

# Report: Challenges and ethical considerations for research in the context of international public health emergencies



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## Table of Contents

<b><i>Challenges and ethical considerations for research in the context of international public health emergencies. Report from WHO-funded workshops in Guinea</i></b> .....	<b>4</b>
<b>Purpose of the workshops</b> .....	<b>4</b>
<b>History and background</b> .....	<b>4</b>
<b>The Nuffield Council Report</b> .....	<b>4</b>
<b>Structure of the workshops</b> .....	<b>5</b>
<b>The Committees participating in the workshop</b> .....	<b>5</b>
<b>The Guinean infectious disease landscape in February 2021</b> .....	<b>6</b>
<b><i>Outline of workshop findings</i></b> .....	<b>6</b>
<b><i>Reactions to the ethical compass</i></b> .....	<b>7</b>
<b>Power and inequality – national and international research</b> .....	<b>10</b>
<b><i>Appendix A: Conference Schedule</i></b> .....	<b>12</b>
<b><i>Appendix B: Detailed Description of Workshop Discussions</i></b> .....	<b>13</b>

## **Challenges and ethical considerations for research in the context of international public health emergencies. Report from WHO-funded workshops in Guinea**

### **Purpose of the workshops**

The purpose of the workshops was to solicit the expertise of key members of the Guinean scientific research and national public health research ethics committees to:

- Identify and define the most critical COVID-19 related research ethics issues in Guinea
- Explore the relevance of the Nuffield Council on Bioethics' (NCoB's) 'ethical compass' in the identification and resolution of these issues
- Identify additional tools or opportunities for adaptation or capacity building to support the use of the NCoB's compass in Guinea.

### **History and background**

Research into serious infectious disease outbreaks such as pandemics raises challenging ethical questions. These can be particularly difficult where outbreaks occur in resource-poor settings or in regions where local governance is contested or unstable. Where they are not properly addressed, these ethical challenges can lead to serious harm, including violations of fundamental rights and interests. They can jeopardize research and related public health interventions and leave an enduring legacy of mistrust and suspicion. The Ebola virus disease epidemic in West Africa between 2014 and 2016 demonstrated the importance of identifying ethical issues, both when undertaking research and implementing public health measures. It is therefore imperative to develop effective means to ensure appropriate identification and management of ethical challenges connected with research, during outbreaks of serious infectious diseases.

### **The Nuffield Council Report**

In early 2020, the NCoB published a substantive report on ethical issues arising in the context of research projects addressing public health emergencies of international concern. (Dr Sheather, one of the members of the working group behind the NCoB's report helped facilitate the Guinea workshops.) The purpose of the report was to provide ethical guidance for organisations and individuals responding to public health emergencies.

In its report, the NCoB developed an 'ethical compass' composed of three widely held values: equal respect, contribution to the reduction of suffering, and fairness, along with a framework for their interpretation. The compass was designed to help those involved at all levels navigate the ethical challenges posed by research into public health emergencies of international concern. The primary purpose of the meeting was to explore the relevance and value of the NCoB's compass during the Guinean response to COVID-19.

## Structure of the workshops

Two full-day workshops with similar structures were held in Conakry, Guinea on the 17<sup>th</sup> and 18<sup>th</sup> of February 2021. The first workshop involved members of the Guinean National Health Research Ethics Committee (CNERS); the second involved members of the Guinean Scientific Council for the Response to COVID-19 (CRS). There was some overlap in membership between these committees. The workshops were facilitated in Guinea by Oumou Younoussa Bah-Sow, President of the CNERS and professor of pneumonology in the Faculty of Medicine of Conakry, and remotely by Dr Elysée Nouvet, assistant professor in Global Health from the Western University in London, Ontario and Dr Julian Sheather, consultant ethicist from the UK. Simultaneous written translation from French to English was provided by Samara Bengall, research assistant at the Western University; with simultaneous translation from French to English provided by Dr. Nouvet where needed.

Following a presentation to orientate participants to the Nuffield Report and its ethical compass, members of the Ethics Committee on the 17<sup>th</sup> of February and the Scientific Council on the 18<sup>th</sup> of February were separated into groups and invited to identify from a prepared list those ethical issues they found to be particularly urgent in relation to Guinean research into COVID-19 and Ebola virus disease respectively. Members were also invited to comment on ethical challenges not contained in the prepared list. Having identified these key challenges, members were then asked, again in groups, to explore the extent to which the values of the Nuffield compass were relevant both to the Guinean context of health research during COVID-19 and to research into global health emergencies more broadly.

The second part of each day was dedicated to an open exploration of an issue that emerged as central to the Nuffield Council's report: questions of power and inequality both within Guinea and between Guinea and partners and stakeholders from resource-rich, usually Western governments and institutions.

As preparation and background to the workshops, participants were earlier provided with a participant package that included the background to the workshops, the biographies of the facilitators, copies of all discussion questions and the French language 16-page summary of the NCoB's report.

A detailed account of the structure of the discussion and running of the workshops can be found as Appendix A. The outline of the conference introduction and Nuffield report outline can be found as Appendix B.

## The Committees participating in the workshop

The National Health Research Ethics Committee was established in 1998. It is an advisory committee charged with ensuring the scientific and ethical integrity of research in Guinea, notably on issues of public health importance. It is influential and does not hesitate to push back when protocols raise ethical questions, including those from western institutions seeking to

undertake research in Guinea. The Scientific Council for the Response to COVID-19 in Guinea was established in April 2020. Its role is to act as an advisor to the government in the oversight and analysis of epidemiological, biological, clinical, therapeutic, anthropological, economic and environmental aspects of and considerations related to the COVID-19 public health emergency. Each of these national committees include 17 members.

### **The Guinean infectious disease landscape in February 2021**

At the time of the workshops, there was a relatively low incidence of COVID-19 with the average daily report for seven days being in the low forties. Vaccinations with the Russian-produced Sputnik V vaccine had started in December 2020 with a small number individuals (60). Guinea is part of the WHO COVAX initiative and hopes to receive vaccines in the next weeks. Critically, a new Guinean outbreak of Ebola virus disease had been announced on the Saturday prior to the workshops.

### **Outline of workshop findings**

The 2014-2016 Ebola epidemic was a key context and reference point throughout the sessions. It had clearly alerted Guinean officials to areas of critical ethical concern throughout the research lifecycle. Two main foci of concern emerged from the experience with Ebola, foci that engaged all three of the NCoB's ethical compass's principles:

- Ebola was identified as a source of extreme suffering and fear for affected populations. These were exacerbated by a widespread feeling that those affected were shown insufficient respect due to a lack of proper community engagement by the Government and international researchers. Communication regarding infection control strategies and the Government's broader public health strategy was mediocre, particularly in the Forest Region. This led to widespread anger and resistance to public health interventions.
- Ebola exposed Guinea to systematic exploitation by foreign researchers. All research into Ebola in Guinea was funded from overseas and, partly as a result, external researchers retained control. Biosamples disappeared, were stolen, or taken out of country to unknown destinations and for uses that have never been disclosed. Many research teams ignored or circumvented guidance for collaboration with local researchers and the management of locally-sourced biosamples. The benefits to local and affected populations of the research was often either unclear or non-existent. Research goals, topics and protocols were largely set by funders, with the value of the research often flowing out of the country – a problem that continues with COVID-19 research.

As a result of these factors, it became clear that Guinea needed to have more national control and governance over research in general and over research in public health emergencies in particular.

If it is possible to talk about positive outcomes from Ebola, the Guinean response to COVID-19 has been informed by lessons learned during that extremely challenging time. These include:

- The Government has been able to fund some research into COVID-19. Critically, all externally-funded research must align itself with the research agenda set by the Government, although there have been internal political tensions here
- Questions concerning the storage, sharing, ownership and uses of biosamples are firmly on the radar of the Guinean Government’s scientific and research ethics committees (CSR and CNERS). As a result, Guinea is now more successful in ensuring that there are national benefits to any research. Guinea has also been successful in gaining some limited access to COVID-19 vaccines
- Community engagement has been integrated into the COVID-19 research and public health response from the beginning of the pandemic, although strategies have at times been confusing and outcomes mixed. Community distrust can be high, the logic of various public health interventions has not always been transparent, and there is a complex landscape of historical distrust, particularly where overseas researchers or agencies are involved
- International collaborations and partnerships have been fairer, with greater acknowledgment of the critical importance of enabling Guinea to benefit from research, although there is still considerable room for improvement
- Unlike the Ebola outbreak, which was localised, and was often seen by external countries and institutions as a security threat, the COVID-19 pandemic has been an occasion for some, albeit limited, demonstrations of global solidarity. Scrambles to secure PPE and to gain early access to vaccines have, however, also highlighted the persistence of serious global health inequalities. The pandemic is also likely to deepen these pre-existing inequalities. Some commentators noted that low-income countries like Guinea were the first in line when ‘guinea pigs’ were required for research into vaccines, but last in line when it came to receiving effective vaccines – it was clear that deep injustices in access to global health goods remain entrenched.

### Reactions to the ethical compass

There was considerable support among both workshop groups for the NCoB’s ethical compass. Contributors felt it identified values that were both universal and resonated with ethical challenges arising during serious infectious disease outbreaks in Guinea. Both members of the CRS and CNERS regarded the compass as a vital tool to enable members to advocate for key ethical norms remaining at the core of decision making by their committees, scientific and research ethics committees, particularly when engaging with Government. All three of the compass’ values were felt to be under pressure when conducting research in public health emergencies.

Overall responses to the compass’s values are given below:

#### *The obligation to relieve suffering*

- Participants strongly emphasised how ‘suffering’ extended far beyond the physical suffering directly associated with contracting serious infectious diseases: suffering was as much social and psychological as physiological
- During both Ebola and COVID-19, members of affected communities were terrified. Witnessing large-scale sickness and death traumatised people. Some fled and fear of the disease combined with historically-based social and political divisions fuelling distrust of government infection control strategies led to panic, violence and even murderous attacks on health professionals
- According to a participating ethnopsychologist, psychological dimensions of outbreaks, particularly anxiety and fear of death often lay at the root of the most destructive rumours and misinformation – combatting them required effective and widespread community engagement
- As with global health inequalities, Ebola and COVID-19 both highlighted and exacerbated entrenched inequalities within Guinean society, particularly inequalities between rural and urban areas, and between Conakry and other cities. In resource-poor settings such as Guinea, there is often little or no social safety net for those who are under lockdown or who get ill and cannot work. Outbreaks of disease have dramatically unequal impacts. Public health responses can drive unemployment, exacerbate poverty and malnutrition and even lead to death – outcomes that make compliance with social distancing methods highly challenging and lead to evasion
- Suffering can also be amplified where responses to infectious disease outbreaks override or fail to respect important cultural values. During Ebola for example, arrangements for burials became a flashpoint. Respect for the dead traditionally required rituals that exposed those involved to risk of infection – but safe burial practice was perceived to violate respect for the dead. Sensitively managing these issues was essential to managing the outbreak. It was essential that this involved anthropologists sensitive to local cultural issues.

### *Fairness*

Participants felt that inequalities of various kinds lay at the core of mistrust, the circulation of rumours and violent responses to infection control and health care teams during the Ebola outbreaks, particularly in Guinea’s Forest Region. Inequalities were seen to fracture the global health research landscape. Continuing concerns about control over the research lifecycle, the transfer of biosamples out of the country due to, at the time of Ebola’s 2013-2016 outbreak, absence of governance systems for biosamples in the country, and the deliberate avoidance by external actors of both national and international research ethics regulations all gave rise to serious equity issues.

Fairness was also about the fair or just access to the benefits of research. Primarily, benefits should flow to the affected populations. During Ebola and as is a norm in global health research, such benefits flowed out of affected communities and countries and back to resource-rich settings. This is perceived by Guinean experts at these consultations as the result of the



involvement of powerful external actors seeking to fulfil their own research agendas and promote their own interests, over those of Guinean populations.

### *Community engagement*

Community engagement was consistently identified as foundational to effective and ethical research during public health emergencies – it would be difficult to exaggerate the importance participants gave to it. Lack of transparency can be expected to breed misunderstanding and distrust in any context. In Guinea, lack of transparency exists against a backdrop of colonial and neocolonial interests, and in a context of national social and political divisions. In this tense climate, it is more common than not for a lack of transparency to be viewed as active obscuring of information. For some, it is also associated, based on past experiences, with a lack of clarity vis à vis intended benefits of research for the country and its populations. If communities are not properly engaged, they will not respect public health interventions and may well respond with resistance and even violence. Community engagement is a population-level expression of duties to respect individuals and to allow them to make informed choices. It is also critical as a method of promoting fairness: communities are given opportunities to shape research agendas and to identify and promote research that is in their interests. Community engagement can also help alleviate community concerns. Even in a context such as Guinea, participants to these consultations stressed community engagement could serve to address and reduce, if not eliminate, sources of fear and uncertainty and ameliorate some aspects of psychological suffering.

Several participants suggested that the inclusion of a positive ethical principle relating to community engagement in the NCoB compass would be helpful in the Guinean context – one possible approach would be to adapt the visual representation of the compass to place community engagement as a central focus from which all the other values flow. These reflections were enriched by observations that in the Nuffield's research stakeholder diagram, there were no roles and responsibilities ascribed to the community, even though the community was pictorially at the centre. This suggested, consciously or not, that affected communities were simply the subject of external forces and without an active role in shaping the research and ensuring its ethical conduct. While there were unquestionably significant power differentials between stakeholders, and they must be acknowledged, in its current form the diagram showed affected communities to be entirely passive – itself a questionable and potentially unethical assumption.

### *Dignity or equal respect?*

There was some discussion as to whether the concept of dignity better captured the morally relevant issue at stake than equal respect. Some argued that it had a more universal root and successfully incorporated the ethical imperative to show respect for cultures. To ensure respect for the dignity of all those involved, and to guard against forms of dehumanisation was described as core to ethical research during global health emergencies.

### *Areas of additional concern*

All the issues identified in the NCoB's report resonated with the workshop's participants. Several additional areas of concern were raised for the Guinean context:

- **Financing:** During Ebola, lack of resources to invest in research, combined with limited research capacity meant that Guinea effectively lost control of the research agenda. As a result, research into COVID-19 has been given greater priority by the Government. This has also increased the capacity and effectiveness of the ethical oversight of research undertaken by any agency in Guinea
- The importance of support and follow-up care for research participants emerged as a key issue during Ebola and remains an important issue during COVID-19. As it focusses primarily on the individual interests of research participants, it is distinct from community engagement but is nonetheless an issue of critical ethical concern
- Participants identified a lack of research into the socio-economic impacts of COVID-19. The pandemic has been viewed principally as a medical and biological issue, with infection control strategies, and biomedical research as the main foci of concern. A failure to identify and mitigate the social and economic aspects of the pandemic is likely to increase inequality and its attendant harms and undermine the effectiveness of public health interventions.

### *Community engagement*

As we have seen, community engagement was identified as foundational to research, both practically and ethically. Questions about what constitutes the community and whose voices should be heard emerged as central. It was argued that community engagement occurs at two principle levels: country level – engaging the whole country – and much more locally, at the level of affected communities.

Critical to effective community engagement was the requirement to fully engage local leaders such as religious leaders. Women were also identified as influential in ensuring effective communication and take up of public health messages. All participants acknowledged that community engagement was both essential but also extremely challenging. Examples of where it had struggled were shared and participants subjected themselves to searching questions about whether their own efforts at community engagement were sufficient. For example, if a researcher was seeking to persuade members of affected communities to participate – to overcome through evidence and reasoned debate the concerns that people may have, to what extent was she respecting their autonomy?

### **Power and inequality – national and international research**

The afternoons of both workshops were dedicated to a relatively unstructured exploration of the impacts of power and inequality on research into infectious disease outbreaks in Guinea. A critical issue raised several times was the impact of conflicts of interest. These conflicts were particularly intense regarding the setting of research agendas: which intervention should be subject to research and why? Were research topics identified based on the needs of Guineans and the benefits they might have for affected populations, or because of the interests of external funders, or the opinions of influential figures?

The President's office was identified both days as ultimately responsible for managing public health emergencies in Guinea. Although advisory committees such as the National Scientific Council and the National Research Ethics Committee sometimes had to press hard to ensure that fundamental ethical concerns were respected in research agendas, they were often successful. One example cited was the successful challenge to the decision to trial interferon during the Ebola outbreak. Important concerns remained however about the possibility that these advisory committees would be reduced to a strictly consultative role and therefore lose the ability properly to regulate the ethical and scientific aspects of the Guinean research agenda. Certainly, there had been some attempts to circumvent the recommendations of the research ethics committee at higher levels.

Participants expressed strong hopes that the NCoB's report and its ethical compass could serve the committees in their desire to lobby for ethically robust research throughout Guinea, and to ensure that attention to ethics throughout the research lifestyle was normalised. Participants recommended that the NCoB's report be widely disseminated and utilised.

## Appendix A: Conference Schedule

TIME	EVENT
9:00am – 9:45am	<b>Welcome Ceremony:</b> Introduction and presentation of conference objectives
9:45am – 10:00am	<b>Coffee Break</b>
10:00am – 10:20am	<b>Orientation:</b> Presentation of Nuffield Report and it's Ethical Compass
10:20am – 11:15am	<b>Discussion 1:</b> Key complexities for Guinea during Public Health Emergencies (PHE): From Ebola to COVID-19
11:15am – 12:15pm	<b>Discussion 2:</b> Clarify the values of the Nuffield compass in the context of health research during the COVID-19 pandemic in Guinea and it's relevance in general
12:15pm – 1:15pm	Lunch
1:15pm – 2:15pm	<b>Discussion 3:</b> Power Dynamics and ethical values
2:15pm – 2:30pm	Coffee Break
2:30pm – 3:15pm	<b>Discussion 4:</b> Priorities and strategies to strengthen the capacity of committees to navigate ethical complexities during PHE
3:15pm – 4:00pm	Conclusion and next steps

## Appendix B: Detailed Description of Workshop Discussions

### **Discussion Number 1**

#### **Key complexities for Guinea during public health emergencies (from Ebola to COVID-19).**

1. The facilitator outlines the main ethical challenges in PHE research raised in the Nuffield report:

- Community engagement
- Consent
- Collaboration and partnerships between local researchers and national or international partners
- Data and samples
- Clinician / researcher + healthcare delivery / experimental treatment

2. The facilitator asks participants to break out into two groups to discuss together. Participants are asked to rank these areas of ethical challenge in order of importance from a) the Ebola context; b) the COVID-19 context. Short discussion to frame the rest of the conference.

3. Summary and analysis of results

What do the two emergencies have in common?

Participants are invited to offer more details on specific situations or factors that have contributed to the prevailing importance of these areas of ethical challenge during Ebola and during the current pandemic.

End of Discussion

## **Discussion Number 2**

### **Determining the values of the Nuffield compass for the Guinean context**

#### Activity

1. The participants are divided into 3 groups.
2. The facilitator projects the three "top" areas of ethical challenge selected by the group for the COVID context - during **activity number 1**.
3. Each group is advised that they will be working around only one of the complexities and are provided with a flipchart to record their thoughts.

#### Group work

4. Each group should answer the following questions for "their" area of ethical challenge:
  - a) How do the details and management of this area relate to the values of the compass?
  - b) Do any of the values dominate in considering this complexity?  
vs. Are there aspects of this particular complexity that are difficult to associate with any of the 3 values? (in other words: would a value be missing for the Guinean context)
  - c) Would any of the principles in the compass be described differently in Guinea

#### Sharing & discussion

5.
  - a) Each group presents its reflections (5 minutes summary of responses + 5 minutes discussion x 3).
  - b) Question (10 minutes): Do participants think they would use the Nuffield compass in the future? Is it useful to help organize the discussions of their Committee? Please give reasons for conclusions.

## **Discussion Number 3**

### **Power dynamics and ethical values**

#### 1. Group work

In groups of 5-6, participants will discuss the following:

A. How do national and international power inequalities manifest in relation to research into public health emergencies in Guinea? What realities and what challenges are manifested in the context, for example, of foreign projects, institutions, or individuals who want to carry out research on Guinean territory?

B. Do these challenges put pressure on the key ethical values identified in the compass – or other ethical values or principles you see as crucial to such research in Guinea

#### 2. Share & discussion on summary

Share and discuss the reflections from the small groups (30 min)