



OPEN LETTER

# Perspectives of different stakeholders on data use and management in public health emergencies in sub-Saharan Africa: a meeting report [version 1; peer review: 1 approved with reservations]

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## Abstract

During public health emergencies (PHEs), data are collected and generated from a variety of activities and sources, including but not limited to national public health programs, research and community-based activities. It is critical that these data are rapidly shared in order to facilitate the public health response, epidemic preparedness, as well research during and after the epidemic. Nonetheless, collecting and sharing data during PHEs can be challenging, especially where there are limited resources for public health and research-related activities during a PHE. In a symposium that brought together different stakeholders that were involved in the 2013-2016 Ebola outbreaks in West Africa, meeting attendees shared their perspectives on the values and management of data during PHEs in sub-Saharan Africa. Key factors that could inform and facilitate data management during PHEs in sub-Saharan Africa were discussed, including using

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report

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data to inform policy decisions and healthcare; a coordinated data collection and management scheme; identifying incentives for data sharing; and equitable data governance mechanism that emphasise principles of reciprocity, transparency and accountability rather than trust between stakeholders or collaborators. Empirical studies are required to explore how these principles could inform best practices for data management and governance during PHE in sub-Saharan Africa.

### Keywords

Epidemics, public health emergencies, Ebola, data sharing, data management, sub-Saharan Africa

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## Introduction

In the past decade, many countries in sub-Saharan Africa have sporadically experienced epidemics or outbreaks of (re-) emerging infectious diseases (EIDs), such as the Ebola virus disease (EVD), Lassa Fever and Cholera (Fenollar & Mediannikov, 2018). However, the 2013–2016 Ebola outbreak in West Africa clearly demonstrated, at least on a visible level, the limited capacity of the affected countries to manage and share data collected during public health emergencies (Chretien *et al.*, 2016; Owada *et al.*, 2016). For example, during the Ebola outbreak in West Africa, there were reports of incomplete filing and late arrival of case investigation forms at data management centres; difficulties in detecting and merging double data entries; lack of clear processes on how death of confirmed cases in holding, treatment and community care centres are reported to the data centres, the absence of a consolidated database that captured and linked all data sources in a structured way; and challenges with moving paper-based patient records from highly infectious patient areas to data capturing centres (Owada *et al.*, 2016; Oza *et al.*, 2019). These suggest that data sharing during PHE may be challenging for many African countries and that there is need to take this into perspective when articulating global governance and mechanisms for data sharing during PHEs.

To capture perspectives on data management during PHEs in sub-Saharan Africa, the Cultural, Anthropological Social and Economic (CASE) working group of the Global Emerging Pathogen Treatment (The GET) Consortium, organised a symposium that brought together stakeholders who were involved in data management, research and the public health response to the Ebola outbreak in West Africa. We report on the outcomes of a two-day symposium, which was held in Freetown, Sierra Leone (26 – 28 September 2018), as part of the fifth annual conference of the GET Consortium. The GET consortium is a multi-disciplinary research consortium that responds to infectious disease and biosecurity issues in Africa (Abayomi & Makinde, 2019). We begin with the format that was adopted for the symposium and highlights of the different presentations. Secondly, we present the different themes that emerged during the symposium. We conclude with a brief discussion on the ethical and social issues to consider when developing frameworks for data management and data sharing during PHEs.

## Format of symposium

The aim of the symposium was to identify practical processes and procedures that will facilitate the effective management and use of data collected during epidemics. Symposium attendees were health care practitioners, data managers, researchers, human rights activists, Ebola survivors and policy makers who were all involved, to varying degrees, in the responses to the 2013–2016 Ebola outbreaks in West Africa, either as part of a research project, a public health program or a national or regional response to the epidemic. Each session of the symposium featured presentations on specific themes, followed by moderated panel discussions and group deliberations from attendees. The presentations were organised around five broad thematic areas namely: 1) gaps in international guidelines for managing data during PHEs; 2) the experiences of Ebola survivors in the

management of clinical samples and data collected during the 2013–2016 EVD outbreaks; 3) ethical and legal challenges in managing data during epidemics; 4) the potential role of an African framework for managing data during epidemics; and 5) lessons learned in managing data following the EVD outbreaks in West Africa.

A total of seven plenary presentations and panel discussions were held with the aim of identifying major points of agreement or contention among symposium participants on the different topics and how identified challenges may be addressed. The panel and group discussions were convened at the end of each plenary presentation to enable participants discuss and debate recommendations. The discussions were recorded and later transcribed verbatim. The transcripts were then analysed to identify themes related to data sharing and. Permission to record and use the data for publication and project reports was obtained from symposium attendees before the start of the symposium.

## Presentation highlights: Ethics and data governance during PHEs and lessons learned

Presentations on ethics and data governance underlined the value of open and fair data sharing during epidemics; good practices for data management and sharing during PHEs; existing regulation for data sharing and principles that could inform data governance during PHEs. In terms of data management the emphasis was on data stewardship and quality (Afolabi, 2018; Chi, 2018) while presentations on ethics and governance (Abayomi, 2018; Munung, 2018; Staunton, 2018) underscored the need for ethics preparedness in the form of having templates for informed consent documents that have clear information on data sharing, model data sharing agreements, as well as collaborative research contracts that allow for fair and transparent data sharing. Such structures would require robust governance and regulatory frameworks that support fair and equitable data sharing practices. The European Union's General Data Protection Regulation (GDPR) was discussed as an example of a data protection regulatory framework that adopts a principles-based approach to data protection and that many African countries have introduced similar data protection regulations (Staunton *et al.*, 2020). The Global Research Collaboration for Infectious Disease Preparedness (GloPID-R) principles for data sharing (GLOPID-R, 2018) and the TRUST consortium's "Global Code of Conduct for Research in Resource-Poor Settings" (Schroeder *et al.*, 2018) were also recommended as guiding documents for developing equitable data management and sharing frameworks in LMICs.

## Presentation highlights: Experiences of EVD survivors

Two presentations (Bonarwolo, 2018; Kabba, 2018) highlighted the research experiences of Ebola survivors during and after the EVD outbreaks, including: issues of stigma, being over-researched, growing mistrust towards scientists, lack of compensation for participants in research, and growing concern amongst survivors that country-level research on EVD did not prioritise the health needs and expectations of EVD survivors. While EVD survivors were reportedly still willing to participate in EVD-related research, their experiences have led to an apparent

loss of interest to participate in EVD-related research. Exceptions to this research fatigue include when the study questions addressed a problem of interest to Ebola survivors; and when survivors are involved in decision-making on the use of their samples and data.

### **Outcome of the symposium: Perspectives of different stakeholders on data management during PHE**

Key themes that emerged from the discussions included the need to define what constitutes data; how data should be managed; secondary uses of data collected during PHEs; and the governance of data generated or collected during PHE. These different themes are presented and where appropriate, relevant verbatim, anonymised quotes from the symposium discussions have been used to support the arguments made by symposium participants.

#### **What is considered “data” in public health emergencies**

Designing data management and governance mechanisms first requires a collective understanding of what constitutes data and what data needs to be widely or rapidly shared during PHE.

*I am more concerned about the possibility that any information may become data and what that actually means for people who may not understand research. They don't see the possibility that whatever information they are asked to provide becomes a commodity or resource for people who want to enrich themselves (Researcher, HIC)*

These different perceptions of what constitutes data, and the value associated to data shaped the remainder of the symposium discussions on data management. The broadly held view was that the value which national governments and institutions placed on data played a central role in data collection and use, including making decisions on what data to prioritise for collection during and after an outbreak.

#### **Using data to inform policy development and epidemic preparedness**

The symposium further highlighted the need to differentiate between the management of different types of data collected during PHEs. For example, there was an agreement that surveillance/epidemiological data should be rapidly shared to improve response and preparedness, while data generated as part of research would undoubtedly require more structured governance. At the time of the symposium, stakeholders were concerned that the West African countries that recorded cases of Ebola were still not using the wealth of data collected or generated as part of health research, either to inform health systems strengthening, epidemic preparedness or clinical and psychosocial support for persons who survived EVD. There was also limited information on how data is being used, by whom and for what purposes?

*Have we followed up to make sure that this data are being used or are data just collected for data collection sake? Because every research component or every funder wants to see the data that are collected, but at the*

*countries, has there been any follow up to see if the data that were collected are actually being used to inform health system strengthening, training in-country or any decisions being taken by the government or is it just data collection, and who is using this data? (Data Manager, West Africa)*

Symposium attendees were of the opinion that data generated through surveillance and public health programs should be promptly shared to improve the timeliness and quality of the public health response. However, some meeting attendees narrated how there has been very little interest by their national governments to invest in strengthening data management during PHE, especially as their governments tend not to heavily rely on data for decision making during PHE.

*Data collected through research and presented to the top policy makers, are gathering dust on the table. So, we must get some thoughts, as to how to create awareness about the absolute need for decision making based on data, accurate data that is collected very well. (Researcher, West Africa)*

Consequently, strong recommendations were made for developing equitable data sharing and management frameworks, with an important first step of raising awareness amongst policy-makers on the value and importance of data and how it could be used for developing evidence-based health policies and health systems strengthening. The recommendations were based on arguments that that the current model of data collection during PHEs in Africa is heavily dependent on volunteers and has several limitations in terms of quality and commitment to use data for decision-making.

#### **Incentives for data sharing**

Acknowledging the importance of data in infectious disease surveillance and research, symposium participants noted that some of the West African countries relied on volunteers and non-governmental organisations to collect surveillance data and this made it challenging to guarantee data quality and, in the case of non-governmental entities, to enforce data sharing policies. To mitigate challenges with data management it was suggested that national governments should devise ways of incentivising data sharing during PHEs.

*A big question is the issue of incentives. What incentives are out there or what incentives can we use for the various people involved with data collection, right from the data collectors up to the national level? Because we have to share these data, as we agree it is important but what are the safety nets? Are there some systems out there we can emulate on how to incentivize those who are involved to willingly, quickly and transparently share these data? (Healthcare worker, West Africa)*

It was emphasised that community-based data collectors, mainly field staff, community liaison officers and other non-governmental or humanitarian organisations are often not considered key stakeholders in data sharing and therefore their

overall contribution to data collection and management tends to be overlooked by policy makers. Arguably, some of the activities of this stakeholder group may not be part of the government's official response, however the data they collect is equally important and should be covered in national and global data management plans. Acknowledging the important role of this stakeholder groups, some symposium attendees raised a question of whether this stakeholder group had an obligation to rapidly share data or to make it publicly available, and if so, through what mechanisms. A scenario was cited in Sierra Leone where volunteer nurses and fieldworkers who were actively engaged in data collection during the EVD outbreak were promised employment (as an incentive) but were laid-off when the outbreak was brought under control. This engendered a negative working relationship between the government, their international development partners and a segment of the health workforce leading to mistrust and the possibilities that fieldworkers may no longer be enthusiastic to support data collection during PHEs

*I am talking as a nurse. The nurses are the ones that are generating this data that people in the international community: WHO, CDC, all the data that they are collecting are being generated by these healthcare workers and when this outbreak occurred, the government, some of us are here, it was pronounced that nurses and health workers should come on board and join the fight. At the end of the Ebola fight, what happened? Now it is good governance. The promise of the government that we should come on board and volunteer, and at the end of the battle, we are going to be absorbed into the government service. And what happened, at the end of the Ebola fight, we were chased out of all health facilities. My take here is now that we are talking about data governance and how are we going to manage our data? If there is going to be any other outbreak, is there going to be any trust? (Healthcare worker, West Africa)*

Participants at the symposium noted that such incidents could undermine data collection and management initiatives.

### Comprehensive and coordinated stakeholder engagement

Equally important was the need for a unified and standardised approach for data sharing and management during PHEs. This was exemplified in the EVD outbreak in West Africa, that saw a wide range of national and international stakeholders involved in data collection activities. While the overall aim was to support the public health response, the lack of coordination and accountability mechanisms meant that it was hard to keep track on the availability of data and how data is being used. This was particularly so for research data.

*We saw that during the outbreak, or at the end of the outbreak, there were series of organizations who came to West Africa to conduct research, several organisations and most of them established partnerships with ministries and universities and so on. But what we noticed is that, there are some problems with collaboration among*

*these research organizations. So, what we would like to see is a uniform research umbrella that would be able to answer questions that the survivors have (EVD Survivor)*

It will therefore be important to explore strategies that have been adopted by different countries, the rationale behind these strategies, and to use the information to develop standardised procedures for data management during PHEs either at the national or continental level.

### Data governance

Another major theme that emerged from the symposium relates to data governance and the discussions centred on access to data and principles that should inform data governance during PHEs.

**Access to data by local researchers.** Participants identified concerns with poor access and un-regulated data use. Given the multitude of stakeholders involved in the EVD outbreaks in West Africa, uncertainties remained on the availability of clinical and public health data collected during the outbreak and how it can be accessed and used by locally based researchers.

*There were concerns about where all the clinical data went. It was not about the government didn't have it, X institution [University in Europe] had access, WHO had access, but nobody else did. What did they make of the data? They were holding it up for their own publications. (Researcher, HIC)*

This was particularly the case for data collected through collaborative projects. In which case the data was mainly available to the HIC research team.

*So, the data are there somewhere, but will we as Sierra Leoneans, as West Africans, Africans, will we get access to that data, the clinical data? We are struggling to find out where the samples are, we are struggling to find out where sample-related data are, we are just about to achieve that. Now we need to struggle and to find where clinical data are and then we can do the proper research. (Researcher, West Africa)*

Participants were, however, unable to identify how to resolve the challenge posed by inaccessibility of data by local researchers. There was consensus, that irrespective of the organisation or entity that was collecting data, it was important to include local researchers in data stewardship and management processes to ensure that data is used to answer questions of pertinence to local health needs.

*So, one of the few recommendations we have is to actually have these research organizations work together for a common good of the research participants, and to have a local ownership of the database and to use it to better support health care services; to support survivors. (EVD Survivor)*

In the case of epidemiological and clinical data, national governments should have ownership and control of the data. Despite consensus on the importance of data ownership and control by national governments, some discussants argued that there was an apparent lack of a data-use culture by many African governments and this account for limited national investments or interest in developing policies that should inform data sharing during PHEs.

*Does our government care about using data to inform decision making? Do they care? They don't. It doesn't matter how we govern that data. Because having data systems, just to say we have data systems, that's not a problem. Like we were talking about what framework works better, but what is our relationship with data? At the remotest parts of our countries, the technicians and nurses that are working there, what do they think about data? What is their relationship with data?* (Data Manager, West Africa)

A counterargument to this claim was that failure by national governments to invest in data management cannot be blamed on policy makers' inability to appreciate the value of data. Rather, healthcare workers and researchers in West Africa have systematically failed to engage policy makers when they design and implement studies during PHEs.

*I am coming from the angle of the government, because I always hear that the government is not supporting data management. I want us to look at it from another angle. You design your research; you carry it out and you don't carry the government along. You do not look at what problems the policy maker is trying to address. You are not interested in the budgeting system of the government what they want to solve? Quite alright, the government is not putting enough money into research, but did you try to reach out to the government, to say we identified this problem in your systems, we are trying to solve this problem? You have to carry the government along from the design and inception, and the government will be ready to say, yes, the results of this your research is going to impact on governance and development. Let us ask ourselves in Africa, do we do that?* (Policy maker, West Africa)

Consequently, African researchers are enjoined to learn to work closely with their national governments and to highlight the importance of data in PHEs. It is hoped that such engagements will motivate national governments to appreciate the importance of effective data management during PHE and consequently to allocate adequate resources within national budgets for data collection and management during PHE.

**Principles for data governance.** The principles that should inform data governance during PHEs, as per the symposium discussions, were similar to those described by some global data sharing entities (GLOPID-R, 2018; Goldacre *et al.*, 2015) and highlighted in the presentations (Afolabi, 2018; Munung, 2018), including, ensuring data quality and accessibility, transparency, accountability, trust and reciprocity. The principle that evoked

the strongest sentiments amongst symposium participants was the principle of trust. Trust is widely cited as a key principle for the governance of data sharing in PHEs (Carr & Littler, 2015; GLOPID-R, 2018) and more broadly for global health and health research.

*No matter what you put together, if the organizations cannot trust themselves, there will always be a challenge for data sharing, and across the reviews that we had for emergency purpose, one key thing that emerged was trust. And adding to that, when I did my study, it was one of the key themes that emerged as a sub-category on governance and preparedness. That means if we cannot work together at normal times, we cannot be sure of working together when there is an emergency.* (Researcher, West Africa)

The symposium discussions highlighted that while the principle of trust was important in data sharing processes, trust is an elusive concept to foreground the governance of data sharing that could engender exploitation and that it is important to acknowledge that fostering mutual trust during PHEs is challenging. A better approach will be to establish contracts and regulations such as data sharing agreements and memorandums of understanding, to guide the activities of the different stakeholders in terms of data management.

*I think the word trust can only exist in a Utopian world. I love it, but historically trust has not worked. It doesn't work for Africans....so, while I would like to engage with partners on a trust basis, and again we have the question what does trust means. We need to define it. You wouldn't go and buy your car and tell the car dealer, oh, I'll pay you when I have money, just trust me. It's not going to work...So, why should that work in science? We must put legal binding documents in place, that tie people's hands, and we must calculate the value of beneficence that must come back.* (Researcher, West Africa)

These different arguments on the importance and relevance of trust as an underlying principle that should inform best practices for data sharing in PHEs, led to a general view among meeting attendees that principles transparency, accountability and reciprocity are more likely to be considered best practices in data sharing during PHE.

#### Ebola survivors: Health research and data use

The symposium revealed a sense of fatigue by EVD survivors to participate in EVD research, especially when the research did not seem to address the perceived health concerns of the survivors.

*Initially, we rejected that we are going to be part of the XX trial, because we don't see that as important to us. We have survived. That's what we believe in. It is now just for us to go on with normal life. But the moment they mentioned the case at Country Y, we spoke to our colleagues and we started attending the programme. Yet most of the results are not that convincing to our question, especially the persistence of the virus in our semen* (EVD Survivor)

Worthy of note is that the Ebola outbreak in West Africa left more than 10,000 EVD survivors (WHO, 2016) and this group remains a population of interest for health and behavioural researchers. The apparent failure to ensure that research and health programmes respond to the needs of EVD survivors has led to a build-up of mistrust between communities and national governments and researchers.

*I think if there are plans for the Ebola survivors from the government, like the ministry of health and sanitation, the ministry of social welfare, the only thing that will help them in proper planning, is first to look at the data of survivors. As it is, we are still having some misconception. We have our own database, the ministry of social welfare has theirs, ministry of health and sanitation has theirs, WHO also have their own data. So, you can see the misconception is because our figures are quite different from theirs. So, in most cases, if you want to plan, let's say if we are talking about requesting for health care, provision for livelihood, how would they plan better without accurate data? (EVD Survivor)*

This again highlights the need for a coordinated data management strategy. The existence of many databases could be attributed to the different organizations that were involved in the EVD response in some of the West African Countries, for example Sierra Leone (Gorina *et al.*, 2020). Equally, limited coordination of the public health response led to different organizations maintaining databases with similar information, yet this has not been harmonized to improve care for patients.

## Discussion

Data generated during epidemics are of great value long after the PHEs have been brought under control and the value of the data lies more in how it is used, rather than its mere availability. Therefore, investing in global, regional and country specific data management and data sharing systems and policies are undoubtedly worthwhile investments. For many countries in sub-Saharan Africa, the untapped data resource can help strengthen the poor health systems and facilitate economic growth and development. Yet data, anecdotally described as the “new oil” (The Economist, 2017), remains an untapped resource in many LMICs. In the context of health and health research, unlocking the potential of data requires ensuring not just access to quality data, but that data is used to inform health policies, and this can be easily visualised in PHEs (Carr & Littler, 2015; Chretien *et al.*, 2016).

The discussions from the symposium demonstrated an overall willingness to share data during public health emergencies in Africa. What remains a challenge is equitable and fair mechanisms for the use of data and the absence in many African countries of data management frameworks that can support the fair and equitable use of data. Several reasons have been advanced for the inertia to share data during PHE including: concerns around stigmatisation of communities; exploitation of researchers in LMICs; the lack of incentive to share data and samples; and access to benefits arising from the use of the data and limited capacity (Goldacre *et al.*, 2015; Modjarrad *et al.*, 2016). These challenges, though complex, are surmountable.

The first thing is for sub-Saharan African governments to recognise the value of health data and to develop their capacity to collect, generate and use health data in ways that will benefit their populations. The second step is to develop governance mechanism for data management that ensures data quality and equitable global access to data. Thirdly, a crucial need exists to strengthen the capacity of sub-Saharan African countries to collect and curate data during PHE.

## Conclusion

Data collected during epidemics are, arguably, a public good, and the collection and management of such data comes at a cost, often to national governments. However, it would appear that many African countries are yet to realise and/or unlock the potential and value of health and research data collected during PHEs. Hence, they fail to use it in informing their response and preparedness to outbreaks of emerging and re-emerging infectious diseases. This symposium is one of few public discussions on data management during PHE in sub-Saharan Africa, a region that has been plagued with multiple PHE in the last two decades. The unlicensed exportation and use of data by actors who come into the continent to provide emergency response support seems to have weakened relations between various stakeholders and may jeopardise rapid data management and sharing during PHE. Discussions on how to strengthen the role of different stakeholder groups in regulating and coordinating data access and use are important.

Secondly, the active engagement of stakeholders in developing data management and data sharing frameworks and in translating these frameworks into practice, is important both for ensuring data use and accountability. While trust is considered important for building and sustaining partnerships, it is a long-term process that is largely dependent on the personal characteristics of those who negotiate the relationship. From the meeting discussions, it will seem that a working relationship based on accountability and transparency will be more objective and liable to the recourse of the law when bridged. Whatever approach to data governance adopted during PHEs, it is critical to recognise that conceptual differences in the principles that should guide data governance may make cross-border harmonisation of data challenging, but not impossible. Therefore, context specific understanding of principles and how they should guide data management and governance during PHE are important.

## Data availability

No data are associated with this article.

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## Author information

With the exception of the first two and last authors, the author list is in alphabetical order indicating equal contributions from all authors.

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# Open Peer Review

Current Peer Review Status: ?

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## Version 1

Reviewer Report 09 February 2021

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**Olushayo Oluseun Olu**

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### General comments

Good public health data is one of the key tools required for effective planning, implementation, monitoring, supervision and evaluation of emergency preparedness and response to public health emergencies. While a lot of data are often collected during public emergencies (albeit often of poor quality), the data is usually not used to guide evidence-based decision making due to several reasons including among others poor timeliness and completeness, inaccessibility and lack of capacity for data management. This symposium (and manuscript) therefore addresses a very important topic. The manuscript has all the required elements but could be reorganized for better comprehension as follows:

### Specific comments

#### Introduction

This section is well written; a brief introductory paragraph on public health emergency data management systems and the type of data that should be collected would be helpful to set the tone for the manuscript. This can then be followed by challenges with data management during public health emergencies which have been well articulated in the current first paragraph of this section. Better articulation of the justifications and objectives of the manuscript would also be helpful.

#### Format of the symposium

- This section has all the key elements. However, for better understanding, I would suggest reorganization of the section into the five broad thematic areas namely 1) gaps in international guidelines, 2) experiences of Ebola survivors, 3) ethical and legal challenges, 4) the potential role of an African framework and 5) lessons learnt in managing data during the West Africa EVD outbreak. Each sub-section should comprise of 3-4 paragraphs which summarize the presentations, panel discussions and conclusions from the thematic session

- You said that the symposium was organized around five thematic areas but then also mentioned there were a total of seven plenary presentations and panel discussions; please clarify?

**Discussion and conclusion**

These sections seem to be repetition and should be merged, abridged and reorganized into the following sections:

- **Conclusions:** to include the first and second paragraphs of the discussion section and the first paragraph of the conclusion section.
- **Recommendations:** to include the third paragraph of the discussion section and last paragraph of the conclusion section.
- The first and third recommendations in the third paragraph of the discussion section are similar and should be merged

**Is the rationale for the Open Letter provided in sufficient detail?**

Partly

**Does the article adequately reference differing views and opinions?**

Yes

**Are all factual statements correct, and are statements and arguments made adequately supported by citations?**

Yes

**Is the Open Letter written in accessible language?**

Yes

**Where applicable, are recommendations and next steps explained clearly for others to follow?**

Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Public health disaster risk management, outbreak investigation and management, health system strengthening

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.**

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