can be used; no => samples immediately destroyed).*

*Where signed consent forms are used, care should be taken to avoid contamination. For example, the participants can sign the forms and keep the pens they used or discard them. The details of the participants should also be separately recorded in parallel in a contamination-free space. The signed consent forms should be carefully placed inside separate sealed Ziplock bags and securely stored for at least 2 weeks before they can be accessed again.*

the region that can be able to review all research proposals within the shortest time possible. Such committees should be equipped with an adequate mix of expertise, resources and technology, including but not limited to an online review system such as RHInno Ethics (<http://rhinno.net>) that can allow members to review protocols remotely, without having to attend face-to-face meetings. Supported by the Community Engagement approaches described above, Informed consent processes should consider the vulnerability of the potential participants and put in place adequate measures to protect them.

### 3. Outbreak Mode Response

3.1 In order to promote best practice during the ongoing public health crisis, adequate preparation is essential. Firstly, a National or regional multidisciplinary team to advise and manage public emergencies should be in place. Secondly, African governments must put in place a public health emergency framework that stipulates what must be done and procedures to be followed during the public health crisis, including to develop a code of conduct to facilitate respectful collaboration and cooperation between stakeholders during the crisis, and to develop a framework for priority-setting at a local level.

3.2 We can try to understand how deferential ethics may apply to routine medical research compared to research during outbreaks caused by high consequence pathogens. During outbreak scenarios which are characterized by chaos and multiple international agency interventions, ethics seems to be relaxed to allow for multiple opportunities for introduction of potential treatment options. During the West African Ebola outbreak which typified the scenario, opportunism was rife. We propose that during such scenarios Ethics needs to be heightened. More ethicists and Data and Safety Monitoring Boards (DSMB) need to

be available to ensure that the participants are not taken advantage of by virtue of the circumstances pervasive during the current COVID-19 outbreak which lacks adequate human and infrastructural resources to cope, and where the outbreak victims are extremely vulnerable due to life-threatening circumstances. Data and specimen governance practices need to be clearly articulated by appropriate authorities.

**Example of clear communication from the government during surveillance to contain the spread of COVID-19:**

*Where data protection laws are in place, the data protection authority or an equivalent authority should provide clear guidance on how stakeholders should implement the laws to ensure the protection of personal data. For example, the South African Information Regulator issued a guidance note on the processing of personal information in the management and containment of COVID-19 pandemic in terms of the Protection of Personal Information ACT 4 of 2013 (POPIA). The note provides guidance to the public and private bodies and their operators on the limitation of the right to privacy when processing personal information of data subjects for the purpose of containing the spread and reduce the impact of COVID-19.*

*Full text of the guidance note is available at [this link](#)*

#### 4. Ethical sharing of data with a view to end the pandemic

4.1 There is differentiation across Africa with regard to our ability to provide appropriate diagnostic capability and analysis of locally generated COVID-19 data. **We call for a Pan-African approach to ensure immediate transfer of skills or to provide support systems to ensure that any locally produced epidemiological data or pathogen genetic data can be rapidly generated and shared. This will shed light on COVID-19 transmission chains and inform government responses.**

4.2 Since the African Center for Disease Control has been encouraging countries, who have the ability, to sequence their own samples, some African countries have already released SARS-COV-2 genome sequences. These positive developments can benefit the continent if we have

a pan-African collective attempt to ensure that every African country can produce local data to inform a local response. This has to be a priority to ensure that we don't resort to importing data from Europe and USA to do our modelling and assume that it will apply to us. A coordinated effort for countries to have clear national plans should be facilitated by the African Union.

#### **Examples of recent SARS-COV-2 genome sequencing:**

*The Democratic Republic of Congo, Nigeria, Senegal and South Africa have released SARS-COV-2 genome sequences.*

*For more information see: The African center for gene technologies,  
<https://www.acgt.co.za/newsroom/uncategorised/africa-contributes-sars-cov-2-sequencing-to-covid-19-tracking/>*

#### The AAS Data and Biospecimen Governance committee.

1. Dr Abdourahmane Sow, West African Health Organization
2. Prof Ambrose Wonkam, University of Cape Town (UCT), South Africa
3. Prof Alan Christoffels, University of Western Cape, South Africa
4. Prof Akinola Abayomi, Nigeria Institute of Medical Research, Nigeria (co-chair)
5. Prof Nicki Tiffin, UCT, South Africa
6. Dr Alia Benkahla, Institute Pasteur, Tunisia
7. Dr Dauda Bege, UPenn, United States of America
8. Francis Kombe, Council on Health Research for Development (COHRED), Kenya
9. Dr Godfrey Tangwa, University of Yaoundé, Cameroon
10. Said Ramadhan, The African Regional Intellectual Property Organization, Zimbabwe
11. Prof Pamela Andanda, University of the Witwatersrand, South Africa (**Chair**)

The AAS Covid-19 team is led by Dr Moses Aloba & Prof Kevin Marsh -  
[covid19team@aasciences.africa](mailto:covid19team@aasciences.africa)

The African Academy of Sciences  
No. 8 Mltoni Lane, Karen | P.O. Box 24916 – 00502 Nairobi, Kenya | Tel: +254 20 896 0674/5

 aasciences | [www.aasciences.africa](http://www.aasciences.africa)