



# Competing ethics in a pilot strategy to implement parasitology training and research in post-Ebola Sierra Leone

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Much of the focus of public health research post-Ebola in Sierra Leone has been on rebuilding the healthcare system. However, very little attention has focused on capacity building in knowledge necessary for (bio)medical research, specifically around emerging opportunistic human pathogens that contribute to the high morbidity and mortality rates in Sierra Leone. In collaboration with academic staff from the University of Makeni, we engaged in a small-scale pilot intervention to strengthen medical parasitology teaching and research. The cultural competencies and ethical expertise provided by Sierra Leonean academics was critical to work in local communities and ensuring consent to undertake research. Yet, at the end of a day of collecting samples, in small pieces of conversation, the staff also explained ethical constraints they experienced taking part in research collaborations. They illustrate that, while on the surface all may seem well with a project, there can be harmful effects in terms of accessibility, ownership, cultural responsiveness and accountability, which should be taken into consideration when establishing networks and collaborations with universities from low-income countries.

**Keywords:** capacity building, ethics, intervention, parasitology, research challenges, Sierra Leone.

## Introduction

While the emphasis of public health research in Sierra Leone (SL) has been on rebuilding stronger and more resilient healthcare systems,<sup>1</sup> multidisciplinary approaches have also emphasised the need for better surveillance measures, diagnostic tools, therapies and awareness regarding hygiene and sanitation. International efforts have also concentrated on building collaborative research platforms between philanthropists, academia, industry and government for Ebola and post-Ebola and for zoonotic and neglected tropical diseases. Similarly, laboratory capacity, while neglected initially in public health,<sup>2</sup> became critical for disease infection prevention and control efforts. There was also a focus on sustainability of medical research and capacity building post-pandemic in low-income countries.<sup>3</sup> However, less attention has focused on the professional capacity building necessary for clinical research to take place, such as in degree programmes.<sup>4</sup> These are the tools and basic skills that professionals need to be able to work in laboratories and detect emerging pathogens in environmental samples.

Post-Ebola, numerous interventions have been set up in SL to rebuild laboratory capacity. However, they typically focus on strengthening diagnostic capacity, the quantity of needed tests, material infrastructure, safety or quality control measures, and they occur in clinical settings, such as district hospitals.<sup>5</sup> While such interventions are critical, they concentrate less on building long-term human capacity, which we argue should also be understood as critical to clinical laboratory and research strengthening. Thus a group of first responders during the 2013–16 Ebola epidemic as part of the UK's response,<sup>6,7</sup> designed a small-scale sustainable pilot intervention to strengthen medical parasitology teaching and research at the University of Makeni (UniMak). We realised that there was a need to be able to build national expertise so that the new laboratories created or enhanced in different hospitals and universities with resources provided by Public Health England (PHE) as part of their legacy programme (e.g. resources that were used to create the PHE Ebola laboratories in the Ebola Treatment Centres) could be used in the future in case of another epidemic,<sup>8,9</sup> such as the ongoing pandemic due to severe acute respiratory syndrome coronavirus 2.

This article describes the way in which a pilot intervention to strengthen (bio)medical parasitology teaching and research at UniMak was established. We describe competing ethical interests that emerged during the project and we argue that these small ethical misgivings illustrate sites of competing ethics. We feel ethical guidelines should be adapted in the Global North to be more inclusive of local contributions and ensure ownership of research in the Global South.

## 90 Pilot intervention project

The Infectious Disease Research Laboratory at UniMak<sup>10</sup> was built in collaboration with scientists from the University of Cambridge and funds from the Wellcome Trust in 2015, as well as with some equipment from the Public Health England (PHE) Ebola Laboratory at the Mateneh Ebola Treatment Centre (ETC) and support from the UK Department for International Development, as part of their legacy plan.<sup>6,8</sup>

Our intervention was designed with parasitologists from the Spanish universities of CEU San Pablo and Miguel Hernandez de Elche, who are experts in the detection of the emerging human opportunistic parasites we studied. Moreover, this project supports the strategies set up by World Health Organization (WHO) in coordination with the SL Ministry of Health and Sanitation and partners to strengthen capabilities for responding to public health emergencies and to reduce mortality and morbidity from communicable and non-communicable diseases.<sup>11</sup>

To ensure sustainability, a significant component of the project was to promote medical parasitology teaching at UniMak. An important part of clinical research capacity building is to ensure that parasitology skills become part of the national curriculum, educational training and professional development and practice. In parasitology research, capacity building across borders has always emphasised building partnerships,<sup>12</sup> but as the One Health initiative has illustrated, this is not free from competing interests and perspectives.<sup>13</sup> One Health argues for multidisciplinary research on human, animal and environmental interconnections, but there are arguments over what perspective, what theoretical (including ethical) paradigms and which reporting protocols should be followed.<sup>14-16</sup> Despite such tensions, the impetus of the One Health approach is also about the need to build capacity to respond to outbreaks of zoonotic pathogens,<sup>17</sup> such as in SL.

### The pilot intervention project

#### Planning phase

Before the project was set up, a member of the team with significant previous experience from the field during the 2014–16 Ebola outbreak visited UniMak. This visit was to ensure that research would be welcomed, to check the priorities of UniMak, to understand what UniMak felt has been successful previously and to discuss ethical issues of future international research collaborations. A pilot project was set up by the principal investigator (PI) of the project with two aims: to explore the potential presence and distribution of emerging enteric human zoonotic parasites and thus identify potential risks for human health and to build capacity by teaching basic parasitology and provide training on novel web-based resources for teaching and learning.

In the UK, the PI discussed the project with the team and requested ethical and governance approvals at De Montfort University (DMU) to perform this pilot intervention. Ethical approval was provided by the Research Ethics Committee at DMU (ref. 1851).

Moreover, as the preliminary idea was not only to engage in research but also exchange knowledge, a DMU PhD student skilled in novel molecular techniques for detecting emerging human parasites visited UniMak in April 2019 for 2 weeks to collaborate with two SL academics. Previous risk assessments (for both travelling and field work) were completed and approved by the Health, Safety and Wellbeing department at DMU on March 2019.

Ethical approval to collect, store and process relevant samples for monitoring different emerging human parasites at UniMak was also provided, with a risk assessment additionally overviewed and approved by the virologist professor at the University of Cambridge who helped build the laboratory.

#### Implementation and knowledge exchange

One of the SL academics was trained at the MA level, while the other had a supervisory role and was a highly skilled PhD who monitored the DMU PhD student. This supervision was inclusive of all the work undertaken in the field, as well as in the UniMak laboratory. Furthermore, the pilot intervention was reviewed by both UniMak academics to ensure that it would work in a classroom setting as well as during fieldwork.

During the project the SL academics also brokered relationships to identify and request permissions from male and female community leaders to enable collection of environmental (topsoil and water) and animal faecal samples from public and private locations of relevance for public health in Bombali district (one of the biggest districts in SL) to study the presence and distribution of different emerging human parasites, key unknown information to tailor and establish interventions to protect human health. The SL academics also assisted the PhD student and provided a short description of our project in the lingua Franca (Krio) and the local language (Temne). This was especially important as the protective gear, such as plastic aprons, gloves and plastic eye protection that was being used to collect samples, was reminiscent of Ebola times and great ethical sensitivity was needed to interact with communities. Their expertise in each community enabled the team to be able to collect samples across multiple locations, as most villages in SL are self-managed entities and permissions had to be requested to work in each new area.<sup>18</sup>

Appropriate standard operating procedures for the various methods to detect the different emerging opportunistic pathogens were provided. However, owing to a lack of appropriate equipment to extract DNA,<sup>19,20</sup> a portion of each sample was submitted to DMU for molecular analysis after gaining permission from the UK Animal and Plant Health Agency at the Department for Environment, Food and Rural Affairs (DEFRA; ITIMP19.0622). Despite efforts to enhance the laboratory capabilities, key pieces of equipment and software were missing for effective implementation of laboratory analysis, owing to a request by our university (DMU) to significantly reduce the original budget of the project proposal by half. This significant budgetary cut had a knock-on effect on our project, leading to the emergence of ethical issues and constraints in the field, such as the lack of available equipment to extract DNA. We discuss these ethical issues in more

195 detail later in this article. The team was unable to adapt the study proposal to meet the new budget due to time constraints, notably the requirement to complete the project by the end of July 2019 (project granted on 21 February 2019).

### Sustainability and teaching capabilities

200 To build on the teaching capabilities of medical parasitology at UniMak and to make our pilot intervention sustainable, a short course on basic parasitology was delivered during the UniMak undergraduate degree of Public Health: Medical Laboratory Sciences. The teaching and learning resource DMU e-Parasitology<sup>21</sup> was used to deliver this short course.

205 Following the success of the short course, UniMak academics have incorporated the DMU e-Parasitology resource in their university's curricula and undertaken curriculum modifications to enhance the medical parasitology of their undergraduate programme. This package is a publicly available and validated teaching and learning website with resources for a complete study of parasitology. Such virtual resources could be used by other universities to enhance and promote the teaching of medical parasitology to tackle different challenges, for instance, inadequate infrastructure, lack of appropriate teaching resources and shortage of qualified educators.<sup>22</sup>

### 215 Sites of competing ethics

220 Ethical guidelines have been developed around clinical research,<sup>23,24</sup> scientific partnerships<sup>25</sup> and checklists for equity in transnational research consortia.<sup>26</sup> Arguments have also been made for sustainability of research during and after epidemics, where foreign researchers 'parachute' in and out of a country instead of developing long-term 'roots'.<sup>27</sup> This situation also arises in One Health, thus, for example, helicoptering has been used for collecting samples for soil monitoring as described above.<sup>28</sup> Bockarie et al.<sup>29</sup> argue that this is because of limited infrastructure and capacity in the Global South, which major funders are now beginning to address. However, there is still a lot of ethical work to consider and undertake to ensure structural change when your African partners express 'misgivings' about the way in which research is being conducted. We need to reconsider our research 'ethics' and how we engage in the material practicalities.

235 Despite ethical guidelines and debates about research being conducted by foreign researchers in the Global South, Kalinga<sup>30</sup> argues that African researchers are placed between a rock and a hard place in terms of their research positionality, and are often kept in a type of handmaiden position, hiding misgivings about research production. We have a lot to learn from African researchers in order to improve not only equity and ethics in our research practices, but research itself. How can we seek decolonisation in education without also engaging in a critical reflection of research practices, rethinking the status quo to reposition Africa in global knowledge production?<sup>31</sup> According to Büyüm et al.,<sup>32</sup> 'decolonising global health advances an agenda of repoliticising and rehistoricising health through a paradigm shift, a leadership shift and a knowledge shift'. Repoliticising and rehistoricising thus means to reflect on political inequalities in

knowledge production and entails rethinking ethical paradigms (epistemological and ontological positioning). The ethical leadership in the bureaucracy of gaining ethical approvals is historically organised via paperwork at universities and institutional funding requirements, the creation of guidelines instead of co-creation, as well as understandings of equity and research partnerships from the perspective of the Global North.

255 Often the misgivings about how research is structured and practised occur in conversational asides, grumbling during field-work or private thoughts, which are not given ethical credence or investigated. We argue that these 'small' moments illustrate bigger ethical misgivings, where action needs to be taken and ethical guidelines and equity improved. Thus, at the end of a day of collecting samples, in small pieces of conversation, the SL staff explained the ethical constraints on their own involvement in the project: including lack of ownership, competing needs and prioritisation of teaching at university, the patrimonial system they worked in affecting reimbursement, lack of time to respond quickly to e-mails, lack of training in writing grants and their own resources to be able to engage in a true global research partnership or even leadership. These personal ethical dilemmas of the SL staff and also researchers in the UK to engage in partnership and capacity building were often competing with the bigger institutional ethics of the pilot project and its timescales. We have organised these ethical constraints that we as a team experienced in four main groups, which we discuss in turn.

### Accessibility of grants and responsiveness

275 The team had to be responsive to grants to be able to take a pilot project forward but noted that most grants were based in the Global North, making decolonisation of research (e.g., owned by Africans) impossible. The major grant funders, such as the European Union, Bill and Melinda Gates Foundation and Wellcome Trust, are all based in the English-speaking Global North and thus, even when developing research consortia in Africa, still control funds and set funding priorities and how funds are structured. While there are numerous funds that African researchers can apply for, such as the UK's Africa Research Excellence Fund (AREF), little work is carried out in building capacity for these applications or communicating about them. Very few of these funding bodies actively give training to African-based researchers and their universities to apply independently to their grants-online systems, making many funding streams inaccessible. There are also limited funding streams that are controlled by African funding bodies, as this is not typically seen as an area of local or global investment nor political duty for international research funders. In fact, some funding streams have a colonial history or are linked to development aid priorities.

290 We also had issues finding smaller pots of money to enable pilot research and a partnership to emerge organically. The UK's Department of International Development and United States Agency for International Development (USAID) both offer small grants for African researchers, but the funding priorities are set by the agencies, for example, for the African Research Network for Neglected Tropical Diseases. This affects innovation in new fields and affects the availability of grants to African priorities and responses, especially to issues that indigenous researchers are best placed to understand.

Similarly, the team had to be responsive to small internal university grants. These are small grants that are given by funding bodies to universities, such as Global Challenges Grants, that have a fast turnover and last-minute modifications, which gives limited time to build partnerships.<sup>25</sup> At our university (DMU) there was not much understanding of why time would be important in terms of the constraints that our partners had to deal with, such as the realities of losing electricity, inaccessibility of the Internet, lack of key laboratory equipment, prioritisation of paid employment and regular experiences of illness such as malaria and enteric infections, as well as obligations to large kinship groups. When the project did gain internal funding, building medical parasitology capacity and education at a small university was not seen as a 'big' or 'trendy' public health priority. In fact, we had to share funding with another project, affecting how much we could afford to pay our SL partners and research assistants, including the provision of specific equipment. This resulted in a 'domino effect' impacting different areas of our pilot intervention and affecting aspects like ownership.

### Ownership

Despite the aims of partnership, the study was defunded and controlled by a PI based in the UK, which affected conceptions of ownership. The intellectual direction and resources were flowing in a top-down direction to the SL partners. They were also involved in their own teaching and research on top of their day-to-day work because of a lack of prioritisation and funding cuts of the pilot project in the UK. While the partners had input into the research design, we argue that the tone was already set and, as a result, research was not experienced equitably. Munung et al.<sup>4</sup> found that if research is not equitable it opens up feelings of exploitation in African researchers, as they are the ones often being requested to effectively 'do' the research without experiencing the research process as empowering or benefiting financially or in terms of career progression. Feelings of exploitation also arise because they are the ones doing all of the groundwork for the project.

### Cultural brokers and ethics

While much of the study appeared to be top-down, it could not have been completed without the cultural competence and ethical sensitivity of working in diverse communities that the partners had built up post-Ebola. The study had ethical approvals in place from both universities, but it still needed ethical approvals or permissions from the communities we were going to work in and collect samples from. This ethical need for local expertise and approvals was initially ignored. Nor were there opportunities within internal or external ethical governance arrangements where such issues could have been raised, and they were only found when our PhD student arrived in SL. Moreover, UniMak governance gave consent to carry out the intervention despite all the protocols and literature of the pilot project being provided in English. Thus this process was shown to be flawed, as there is a need to consider ethics in relation to social and cultural norms, including literacy, and thus a need to translate all documents into local languages. Likewise, cultural sensitivity training in how to work in differing communities is needed to aid foreign researchers.<sup>30,33</sup>

As well as dealing with the above issues, there were challenges in introducing the DMU researcher to the basics of fieldwork. Challenges included engaging in additional emotional labour, use of their private time, laboratory space and resources to start sampling collection and storage to meet the tight time schedule requested by the funder, on top of their expected duties as lecturers. These competing demands affected accountability within the project.

### Accountability and trust

Accountability and trust are difficult to gauge in SL's patrimonial culture, where the benefits of research do not always trickle down to the research assistants, despite terms of payment and agreements made with the university. These feelings of frustration and unfairness experienced by SL researchers meant mistrust from the team towards UniMak. It was also difficult to know what to do in regards to this, especially in the middle of a project that has to produce results in a short turnaround to justify the grant, causing a trust to breakdown from the view of the SL researchers. This manifested as the 'elephant in the room' in terms of accountability of both universities and ignoring SL staff as beneficiaries, as discussed by Asgary and Waldman.<sup>34</sup> Although we did not have ethical guidelines in place to ensure internal accountability at UniMak, SL staff benefitted from the project in terms of skills and outputs, which could facilitate their career progression.

There were also issues in terms of commercial accountability and the time it took samples to reach our laboratory at DMU for molecular analysis of parasites to the species level. Unfortunately, the samples were shipped just before the end of the financial year at DMU (end of July 2019), which categorised our project as completed. Thus completion of the project and writing up of results became challenging due to limitations in funding. Despite the lack of funds, project timescales to provide results were still running to justify our grant. This was often experienced as another burden on SL staff, who had to deal with such requests post-project with no further payments. The impact of inadequate funding on retaining newly trained health professionals in West Africa has also been described elsewhere.<sup>3</sup> While in the Global North we were prepared, had permanent research contracts and were aware that a project often continues after funding ends, this was not experienced the same way by our collaborators. Accountability should be understood in broader terms of universities to their staff as well as to researchers in the Global South, who are frequently put in inequitable positions.

### Conclusions and recommendations

This pilot intervention project was successful in building and strengthening research and teaching capabilities on medical parasitology at UniMak, i.e. by building knowledge necessary for (bio)medical research to respond to future outbreaks of infection by emerging zoonotic parasites. While we have noted several ethical guidelines and frameworks that guided our research, ethical misgivings rumbled in the background of this project. These need to be addressed in more robust global ethical guidelines that ethics committees and governance structures can take forward. Ethical governance is usually about humans or animals,



but we rarely think about issues of partnership or beneficiaries or even what ‘the good’ would entail in the Global South, in terms of One Health in research collaborations,<sup>15</sup> despite discourses of decolonisation in education and research production in global health. Based on the sites in which we have identified ethical misgivings in the small moments of fieldwork, we make the following recommendations.

First, we argue that ethical governance structures, nationally and internationally, need to make explicit as part of research protocols, what kind of partnership is being embarked on in a research project and how ‘co-ethics’ is envisaged. This requires a rethinking of the way in which we approach governance so that it is supported by all research partners and universities involved. The ethical strengths and weakness should be outlined and how the cultural competence of the partners will aid a project’s success.

If it is a new collaboration, the team needs to elucidate what ethical practices each collaborator will be following to ensure that research occurs in an equitable manner as part of a memorandum of understanding. Similarly, if it is a long-term partnership, the equal benefits to members of the team could be elaborated, as well as the skills that will be shared mutually between the partners. If the partnerships seek a transferal of skills and expertise from one area to another for educational or other purposes, this should also be made explicit.

Second, universities need to acknowledge that they form a part of ethical procedures and political and financial dynamics that affect clinical research production. As part of major research platforms, they should take a more active role in identifying their own ethical limitations, for example, in financial oversight, which could be done by an independent global research ombudsman to ensure more transparency.

Third, funders need to do more to ensure equity in practice by making grants processes more accessible and ensuring reasonable adjustments are in place for African researchers. Instead of researchers facing the pressure of functioning in an unethical system, we argue that funders could work with existing bodies, like the British Council, to ensure more outreach, training and accessibility of infrastructure needed to participate in funding on a more equitable basis. There is also a presupposition about funding streams going from North to South, but they can also shift from South to North, which could also be encouraged. For instance, imagine a Sierra Leonean PI investigating the impact of COVID-19 on the African diaspora in the UK. Likewise, independent African funding bodies should be established to aid decolonisation of research and research ethics so that funding, priorities and research infrastructure and development are controlled by Africans and African funders. This could be done in several ways, by researchers lobbying African governments and pan-African institutions to set one up, to make it a condition of development aid or to ask major international funders and philanthropists to divest some of their power and control by setting one up themselves.

Fourth, funders, commercial sectors and universities need to do more to narrow the infrastructural and capacity gap that exists when research is undertaken in low-income countries. There should also be more thought given to smaller pots of money being made accessible to ensure piloting of projects and small-scale research interventions controlled by African PIs and with research

questions and priorities set by them. The sustainability of research design could also be improved by thinking about in-kind contributions to laboratory infrastructure or capacity building of educational courses by offering training to build up to the PhD level or continuing professional development schemes.

In relation to what we as individuals can do, we can do small things like listen, describing ethical misgivings and taking seriously calls to decolonise. We can start writing honestly about our collaborators’ ethical misgivings and asking why things are not more equitable and we can begin questioning institutional ethics, governance and guidelines as they currently function in clinical and other forms of research. We can begin to lobby governments, our universities’ ethical committees and major funding bodies, as researchers, to rethink the way they understand ‘ethics’, because research is not equitable.

We also recommend more field experience and hands-on time with collaborators instead of ‘parachuting’ in researchers who build their careers on a crisis and are never heard from again. We recommend funders and universities make mutual funds available to work for a university or country to gain grassroots experience and build relationships. In our case, working in the country and visiting the university to gain appropriate knowledge of the field was the key to successfully implementing our pilot intervention and developing a trustworthy partnership between both universities in a very short time. Any visits or work would also provide an excellent platform for drafting and agreeing on a joint project with an African PI, which will allow a rethinking of the ethical issues and limitations that we have described. Projects can run smoother as African participants will feel engaged at the start and as ‘owners’ of research in the Global North or South. This will also lead to better capacity building and allow co-creation of ethics.

In conclusion, we argue that ethical misgivings about the way in which research is conducted should not be ignored. They illustrate that while, on the surface, all seems well with a project, there is a harmful effect occurring in terms of accessibility, ownership, cultural responsiveness and accountability. It is essential that we question why researchers feel such misgivings and investigate how we can change our ethical policies and practices to become more inclusive and sustainable long-term. It is not acceptable that ethical misgivings are normalised as ‘just the way things are’. Presently the onus is on researchers to change research practices, not on universities, commercial sectors or funders, who we argue should bear the responsibilities and costs to ensure more equitable policies and practices as well as contribute to decolonisation of research. Instead of ‘ethics’, regardless of what research you are doing, solely becoming a tick-box exercise, it has to be seen as organic and in keeping with the ethical concerns and cultural sensitivities of the people we work with and for beneficiaries. We have to become nimble, agile, open and sensitive to culturally change our understandings of ethics in tune with the times in which we live.

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