

# Research ethics preparedness during outbreaks and public health emergencies: Focus on community engagement

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## Abstract

Research represents an essential component of the response to infectious disease outbreaks and to other public health emergencies, whether they are localised, of international concern, or global. Research conducted in such contexts also comes with particular ethics challenges, the awareness of which has significantly grown following the Ebola outbreak in West Africa, the Zika outbreak in Latin America and the COVID-19 pandemic. These challenges include the need for implementing meaningful community engagement with the researched communities, not just to build unidirectional trust towards the research team, but to achieve a genuine and mutually respectful partnership before, during and after the research. Here, we describe the real-life experience of 10 well-established research clinics in Nairobi, where a successful experience of community engagement linking prevention and care to research was interrupted during the COVID-19

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pandemic. We contrast this experience with the concept and processes of community engagement as described in selected scientific manuscripts and guidelines, to formulate some conclusions and recommendations. We contend that more action is needed, from research ethics committees and other key-research stakeholders, to align policies and practices with ethics guidance and with evidence-based recommendations from the academic literature, to achieve meaningful community engagement during emergency research, irrespective of the scale and location of an outbreak or public health crisis. Failure to do so, will aggravate the (postcolonial) asymmetries of power in global health and local systems.

### **Keywords**

Research ethics, emergency research, outbreaks, public health, community engagement

### **Introduction**

Research represents an essential component of the response to infectious diseases outbreaks and to other public health emergencies, whether they are local, of international concern, or global (Lurie et al., 2013). High-quality research, including but not limited to epidemiological studies, interventional clinical trials, cluster randomised trials, diagnostic research, health systems research, and qualitative and mixed-methods research, is essential under these circumstances. These studies generate knowledge that allows policy makers to institute changes, and to prevent and minimise morbidity and mortality. The evidence generated also supports the recovery of individuals, communities and health systems, and helps to equip health systems with tools and expertise to respond to ongoing and future emergencies. However, research conducted in such (public health) emergency contexts also comes with particular ethics challenges.

These ethics challenges are not new, but awareness has significantly grown across the scientific community and beyond over the last 10 years, following the particular experiences from two major public health emergencies of international concern (PHEIC). These are the Ebola outbreak in West Africa and the Zika outbreak in Latin America. A PHEIC is ‘an extraordinary event which is determined [by the World Health Organization] to constitute a public health risk to other States through the international spread of disease and to potentially require a coordinated international response’ (World Health Organization (WHO), 2019). Thus, it is not surprising that research ethics concerns gained broader international visibility in recent years. Furthermore, the challenges encountered during the COVID-19 pandemic brought a myriad of global health research and ethics concerns. Experience from the two PHEICs and from the COVID-19 pandemic have highlighted a number of complex questions (Nuffield Council on Bioethics, 2020), for instance:

- How can the study design, ethics review and consent process be sensitive to the local context, and take into due account the individual and societal vulnerabilities created or exacerbated by the public health emergencies?
- In what way can the different stakeholders contribute to ensuring equal and fair partnerships in collaborations between researchers from the Global North and the Global South?
- How can researchers and research institutions protect front-line research workers, and help them to address the concrete ethical dilemmas they meet on a daily basis?
- By what means can the voices of those who are most affected by public health emergencies be meaningfully included in deciding what research takes place, where and how?

In a rapidly evolving international research and policy landscape, ‘ethics preparedness’ is increasingly identified as an important foundation for effective research during outbreaks and other public health emergencies. The current version of the Declaration of Helsinki (which is undergoing a revision process at the time of writing) does not explicitly mention research conducted in emergencies (World Medical Association, 2013), implying that an emergency cannot be taken as a justification for compromising ethics principles and the protection of research participants. Different scholars have been reflecting on how to design, conduct and report research that addresses public health emergencies in a timely manner (Abeyasinghe and Leppold, 2023; Ambrogi et al., 2023; London et al., 2018; Lysaght et al., 2022; O’Mathúna, 2015; O’Mathúna and Upadhaya, 2022), while being ethically, socially and scientifically sound (Canario Guzmán et al., 2017; Folayan et al., 2016; Saxena et al., 2021; Singh et al., 2022). Furthermore, different research and policy papers have looked at how research ethics committees (RECs) can carry out sound and meaningful reviews in emergency contexts (Alirol et al., 2017; Bain et al., 2018; Ekmekci et al., 2023; IJkema et al., 2021; Maketa et al., 2022; Palmero et al., 2021; Saxena et al., 2019; Schopper et al., 2017; Tansey et al., 2017), to ensure the protection of the research participants and of their communities, without delaying relevant research (Burgess et al., 2023; De Crop et al., 2016; Faust et al., 2021; Ramesh et al., 2022; Sisa et al., 2021; Wright et al., 2023).

Our paper will focus on an element that seems to be recurrent in the literature on research ethics and research ethics review in (public health) emergencies, namely, the role of RECs in promoting meaningful engagement with the community. We selected this topic because, despite already being emphasised in authoritative ethics guidance documents such as the guidelines of the Council for International Organizations of Medical Sciences (CIOMS) for Health-related Research Involving Humans (Council for International Organizations of Medical Sciences (CIOMS),

2016), for Clinical Research in Resource-Limited Settings (CIOMS, 2021), and the TRUST Code, a Global Code of Conduct for Equitable Research Partnerships (TRUST, 2018), it is still relatively unknown to many researchers and research sponsors. Perhaps this low awareness is due to the fact that community engagement is not explicitly mentioned in other key-guidelines, particularly the Declaration of Helsinki and the Good Clinical Practices of the International Conference of Harmonisation (Ravinetto et al., 2016). Moreover, the process of engaging with a research community may be compounded by the restrictive funding provided, and by difficulties related to structural vulnerabilities, which are intersectional and stigma-aggravated (Schroeder et al., 2024). Thus, the implementation of ethics guidance for community engagement during outbreaks and public health emergencies, whether localised or of international concern, needs to be informed by context-specific experience that *precedes* the emergency.

## Methods

First, in order to set the scene, we describe the real-life experiences of a clinic director and a community researcher (JK and JA) who are affiliated to 10 well-established research clinics in Nairobi County. The clinics have a wealth of experience linking community engagement and prevention, treatment and care of sexually transmitted infections (STIs) and HIV to research studies. This successful, well run and functional platform was interrupted by the COVID-19 pandemic, as we will describe.

Second, we contrast this experience from Nairobi with the concept and the processes of community engagement as described in selected scientific manuscripts and guidelines.

Third, we formulate some conclusions and recommendations with regard to community engagement in research during outbreaks and (public health) emergencies.

### *Engaging with a vulnerable research community in Nairobi, Kenya: Lessons from the field*

By ‘Nairobi sex workers’, we refer here to a community of more than 40,000 sex workers registered in 10 programmes/research clinics located in Nairobi County, Kenya. The clinics are specialised in the prevention and treatment of STIs, including HIV. Despite the unfavourable legal framework that indirectly criminalises individuals engaged in sex work in Kenya, sex workers have been increasingly and more meaningfully engaged in research since the early 1980s. From 1985, when HIV was first detected among those engaged in sex work, and onwards, several key stakeholders, including but not limited to senior researchers and

research funders, realised that the engagement of sex workers in research required a different approach compared to the approach used when engaging members of the general population. In this specific context, sex workers who rely on selling sex for economic survival and are highly stigmatised and are often distrustful of authorities and health care providers, including research institutions (Schroeder et al., 2024). A tailored strategy was therefore needed to engage them in research, and to ensure they were reached for care, research and public health measures.

Building on these premises, various contextualised methods of community engagement have been developed over the past two decades. The most effective one, which is being continuously refined, involves mediation between researchers and sex workers through so-called ‘peer educators’. These peer educators are carefully selected by the programme and research teams of the 10 Nairobi County clinics, in consultation with active members of the sex worker community. To be selected as mediators, these peers need to have a minimum level of education, must be active or have been active in sex work and should have a positive legitimacy and influence vis-a-vis the sex workers in this community. Those who match these criteria undergo a training itinerary, during which they are sensitised to public health issues and trained on how to engage with other sex workers.

The meaningful engagement of community members through mediators (peer educators) ensures that prevention and treatment services in the research clinics are actually used, and that participation in research is considered meaningfully. The project aims to have skilled and motivated mediators active in the target group, with at least one mediator per high-volume hot spot (e.g. a specific building, a certain hotel, or the streets used by the sex workers to meet clients), able to communicate about the clinics and create demand for available health care services. Over the years, the approach has been successful in creating and improving a network of peer-led, hot spots-based models for community engagement. The peer educator strategy, in turn, allowed for better (out)reach and coverage; it eased the distribution of needed prevention commodities, and it improved the communication and trust between the clinics and the sex workers at the hot spots. Moreover, it ensured that representatives of sex workers are involved in all key implementation aspects of ongoing HIV prevention, treatment and research activities at the 10 Nairobi clinics.

Unfortunately, at the height of the COVID-19 pandemic between 2020 and 2021, the successful community engagement involving Nairobi sex workers was interrupted. The following summarises the circumstances that led to this unwanted situation, and the consequences of the situation, in five points:

1. Whilst (health) researchers were allowed to continue their work during the COVID-19 lockdowns (using various protection measures), this was not the case for the peer-educators. Their access to the clinics was restricted by the

authorities, as they were regarded as citizens rather than research contributors, thus creating an unfortunate divide between the researchers and the peer educators.

2. The research funders for the Nairobi clinics decided not to fund COVID-19 control measures, thus community engagement activities stalled. Hence, the peer educator programme was greatly affected as funders considered that the necessary protective personal equipment supplies were too expensive, efforts needed to get approvals too time-consuming, and the risk of contracting COVID-19 infection too high. Local health authorities, research ethics committees and other concerned policymakers provided no guidance on when and how to re-open the 10 clinics to clients to enable access to the lifesaving, free STIs/HIV health care services for the peer educators and the 40,000 sex workers who are part of the clinics' clients.
3. Local health authorities, RECs and other concerned policymakers did not seek community engagement activities for research during the pandemic and thus implicitly supported the position of the research funders, even though their main allegiance should have been with the research participants.
4. The loss of trained and active peer educators due to inactivity during the pandemic led to a loss of expertise, experience and motivation in the community engagement programmes along the continuum of prevention-care-research.

The COVID-19 pandemic therefore had a devastating effect on a well-functioning community engagement system for research that targets a particularly vulnerable group.

### *Engaging with communities in (public health) emergency research: Patterns and challenges*

Early and ongoing engagement with the communities hit by a (public health) emergency is ethically important in its own right, whether in prevention and care, public health surveillance (WHO, 2016, 2017) or research. Community engagement is also essential to establish and maintain trust and accountability, through a genuine, transparent and inclusive two-way dialogue between researchers and communities. This is always true, but it is even more important when research is conducted in emergency situations, where (unwanted) uncertainties and miscommunication can create and fuel mistrust and fears, as happened in several settings during the COVID-19 pandemic (Decouttere et al., 2021; Gabarron et al., 2021; Nguyen et al., 2023).

Externally funded researchers often informally report that it is difficult to get funding for community engagement, whether in emergency situations or not. As

can be seen from the Nairobi Clinics case, even well-established and well-functioning community engagement systems can be at risk during an outbreak – in this case, a pandemic. At the same time, ‘not involving communities throughout the research process may be attributable to prejudice and a failure to recognise privilege. The result is a loss for all involved’ (Schroeder, 2023).

The WHO Guideline *Standards and operational guidance for ethics review of health-related research with human participants* recommends that RECs should check that researchers actively engage with communities in decision-making about the design and conduct of research, while being sensitive to and respecting of a communities’ cultural, traditional and religious practices (WHO, 2011). This guideline goes as far as to require that mechanisms are put in place for obtaining community input into the ethics review system itself. The experience of the Nairobi clinics indicates that this guideline was not followed during the COVID-19 pandemic, as relevant RECs did not seek community engagement activities when approving study protocols.

The CIOMS (2016) guidelines, which specifically address research in disaster and disease outbreaks, explicitly require community engagement. The TRUST (2018) Code has places great emphasis on community engagement, which is mentioned in at least five articles. When it comes to peer-reviewed papers, several authors mention, with different degrees of emphasis, the importance of community engagement (Alirol et al., 2017; Burgess et al., 2023; Maketa et al., 2022; Palmero et al., 2021; Tansey et al., 2017). Some explicitly recommend that RECs should require community engagement measures when reviewing protocols; others express concerns about a specific form of community exploitation, which is related to the exclusion of local stakeholders from the governance of research data and especially biosamples collected during outbreaks. This exclusion can result in serious injustice when samples are stored, exported and used in future research that does not result in any benefit for the community in the country of origin (Schopper et al., 2017).

It is noteworthy that even if the concern for engagement with the researched communities seems to be ubiquitous, the emphasis is often on community engagement as a means to build trust, sometimes unidirectionally, that is, trust of the community towards the research group. For instance, fostering contact with the community leadership can be seen as a way to help to address distrust and communicate effectively in order to gain support for a study design (CIOMS, 2016). Engagement can then prevent communities’ negative perception of research that might compromise the outbreak response effort (Alirol et al., 2017).

However, other important and more bidirectional reasons for community engagement are provided, both in guidance and in the literature. These include: the need to ensure cultural congruence and sensitivity (CIOMS, 2016); the need to ensure that the community perspectives are fairly represented and to avoid

violating customary practices (TRUST, 2018); the need to ensure ethical research (Palmero et al., 2021); and to show respect to the affected communities (Burgess et al., 2023; Palmero et al., 2021).

These views seem to promote a research ethics framework where the communities hit by disasters and outbreaks take on the role of stakeholders or partners, rather than of mere providers of data and samples who are requested to passively trust the research enterprise. However, such a scenario is not systematically visible. In many cases it remains at best aspirational, as also shown in our Nairobi case study where funders stopped their support for community engagement when the pandemic hit. In this outbreak context, the Nairobi peer educators were not recognised as essential members of the research team, while RECs also failed to ensure that research was continuously embedded in a strong community engagement model.

According to Schopper et al. (2017), the communities hit by outbreaks are rarely engaged in research governance. More recently, the work of Burgess et al. (2023) emphasised that the sense of urgency limited the potential for rigorous or authentic community engagement in COVID-19-related research. Moreover, even if ethics guidelines clearly indicate that community engagement should begin with the study planning (CIOMS, 2021; TRUST, 2018), and continue through assessment of the use of local resources, seeking community assent, post-study feedback and evaluation (TRUST, 2018), and the feedback of results (Palmero et al., 2021), there is no evidence that this systematically happens in emergency research or research during global crises. Alirol et al. (2017) regret the lack of information on how research results would be shared with participants and their communities, while Tansey et al. (2017) propose positive approaches to address current weaknesses in community engagement. In particular, they suggest collaborating with local researchers and authorities, and partnering with organizations that were working in the region before the disaster or outbreak. Tansey et al.'s position, as well as Alirol et al.'s (2017) remark that close collaboration of local and international researchers is essential for building meaningful community engagement based on understanding of the local culture, attitudes, and the socio-psychological situation, also draw a clear link between *community engagement* and *fair collaborative partnership*. Alirol et al. (2017) explicitly state that the involvement of local scientists was essential in the Ebola research contexts, to prevent or mitigate community mistrust, but they regret that the RECs lacked information on the role of country researchers and health systems.

Meaningful partnerships cannot be built *during* an emergency, nor *after* a disaster has occurred or an outbreak has been declared, but they should be built in 'peace time', aiming at joint, coordinated preparedness for outbreak and disaster response, including research.

In the worst case, as shown in the Nairobi case study, a well-functioning community engagement system is significantly undermined during an outbreak, with a



loss of trained community researchers (in this case, peer educators) which hampers engagement with the community during the emergency, and weakens prevention, care and research in the years to come. Tansey et al. (2017) extend the concept of preparedness to community engagement by encouraging the building of solid connections with local civil society organizations and international NGOs with longstanding partnerships with communities.

In addition to recognising the essential role of RECs in outbreaks and disasters, detailed recommendations for ethics review under such circumstances have also been formulated. According to Burgess et al. (2023), RECs should play a role in shaping researchers' practices and involving local communities, which they consider of particular importance in research during public health emergencies. Based on the COVID-19 experience, which revealed a dramatic lack of models to practically implement authentic community engagement in the context of the pandemic, they also advocate for further research to explore the role of RECs. This is in line with the position of Maketa et al. (2022), who contend that RECs should require explicit measures for community engagement in research protocols and with Tansey et al. (2017), according to whom RECs should encourage researchers to engage with communities. Moreover, Saxena et al. (2021) wish for a proactive role of RECs to ensure adequate governance of data and samples, based on justice considerations and laying out how data and samples will be made available for public health and other purposes, first and foremost for the benefit of the communities from which they were drawn. This is in line with Maketa et al. (2022), who ask RECs to require explicit measures for equitable data and sample sharing agreements, and with Palmero et al. (2021) who recommend that a local REC reviews the governance and use of data and samples, to safeguard the interests and wellbeing of donors.

Overall, there seems to be an implicit and/or explicit view across different authors that RECs that review research carried out during disasters and outbreaks should pay particular attention to measures built (or not built) into research protocols that ensure engagement with the community, and to prevent situations of injustice and exploitation. Sadly, the importance that the academic literature and ethics guidance gives to RECs' roles during outbreaks in respect of community engagement is not necessarily translated into policies and practices. For example, it stands in marked contrast with the experience of the Nairobi clinics, where RECs did not react to funders' decisions to stop supporting community engagement activities. This inaction could imply acquiescence to the reasoning that research can reasonably continue in the absence of engagement with the research communities as if it was a purely technical activity that does not require a human component.

As noted above, it appears that a lot of ethics reflection on community engagement in emergencies was prompted in recent years by the experiences of

health-related research in the field of Ebola viral disease, the Zika virus, and the COVID-19 pandemic. It would be important to carry out a formal systematic review to map the current body of knowledge concerning ethics (and ethics review) in other outbreaks that regularly hit socio-economically vulnerable communities but are localised (often in remote rural areas) and thus gain less mediatic and (ethics) scholarly attention, such as cholera and measles. This could help us to understand whether similar challenges and concerns arise, including but not limited to community engagement and how the challenges are dealt with by RECs and other stakeholders. A similar exercise might be needed for (re)-emerging diseases, such as Mpox, which is characterised by a high risk of stigmatisation and, like COVID-19, by North-South inequity in access to vaccines. It is also hoped that the broad ethics reflection triggered by challenges observed in Ebola, Zika and COVID-19 research will trigger a broader reflection that encompasses any outbreak and disaster research, independently of the kind of disease and of the size and location of the emergency.

## Conclusion

Research conducted during outbreaks and other public health emergencies, whether of international concern or localised, should uphold the same principles and values required in research in stable contexts, such as fairness, respect, care and honesty (TRUST, 2018). To achieve this aim, and to prevent situations of injustice and exploitation, meaningful and continuous engagement with the researched communities – ideally linked to preventive and healthcare services – is essential. There is increasing awareness that RECs should require community engagement measures when reviewing such ‘emergency’ research protocols, not just to build unidirectional trust from the community towards the research team, but to achieve a genuine and mutually respectful partnership before, during and after the research. Community engagement will be much more meaningful and effective if built before a crisis arises, and if maintained and consolidated after the end of the (acute phase of the) crisis. Lack of fair engagement would conversely fuel the risk of parachute research and ethics dumping (Schroeder et al., 2018), and it would decrease the likelihood that research findings are effectively implemented locally in routine care. Overall, the lack of engagement will aggravate the (postcolonial) asymmetries of power in global health, but also local power asymmetries, for instance, when peer-educators from the local community are not recognised as equal partners in research. Notwithstanding the increasing awareness, there are serious shortcomings in not recognising the importance of community engagement in practice, as shown by the Nairobi case study included in this paper. More action is needed, particularly from RECs and other key research stakeholders, to align policies and practices with ethics guidance and with evidence-based

recommendations from the academic literature to achieve meaningful engagement. Finally, ‘ethics’ lessons learned during the experiences of major outbreaks should also be applied by researchers and RECs to more localised and less media-tised outbreaks and crises that regularly hit vulnerable communities in resource-limited settings.

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