Africa APPG inquiry: Ebola and community led health systems

Response to call for evidence by the Ebola Response Anthropology Platform

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Introduction

The ongoing 2014-15 West Africa Ebola epidemic is a global health crisis of exceptional scale. While the epidemic appears to be declining, there is no doubt that the epidemic has long term implications for global infectious disease control, health system responsiveness and the broader social, economic and political welfare of people affected by major health crises.

The Ebola Response Anthropology Platform is pleased to respond to the questions raised by the APPG inquiry. The Platform was established in October 2014 by staff from the London School of Hygiene and Tropical Medicine, the Institute of Development Studies, the University of Sussex, the University of Exeter and Njala University, Sierra Leone. Core members of the Platform have long-term ethnographic experience and international reputations in the West African region, medical anthropology, international development and humanitarian assistance. Our aim is to provide a forum for anthropologists and outbreak control teams to work together to develop a co-ordinated, adaptive and iterative response to the Ebola epidemic. By drawing upon existing anthropological expertise, and undertaking targeted fieldwork, it is hoped that efforts to contain the epidemic will be enhanced by providing clear, practical, real-time advice about how to engage with crucial socio-cultural and political dimensions of the outbreak and build locally-appropriate interventions.

Since October 2014, we have worked closely with the UK Department for International Development, Ministry of Defence, World Health Organization, UNMEER and a number of non-governmental organisations. In the first three months of the Platform's existence, we wrote and/or contributed to 32 written briefings or policy guidance documents. In addition, core members of the Platform have contributed to a number of high-level working groups, including the Anthropology and Social Science sub-group of the UK Government Scientific Advisory Group for Emergencies (SAGE), Oxford clinical trials steering committee; Scientific Steering Committee for Faviparavir trial in Guinea; WHO Ethics of Ebola Therapeutics Consultation and the WHO SAGE Working Group on Ebola Vaccines and Vaccinations.

This submission draws upon this work and highlights the need for developing health systems and health crisis response mechanisms that actively seek, engage and adapt to local voices and concerns in the communities they serve. We emphasise the key role that anthropologists can play in facilitating these processes and recommend their inclusion in all future humanitarian crisis responses. In addition, we call for a long term commitment to developing local anthropological expertise, focusing on those countries vulnerable to humanitarian crises.

We present our submission concisely in bullet points and primarily refer to our work in Sierra Leone. We shall be happy to expand on any particular point on request.

1. What lessons can be learnt from the recent Ebola crisis in West Africa regarding the role of communities in response to health crises, and more broadly in relation to health systems at the local level?

- In Sierra Leone, there is increasing evidence that the incidence of Ebola started to decline in a few districts (notably Kenema and Kailahun), before there was a concerted international response. In other districts, it is harder to analyse the relationship (or lack of relationship) between changing patterns of Ebola and international assistance.
- Research undertaken by core members of the Platform suggests, however, that local responses within villages, as well as responses at section and chiefdom levels, played a vital role in curtailing the epidemic. While formal response interventions (such as the establishment of community care centres) assisted community responses, they would have been insufficient in themselves to reverse transmission without individuals, households and wider community groups actively learning and responding to the crisis. Indeed, it seems likely that locally generated responses such as the active imposition of bye-laws restricting movement, changing care practises for the sick and the deceased were more effective at interrupting transmission.
- A large body of anthropological research undertaken in West Africa and other parts of sub-Saharan Africa demonstrates that care seeking practices are not only influenced by local assessments of the availability and quality of health services, but also by local understandings and responses to a wide variety of social, economic and political issues.
- In the context of weak and fragile public services (i.e. contexts that are particularly vulnerable to major infectious disease epidemics), people often place great trust in non-formal health providers in both non-crisis and crisis situations. Typically, this trust is an entirely justified pragmatic response to inadequate and/or inaccessible formal health services. It is thus inappropriate to interpret responses such as a reluctance to seek biomedical care at a community care centre as a reflection of unchanging cultural or traditional beliefs and practices.
- Failing to engage with local actors, networks and institutions and not engaging seriously with local concerns can lead to national or international actors designing interventions that are not in the best interests of those people they purport to help. In some cases, this can end up generating local resistance and hostility.
- A coordinated response that is organised along centralised, top-down modes of command and information management is particularly prone to making and failing to correct assumptions about contemporaneous priorities of those affected by a potentially rapidly evolving outbreak.
- Differences in social practices are particularly prone to misinterpretation and misrepresentation by those unfamiliar with a particular social group. Where an outbreak is primarily driven by such social practices, it is imperative that operational decisions can be substantively altered by those living and working at a local level.
- Poor engagement, refusal to comply and/or active hostility towards external response personnel should in the first instance be interpreted as a problem with the nature of the response itself, rather than problematizing the communities involved.
- How a major health crisis, and formal responses to that crisis, influence care-seeking and at-risk practices is context specific, limiting the extent to which interventions developed in one crisis can be effectively rolled out, unchanged, in another crisis. Nevertheless, some useful generalisations can be made, including the need to put in place robust community

engagement mechanisms enabling community concerns to be considered alongside clinical and epidemiological ideas and advice.

2. What more could the UK be doing to promote and enable the community engagement and ownership of health and health systems abroad, particularly in African countries?

- It would be helpful to promote people-centred health systems that involve, and are accountable to, the many different groups that make up 'communities'. Such an approach involves recognising that a one size fits all approach is unlikely to be effective.
- Improving the extent to which a health system engages meaningfully with local communities necessitates a detailed understanding of past and current relationships between different community and health system actors in each locality, recognising the ways in which external interventions can re-inforce existing hierarchies and the fact that they do not necessarily reach out to the poorest and most marginal groups.
- All health and health system policies should actively consider their potential social, economic, political and cultural impacts for different social groups.
- In contrast to recent experiences with the West African Ebola outbreak, it is critical that community engagement is not considered expedient or of secondary importance to clinical or logistic concerns during an acute health crisis.
- The UK Government should recognise the serious harms that can result from centralising the UK government's humanitarian and development decision-making bodies in Whitehall, and balance the need for a degree of central oversight of government activities against the increased risk of unintended consequences that result from decisions being made without a detailed understanding of the local situation.

3. To what degree are the current policies, resourcing and programming of the UK Government promoting community engagement and ownership of health and health systems in low- and middle-income countries?

It is beyond the remit of the Ebola Response Anthropology Platform to respond to this question.

4. What are the principal challenges and gaps in responding to the Ebola crisis in rural and interior areas? What actions could be taken by the UK Government to improve that response?

- Rural and 'interior' areas should not be considered to be separate or remote from urban areas. People move frequently between rural and urban areas (and across national borders) for a wide array of social and economic reasons, including the search for health care.
- The Ebola response has been characterised by centralised, top-down operational and information management structures. This has meant that the response has been slow to recognise and adapt to local concerns and challenges, particularly in the early stages of the epidemic. Key challenges experienced at the beginning included failing to recognise:

    - the harmful effects of early health communication messages that inadvertently dissuaded people from seeking care;
    - that many people did everything they could to respect for the dead, even if this was at the expense of protecting their own health;
    - that punishing and blaming people for not accessing dysfunctional interventions (e.g. emergency call centres, ambulance service and clinical care facilities in the early months of the outbreak) is likely to further alienate them from the response;
    - that the way in which interventions are delivered, and by whom, has as much of an impact on their effectiveness and acceptability as the nature of the intervention itself. The centralised organisation of safe burials in Sierra Leone, which was done by burial teams from the district headquarters is an example of this. Despite efforts to make medical burials more acceptable by allowing family members to attend funerals there was persistent unhappiness that the actual procedure was carried out by 'strangers' or by people of the wrong gender or age. Some districts attempted to overcome this by creating chiefdom burial teams where locals from the chiefdom would be trained and involved in burials in their locality alongside the district burial teams. However these chiefdom burial teams were often not given the supplies and transport needed to perform their role effectively , meaning that the de-centralisation and local ownership of burials was limited and continued to cause dissatisfaction.
- While some of these challenges could reasonably have been foreseen, others were less easy to predict. The lessons to learn include the following:
    - Local concerns and priorities need to be taken very seriously from the very beginning of any crisis response.
    - It is important to establish explicit pathways for understanding and responding to heterogeneous local (i.e. sub-district level) contexts. Such pathways only work if there is mutual trust and respect between response personnel and the communities they serve. Developing trust and respect takes time, meaning that it is all the more essential to prioritise this during non-crisis situations.
- The UK Government can help create the space for local voices to be heard and give legitimacy to these voices through mechanisms such as the Ebola Response Anthropology Platform. The experience, skills and position of anthropologists make them ideally placed to provide an independent means to access multiple community voices with expertise in avoiding misinterpretation of concerns and misrepresentation of 'the community' through for example the over-representation of more powerful individuals or groups.

5. What, if any, are the barriers to successful and sustainable engagement of communities in health crisis response

- Inadvertently or actively characterising local social practices as problematic in themselves without considering why it might be preferable to continue with practises that from the outside appear to be risky.
- Lack of information flow from the local level to operational centres, and a reluctance to amend programmes in the light of local concerns.
- Focusing communication efforts on standardised messages that attempt to convey solutions that may not be appropriate for a given local context, rather than supporting and enabling local problem solving.

- The tendency when faced with a worsening crisis to rely increasingly on outside support and intervention, at the expense of efforts to meaningfully engage with different community groups.
- 'Elite capture' and over-representation of more powerful groups. Although it is important to consider the potential for elite capture – particularly when the transfer of resources is involved – it is also important to note that the potential for elite capture can act as a deterrent. It is crucial that the danger of misrepresentation is addressed not by avoidance or caution, but by reflective engagement with multiple community voices.

6. What external policy, strategy and programming models could the UK Government support or adopt in order to improve their own and wider global response to this issue?

- During this and previous Ebola outbreaks, anthropologists have played a unique role in accessing local voices to effectively convey crucial local considerations and concerns to response personnel.
- The Ebola Response Anthropology Platform is one of a number of networks of anthropologists that was rapidly mobilised in order to contribute to the Ebola response during this epidemic. Brought together at speed, the Platform is an active network of national and international anthropologists with regional ethnographic experience and/or expertise in medical or humanitarian interventions.
- The contribution that the Platform and other anthropologists have made to the current crisis response illustrates how scholars at a range of universities can usefully contribute to humanitarian interventions. .
- The request for anthropological expertise during the Ebola crisis from UK DFID, the Ministry of Defence, international NGOs, WHO among others was heartening and reflects a growing recognition that it is vital to understand the socio-cultural, political, economic and historical context in which humanitarian interventions occur, if the interventions are to be effective. Given that the demand for, and mobilisation of, anthropology scholars is so novel, it is important to consider how long term support of this kind can be provided effectively.
- As Ebola transmission stops and this particular crisis resolves, the expertise that anthropologists who have been involved with the response have acquired may get lost unless there is an ongoing long term commitment to maintaining and developing anthropological capacity in the area of humanitarianism, both in the UK and countries vulnerable to crises.
- A critical component of the success of anthropological engagement with the Ebola crisis response was the involvement of local anthropologists. Yet the dearth of local anthropological capacity in the region (as well as many other regions equally vulnerable to major health humanitarian crises) is also one of the major constraints of effectively integrating anthropologists into crisis responses. It is imperative that efforts to develop mechanisms enabling a more effective short-term anthropological mobilisation around particular crises is complemented by sustainable long-term capacity building of local anthropological expertise in crisis-prone regions.
- Local anthropologists would be invaluable in efforts to develop more people-centred, locally engaged health systems in weak and fragile states even during non-crisis situations. Actively developing local anthropological expertise in order to contribute to non-crisis health system strengthening programmes would be an ideal method to foster more community led health

systems, while simultaneously developing well-trained local anthropologists with excellent local relationships who would be ideally positioned to respond to major crises.

We therefore propose that the UK government supports a sustainable capacity for fostering and mobilising anthropological expertise in medical humanitarianism and international development.

7. In your opinion, is there value in the stress testing of health system function and if so what models could the UK support to promote health system preparedness for future crises?

- It is unlikely that any simulation of the 'stress' that a health system will face when confronted with an epidemic similar to Ebola will give useful information about how the many actors and institutions involved will respond in reality.
- While such 'testing' may be useful to streamline central operational procedures, community responses in a 'test' are highly unlikely to reflect responses during a genuine major outbreak. If stress testing is undertaken, it is therefore imperative that it be recognised as testing only a part of the overall response.
- Finally, weak or fragile health systems are characterised by substantial 'stress' even in a non-crisis situation. Rather than simulating the effects of an additional, system-wide stress such as an infectious disease epidemic, more should be done to understand everyday stresses to health systems, their impacts and ways of mitigating or avoiding them.

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This report was written by Melissa Parker , Fred Martineau and Annie Wilkinson on behalf of the Ebola Response Anthropology Platform, independently from our funders whose views may differ from those expressed here.

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