OPEN LETTER

REVISED Perspectives of different stakeholders on data use and management in public health emergencies in sub-Saharan Africa: a meeting report [version 2; peer review: 1 approved, 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 as 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. 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 data to inform policy decisions and healthcare; a coordinated data collection

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and management scheme; identifying incentives for data sharing; and equitable data governance mechanism that emphasise principles of reciprocity, transparency and accountability rather that 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.

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Any reports and responses or comments on the article can be found at the end of the article.

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

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REVISED **Amendments from Version 1**

We have revised the main text in light of the comments made by the reviewers. In the introduction, we have added a paragraph to highlight gaps in public health emergency data management systems in Africa and the type of data that should be collected during public health emergencies. In the section titled "Format of Symposium", we have added three new paragraphs that present a summary of the symposium discussions on ethical issues in data sharing and the potential role of an African framework. The discussion and conclusion sections have been merged. We have added a paragraph to the discussion on the persistence of data management challenges during the COVID-19 pandemic and have highlighted an initiative that seeks to address this from a governance perspective.

Any further responses from the reviewers can be found at the end of the article

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.

Generally, many African countries continue to use paper-based systems for capturing and recording health data. This could lead to delays in transforming the captured data to a digital format which can be easily shared with other stakeholders. During PHE when data is urgently needed for informing the public health response, such an approach could be overwhelming given the volume of clinical, epidemiological and behavioural data that may be collected within a short period of time, including research data and records of biospecimens collected from patients. The Ebola outbreak in West Africa brought to light gaps in public health data management in African countries and the impact it could have on future outbreaks of (re)-emerging infectious diseases (Awini *et al.,* 2017; Owada *et al.,* 2016). The outbreak also demonstrated that many African countries were lagging behind in terms of using data to inform and plan a response to a PHE. Given advances in information technology, data collection, cleaning, and analysis during PHE can be tremendously improved to facilitate rapid data sharing. For this to be effective, however, it is important to first understand perceptions around data use and management in PHE, including existing challenges and how they may be addressed.

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 (n=4) and panel discussions (n=3) 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 to discuss and debate recommendations. The discussions were recorded and later transcribed verbatim. The transcripts were then analysed to identify themes related to data sharing. 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. GloPID-R proposes seven principles for data sharing in PHEs namely timeliness, ethical, equitable, accessible, transparent, fairness and quality. While the he TRUST consortium's "Global Code of Conduct for Research in Resource-Poor Settings' is anchored on four values: fairness, respect, care and honesty.

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.

Presentation highlight: Ethical issues in data sharing during PHE

Two speakers specially addressed ethical issues in data management during PHE (Abayomi, 2018; Chi, 2018). Their presentations made reference to a WHO consultative meeting in 2015 that aimed to advance the development of global norms on data sharing in PHE. A key outcome of the meeting was a re-affirmation that timely and transparent data sharing should be a global norm during PHE (Modjarrad *et al*., 2016). Additionally, journal editors made a commitment to ensure that the public availability of data would not interfere with publication timelines nor prejudice article publication at a later stage, either during or after the PHE. Researchers and public health officials were urged to ensure that shared data had undergone quality control. Acknowledging that in some instances certain factors may undermine data sharing during PHE, the WHO consultative meeting made provisions for data generators and stewards at the local, national, and international level to opt out of data sharing during a PHE, in which case they are expected to provide reasons for their decision. It was then recommended that there is a need to incentivize data sharing during PHE and to strengthen public health data management in LMICs.

Although data sharing in PHE has been recommended by the WHO as a global norm, many African countries lack the financial and infrastructural capacity to manage and use the different types of data collected during a PHE. As a result, while many African countries will, in principle, be willing to share data timeously, they will have to rely on international agencies and partners to facilitate the process, especially for data generated as part of research. To this effect, there is a need to strike a balance between international collaborations and the data sharing revolution (Abayomi, 2018). Such collaborations can be enhanced through a) African political leadership that is supportive of science, research and development; b) African ownership of research conducted on the continent, 3) the development of data sharing policies; 4) wide stakeholder consultation, and 5) leveraging the use of technology to reduce the disparities in capacity and infrastructure. Furthermore, data governance issues need to be addressed, including secondary use of data, data access, commercialisation, return of results, and beneficiation.

The potential role of an African framework

A question that was asked to panellist was whether there is a need for an afro-centric A question that was asked to the panellists was whether an afro-centric framework for data management in PHE is required. The panel had diverse views but agreed that an international data sharing framework that takes into cognizance values and principles that are peculiar to the different global settings will be ideal, especially if such a framework is grounded in principles like solidarity, reciprocity, trustworthiness, and accountability. Some panellist argued that the priority should rather be on engaging policy makers on the importance of data in PHE preparedness and response and to push towards public appreciation of PHE data as a national asset that should be used for the benefit of all, as long as there are governance mechanisms to ensure equitable access and use of the 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 policymakers 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 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 these 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 of 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 unregulated 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.

Conclusion

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 and the second is to develop governance mechanisms for data management that ensures data quality and equitable global access.

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, 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.

Recommendation

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 breached. Many of these issues have once again come to the fore during COVID-19. The Access to COVID-19 Tools Accelerator (ACT-Accelerator), for example, was established to respond to the COVID-19 pandemic by scaling up the development and equitable distribution of tests, treatments and vaccines and strengthening underlying health systems infrastructure. To achieve this goal, it was recognised that the collection, linking, sharing, and timely access to data, including personal data, is essential, but undertaken through privacy preserving methods rooted in human rights and supported by a clear and transparent governance framework. The Framework for the Governance of Personal Data for the Access to COVID-19 Tools Accelerator was thus developed (FIND, 2021). The Framework is guided by the substantive and procedural principles that includes transparency, accountability and engagement, and provides guidance on data collection and storage, retention of data, data management, access to data, and responsibilities of those using personal data. It also provides guidance on future post-pandemic use of personal data collected during COVID-19 and includes recommendations on in-country governance structures for health-related data.

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.

Author contributions

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

Acknowledgement

We are grateful to all panellists, representatives of Ebola Survivors Associations in Liberia and Sierra Leone, and all symposium attendees for their contribution. Morenike Oluwatoyin Folayan read and provided feedback on the draft manuscript.

References

Abayomi A: **Ethical Issues for Data Sharing in Public Health Emergencies from an African Perspective and Field Experience**. In: *Symposium on data management in public health emergencies in Africa* (ed). GET consortium fifth annual conference Free Town, Sierra Leone, 2018.

Abayomi A, Makinde D: **How and Why the Global Emerging Pathogens Treatment Consortium Was Created.** In: Tangwa GB, Abayomi A, Ujewe SJ, & Munung NS (Eds.), *Socio-cultural Dimensions of Emerging Infectious Diseases in Africa: An Indigenous Response to Deadly Epidemics*. Cham: Springer International Publishing. 2019; 15–19.
Publisher Full Text

Afolabi M: **What Constitutes a Good Governance System/Framework for Data Management in PHEs**. In: *Symposium on data management in public health emergencies in Africa* (ed). GET consortium fifth annual conference, Free Town, Sierra Leone. 2018.

Awini EA, Bonney JHK, Frimpong JA, *et al.*: **Information gaps in surveillance data and effects on the Ghanaian response to the Ebola outbreak in West Africa.** *Ghana Med J.* 2017; **51**(3): 115–119.
PubMed Abstract | Publisher Full Text | Free Full Text

Bonarwolo K: **Experiences of Ebola Virus Survivors on the Management of Clinical Samples and Data During the Ebola Outbreak in West Africa**. In: *Symposium on data management in public health emergencies in Africa* (ed). GET consortium fifth annual conference Free Town, Sierra Leone. 2018.

Carr D, Littler K: **Sharing Research Data to Improve Public Health: A Funder Perspective.** *J Empir Res Hum Res Ethics.* 2015; **10**(3): 314–16.
PubMed Abstract | Publisher Full Text | Free Full Text

Chi PC: **Ethical, Legal, and Social iIssues Related to Data Management in the Context of Public Health Emergencies**. In: *Symposium on data management in public health emergencies in Africa* (ed). GET consortium fifth annual conference Free Town, Sierra Leone. 2018.

Chretien JP, Rivers CM, Johansson MA: **Make Data Sharing Routine to Prepare for Public Health Emergencies.** *PLoS Med.* 2016; **13**(8): e1002109.
PubMed Abstract | Publisher Full Text | Free Full Text

Fenollar F, Mediannikov O: **Emerging infectious diseases in Africa in the 21st century.** *New Microbes New Infect.* 2018; **26**: S10–S18.
PubMed Abstract | Publisher Full Text | Free Full Text

FIND: **Framework for the Governance of Personal Data for the Access to COVID-19 Tools Accelerator.** 2021; Accessed 07 March 2021.
Reference Source

GLOPID-R: **Principles of data sharing in public health emergencies**. 2018; 7.
Reference Source

Goldacre B, Harrison S, Mahtani KR, *et al.*: **Background Briefing for WHO consultation on Data and Results Sharing During Public Health Emergencies**. In: Centre for Evidence Based Medicine, University of Oxford, 2015; 23.
Reference Source

Gorina Y, Redd JT, Hersey S, *et al.*: **Ensuring ethical data access: the Sierra Leone Ebola Database (SLED) model.** *Ann Epidemiol.* 2020; **46**: 1–4.
PubMed Abstract | Publisher Full Text | Free Full Text

Kabba Y: **Survivors Perspective to Research in an Epidemic Situation**. In: *Symposium on data management in public health emergencies in Africa* (ed). GET consortium fifth annual conference Free Town, Sierra Leone. 2018.

Modjarrad K, Moorthy VS, Millett P, *et al.*: **Developing Global Norms for Sharing Data and Results during Public Health Emergencies.** *PLoS Med.* 2016; **13**(1): e1001935.
PubMed Abstract | Publisher Full Text | Free Full Text

Munung NS: **Framework for the Management of Data in Public Health Emergencies**. In: *Symposium on data management in public health emergencies in Africa* (ed). GET consortium fifth annual conference Free Town, Sierra Leone. 2018.

Owada K, Eckmanns T, O'Bai Kamara KB, *et al.*: **Epidemiological Data Management during an Outbreak of Ebola Virus Disease: Key Issues and Observations from Sierra Leone.** *Front Public Health.* 2016; **4**: 163.
PubMed Abstract | Publisher Full Text | Free Full Text

Oza S, Wing K, Sesay AA, *et al.*: **Improving health information systems during an emergency: lessons and recommendations from an Ebola treatment centre in Sierra Leone.** *BMC Med Inform Decis Mak.* 2019; **19**(1): 100.
PubMed Abstract | Publisher Full Text | Free Full Text

Schroeder D, Cook J, Hirsch F, *et al.*: **Ethics dumping: case studies from north-south research collaborations**. Springer International Publishing. 2018.
Publisher Full Text

Staunton C: **International Norms in the Sharing of Health Data**. In: *Symposium on data management in public health emergencies in Africa* (ed). GET consortium fifth annual conference Free Town, Sierra Leone. 2018.

Staunton C, Adams R, Anderson D, *et al.*: **Protection of Personal Information Act 2013 and data protection for health research in South Africa.** *International Data Privacy Law.* 2020; **10**(2): 160–79.
Publisher Full Text

The Economist: **The world's most valuable resource is no longer oil, but data**. In: *The Economist.* 2017.
Reference Source

WHO: **Clinical Care for Survivors of Ebola Virus Disease: Interim Guidance**. In: WHO. 2016; 31.
Reference Source

Open Peer Review

Current Peer Review Status: ? ✓

Version 1

Reviewer Report 10 February 2021

https://doi.org/10.21956/wellcomeopenres.18161.r42332

✓ **Sharon Abramowitz**
UNICEF, New York, NY, USA

The article presents the deliberations at a scientific conference convened by the Cultural, Anthropological Social and Economic (CASE) working group of the Global Emerging Pathogen Treatment (The GET). The aim was to capture perspectives on data management during PHEs in sub-Saharan Africa, focusing on five thematic areas: 1) gaps in international guidelines for managing data during PHEs; 2) the experiences of Ebola survivors in the3) 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.

What I liked:
The article is a valuable insider resource on what transpired with data sharing during the WA EVD outbreak. As a scholar on the event, I intend to return to this article regularly as a resource. The thematic structure of the conference is compelling. The themes identified provoked challenging discussions. The stakeholders represented invited a wider range of views and experiences than typical/conventional deliberations on data sharing - they do put the users and objects of the data at the center of the discussion and raise provocative questions about existing cultural attitudes by data owners towards data stewardship. The African ownership and authorship of the article and the process are essential. The article sets forth current key documents, processes, and foundational principles to inform PHE data sharing.

What I disliked:
The continued persistence of these challenges is felt in the current COVID-19 outbreak. It would be helpful if the abstract and the introduction could be adapted to address contemporary outbreak conditions. Also, several of the citations are paywalled, which rather flies in the face of an article highlighting needed changes for data sharing and open access.

Recommendation:
Index. Indexing this letter in this forum will help ensure that this deliberation is more elevated to a higher profile of visibility in international discussions on PHE data sharing. Also - given the focus

on presentations and deliberations, is it possible to request that the authors include the slideshows or PDFs of the presentations as a supplement? In particular, the presentations should be made available as soon as possible.

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

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: Authored Wellcome-Trust commissioned report on the same topic. https://www.glopid-r.org/wp-content/uploads/2019/07/data-sharing-in-public-health-emergencies-yellow-fever-and-ebola.pdf

Reviewer Expertise: anthropology, PHE, humanitarian, community engagement

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.

Author Response 08 Mar 2021

Nchangwi Munung, University of Cape Town, Cape Town, South Africa

Thank you Dr Sharon Abramowitz for your detailed review of our manuscript. We found the comments very helpful, especially in informing our every day work as researchers.

With respect to the comment on adapting the abstract to reflect the data management challenges in the current (Covid-19) pandemic, we thought a paragraph on that will do more justice than just a few sentences in the abstract. Also we do not want potential readers to assume, by reading the abstract, that the manuscript will also cover information on data management during the COVID-19 pandemic. To this effect, we have added a paragraph to the discussion on the persistence of data management challenges during the COVID-19 pandemic and have highlighted an initiative that seeks to address this from a governance perspective.

Thank you for the feedback.

Competing Interests: No competing interests were disclosed.

Reviewer Report 09 February 2021

https://doi.org/10.21956/wellcomeopenres.18161.r42335

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Olushayo Oluseun Olu
World Health Organization (WHO) Country Office, Juba, Sudan

General comments
Good public health data is one of the key tools required for effective planning, implementation, monitoring, supervision ad 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 follow:

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 summarizes 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.

Author Response 08 Mar 2021

Nchangwi Munung, University of Cape Town, Cape Town, South Africa

Thank you Dr Olushayo Oluseun Olu for your detailed feedback, pointers for improving the overall structure of the manuscript and for the comments. We have revised the manuscript based on the suggestions you made.

Introduction
A paragraph has now been added to the introduction to include data collected during public health emergencies and data management systems.

Format of the symposium. We have now added a summary of the presentations and panel discussions for each of the subsections, as suggested. In the section titled "Format of Symposium", we have added three new paragraphs that present a summary of the symposium discussions on ethical issues in data sharing and the potential role of an African framework.

Based on the comment about the number of plenary sessions and thematic areas, we have added the number of plenary presentations (n=4) and panel discussions (n=3)

Discussion and conclusion
These sections have now been merged as suggested and also revised accordingly.

We thank you again for taking time to review the manuscript and for the constructive feedback including suggestions on re-arrangement of the text.

Competing Interests: No competing interests were disclosed.