Africa APPG inquiry:
Community led health systems & the Ebola outbreak

Submission from the Institute of Development Studies (IDS)

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INTRODUCTION

The Ebola crisis of 2014-15 has brought questions around the roles of communities and health systems into sharp relief – both in relation to crisis response, and to the challenges of post-crisis recovery and building resilience to future epidemics. The Institute of Development Studies is pleased to make this submission to the APPG inquiry on these crucial questions.

The Institute of Development Studies (IDS) is a leading global institution for development research, teaching and learning, and impact and communications, based at the University of Sussex. Our vision is a world in which poverty does not exist, social justice prevails and sustainable economic growth is focused on improving human wellbeing. We believe that research knowledge can drive the change that must happen in order for this vision to be realised.

The Institute is creating and pursuing a vision of 'engaged excellence' and a more global positioning to ensure that rigorous, robust research evidence is co-created and shared with change agents positioned to act, around local, national and global development challenges. We are strategising to make substantial progress on what we see as the three defining challenges in contemporary times: reducing inequalities, accelerating sustainability, and building inclusive and secure societies. We are ensuring that research, evidence and policy engagements in the Institute's specific thematic clusters contribute substantively to these major global challenges.

The evidence and analysis we provide here draws on several strands of work by IDS and partners:

1. Aspects of work under the auspices of the *Ebola Response Anthropology Platform* (www.ebola-anthropology.net) established in 2014 by researchers at IDS, the London School of Hygiene and Tropical Medicine, University of Sussex, University of Exeter and Njala University College Sierra Leone, to draw social and cultural knowledge and advice into the Ebola response. The Platform is likely also to make a separate submission to the APPG inquiry drawing more substantially on its work.
2. The *Ebola: Lessons for Development* initiative (http://www.ids.ac.uk/project/ebola-lessons-for-development) co-ordinated by IDS during 2014-15 to consider the social, political and economic dynamics underlying the crisis, and implications for future recovery.
3. Longstanding research on health systems and development, including community dimensions, conducted by researchers at IDS with international partners, including through the Future Health Systems Consortium (http://www.futurehealthsystems.org/).

While this submission draws evidence from these broader streams of work, direct contributors are Amber Huff, Melissa Leach, Annie Wilkinson and Pauline Oosterhoff.

EVIDENCE

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?

(a) Lessons learned regarding the role of communities in response to health crises

Members of affected communities have crucial roles to play in the context of epidemics and outbreaks of infectious diseases like Ebola. Research is currently underway to determine which factors brought the epidemic under control (as it appears to be in Liberia and Sierra Leone). In the meantime, it is important to note that in some places the curve of the epidemic had turned before the arrival of significant Ebola control efforts (e.g. in Liberia, in Eastern Sierra Leone and in countless individual villages). The virulence and horizontal transmission of an epidemic often decrease over time without intervention, but factors at the community level were highly likely to have been significant to control in the Ebola epidemic. As a disease that spreads through social networks, in care settings and in the context of funerary practices, the role of the community can be both positive and negative, either driving or curtailing spread. It is therefore vital to understand which factors influence community responses.

In a great many instances, local populations have experience of, have learned from, and frequently have initiated behavioural changes that have limited the spread of, infectious disease outbreaks, including outbreaks of Ebola Virus Disease, both alongside and in the absence of external intervention. For example, in previous outbreaks in Uganda and Congo local populations have drawn on a wealth of knowledge to devise effective control strategies that adapt social and ritual practices to balance socio-cultural and infection control priorities. Evidence from this outbreak shows that adaptive behaviours occur rapidly. In July, communities in urban Liberia were organising local task forces to carry out neighbourhood surveillance, and families were planning how to deal with sick loved ones in their households. The use of plastic bags as makeshift protective gear was a local innovation, the use of which diffused rapidly though social media and word of mouth. As early as September, villagers in Sierra Leone were familiar with Ebola transmission pathways and had changed their care practices to report sickness to chiefs and Ebola health facilities. By and large, these villagers comply with extraordinary measures such as quarantine and medical burial. Elsewhere synergies have been found between local ritual concerns and biomedical ones, as demonstrated in the burial of a pregnant Kissi woman.

Behaviour change and effective control strategies do not have to be based on everybody thinking and believing the same, and this is unlikely to ever be achievable. Anthropological evidence and analysis has underlined the social, cultural and material significance of practices around caring for the very sick and dead in communities in this region. While there is variation between groups, proper protocols to ensure a 'good' death and settle matters of kinship and inheritance are central, as are the roles of local institutions – such as the women's and men's initiation societies - in upholding these. Disrespect for such practices by outbreak control teams has in many instances incited local resistance and encouraged hiding of cases, thwarting control efforts.

Ebola has shown how epidemics can be amplified when trust and mutual support between communities, health systems and the state or international organisations is absent. Systemic socioeconomic inequalities, exclusions, and a lack of bureaucratic transparency have resulted

in a situation in which everyday people often do not trust the explanations, intentions or interventions promoted by government representatives and foreign organizations. This distrust and suspicion is rooted in long histories of states and international actors being disinterested in poor and rural populations until there were things of value, like slaves, land or minerals, which could be gained from them. Likewise, officials and aid workers often dismiss the fears, concerns, and behaviours of affected populations as 'ignorance' or 'tradition' instead of confronting the realities and politics of everyday life. This leads to local suspicion around and resistance to even the best-intentioned intervention programmes, erects barriers to effective community engagement and collaboration, and limits the appreciation of local knowledge, experience, and concerns in the context of international response efforts.

Effective responses need to be organised around meaningful collaboration from the beginning, in ways that involve local people and local knowledge in designing response strategies in partnership with biomedical, social science and other expertise. Considering all of this, radically greater investment is needed to learn from and support successful local response capacity, and to demonstrate how substantive collaborations can be realised at scale. In order to ensure that interventions are appropriate, inclusive, and relevant to context, local experience, knowledge and perspectives on containing infectious diseases should be at the centre of public health and biomedical response strategies.

(b) Lessons learned regarding the role of health systems at a local level

In terms of health systems, it is not controversial to say that the public health systems of the most heavily affected West African countries have failed on a basic level to protect local populations in the context of the Ebola epidemic, and may even have amplified spread through nosocomial infections. Health systems in these – as in many low-income countries, where outbreaks are most likely to occur - have been chronically under-supported and have often been gutted by policy reforms aimed at decentralisation and privatization. As a result, they do not have the means or resilience to respond to infectious disease outbreaks or other emergencies and crises. At a local level, staffing, materials, and medicine shortages means that people cannot reliably access care, and that the ability for local clinicians and staff to respond to emerging crises is compromised.

Building a resilient health system over the longer term requires time, hard work, political will, and will have to think beyond 'rebuilding' to 'building differently' in the post-Ebola context. We should be aware of the limits to humanitarian responses and on over-reliance on NGOs and vertical, disease-specific programmes to deliver services, as they rarely achieve the longer-term system strengthening which is required. System strengthening that would improve responses to Ebola and other epidemics includes developing a better surveillance system and offering care in terms of health and safety to all health workers, both formal and informal. These efforts have to be undertaken simultaneously with other health system measures such as reducing maternal and infant mortality. What is needed is a strategy towards universal access starting at the primary health level.

In Sierra Leone, Peripheral Health Units (PHUs) offer primary care at the community level. They are the first step in the triage and referral process that would – ideally - detect notifiable or unusual diseases early. However, they are perceived as gendered facilities, providing primarily maternal and child health care. This is a reflection of the substantial donor, government and NGO funds which have been channelled towards maternal and child health targets – most iconically in the Free Health Care Initiative which offers free health care to

pregnant women, nursing mothers and children under five. PHUs, and hospitals, are therefore often not the first point of call for men, children over 5, and women not pregnant or nursing. Pharmacies and informal health providers are popular instead, where prices may be lower and distances to travel shorter. Without truly universal access (affordable and equitable) at the level of primary care, the capacity of a health system to detect and respond to disease is dangerously skewed.

The pre-Ebola system where nurses were not trained in basic triage or infection control, and where they did not have the sanitary facilities or the equipment needed to implement such strategies even if they were trained, does little to build confidence in a formal health system. The popularity of Ebola Community Care Centres (CCCs), many of which offer free treatment for common (Ebola-like) diseases, and which have water and electricity illustrates the unmet need and the fact that people do respond to evidence of high quality care. They also respond to low quality care, by avoiding it.

Thus, perhaps some of the most salient lessons learned from this crisis regarding health systems at a local level relate to the need not to rebuild a dysfunctional health system, but to 'build differently' for the long term going forward. This would involve the following:

- Invest resources in basic public health measures that strengthen disease surveillance and reduce the risk of transmission of infections. Zoonotic spillover events (when a human is infected by a virus or bacterium that normally affects another animal) can be contained if there is capacity for early detection, tracing of contacts and quarantine measures that are appropriate. This hinges on primary care facilities that are attractive, perceived as effective and accessible for all, and could be hubs for outreach into harder to reach communities and social groups.
- Attention must be paid to ensuring safe and quality care. This means putting in effort and resources to build capacity for health worker training in affected countries, to train, supervise and pay people who are already health workers, to ensure safe occupational environments for health workers and to give reliable access to safe drugs
- Building trust in health systems through improved services. People need to experience high quality and compassionate care, where they feel that their lives matter.
- Improve accountability and public administration of services. There are structural factors in the public administration of health care such as payment mechanisms, staff incentives and training that influence how staff interact with patients. Regular payment of staff is likely to make nurses more sympathetic and diminishes the need for them to charge fees for things that should be free.

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?

Engagement of local stakeholders and communities is key for future policy for epidemic preparedness, and for the long-term effort of building a resilient health system. Therefore, concerns for broad community engagement should be mainstreamed into post-epidemic research and planning. Serious efforts should be made to encourage and strengthen bottom-up policy making and public accountability. This involves collaboration between civil society groups and the private and public health sector. Currently health services available at the community level do not meet the needs of local people. Essential health services should be universally available, but there are different ways of offering these essential services and there should be room to discuss how the quality of the service delivery can be improved.

Planners can begin with identifying the needs of different groups of people by asking them about their needs, without the appearance of prejudice or dismissal, to help open new, inclusive spaces of dialog. Public engagement of the formal health sector at the local level can improve primary health, and may also make expert knowledge more accessible to everyday people.

Serious effort at community engagement is essential for developing appropriate services and to establish to what degree communities want 'ownership' and what this means. Ownership should not be confused with poor communities taking over the work of the state to provide health care. Care should be given to avoid the impression that that the poorest contribute their time and labour without payment while local elites take the paid jobs as has been the case. Local and international social scientists can play important roles in facilitating community engagement and strengthening upwards and downwards public accountability and the two-way flow of knowledge.

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?

In recent years the UK Government through its bilateral aid programme has contributed considerable resources to policies and programmes aimed at health care access, focusing on the 26 low income countries that are DFID's current target focus. The UK has also contributed resources to international initiatives such as the Global Fund to fight AIDS, TB and Malaria. However, much of this effort has focused on vertical, single disease or social group-focused interventions. There has been insufficient attention to the broader building and strengthening of health systems, and to full community engagement and ownership of these processes. This should be a priority for the future, amidst a focusing of aid resources on universal health care access.

Note should also be made of the important support to evidence and analysis towards health system building provided through DFID's support to Research Programme Consortia (RPCs) and related major policy-oriented research programmes. These have provided a very effective vehicle to design, pilot and learn from interventions in health system strengthening across a variety of low- and middle- income contexts. It is important that this support continue, and if possible link with expanded efforts also from UK Research Councils (the Medical Research Council, Economic and Social Research Council). Lessons from the Ebola crisis highlight important opportunities to focus such support even more strongly on strategies for full community engagement, health systems governance, and integrating surveillance capacities into broader health systems.

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?

The Ebola-affected countries all have large rural and interior areas poorly served by transport networks. Especially in the rainy season, sheer inaccessibility prevented outbreak control teams from reaching many areas and made it very difficult for people to access health facilities. The strategy of developing decentralised ECUs/CCCs aimed to respond to this challenge, but was only partially effective.
As the outbreak progressed, ambulance services to more distant locations improved, as did the system of phone numbers to call for people concerned that they had Ebola. Challenges

remained however for the most inaccessible villages and for people lacking access to a mobile phone network/service.

Future responses to epidemics could be improved by investments in fully decentralised health services, so that the distance rural people have to travel to reach PHUs is reduced. Investments in improving rural road networks and transport facilities could valuably be integrated with such health system building. There are also major opportunities to enhance epidemic surveillance and response through the use of mobile and digital means, for instance through SMS-based services. A number of pilot schemes are in development, mostly by business and philanthropic actors. These deserve more co-ordinated attention and support in the context of a UK government strategy to (re) build health systems and epidemic preparedness.

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

Atmospheres of mistrust and exclusion are among the most salient drivers of epidemics, and have caused troubled interactions between response workers and communities in the most affected countries. There has been sometimes violent resistance to Ebola interventions – with many examples in Guinea and Sierra Leone. These instances of resistance, and the rumours and conspiracies that have circulated around Ebola and the responses of national and foreign outbreak control teams, reflect longer-term histories of distrust and exclusion, as well as of resource appropriation and political interference by state and business actors. The details of such dynamics vary between countries and regions. However their importance underlines that future sustainable engagement of communities in health crisis response also requires wider attention to governance in the region, including the building of inclusive, accountable relationships between citizens and the state, the fostering of trusted local and intermediary institutions, and effective regulation of corporate investments (eg. in land and mining) to ensure that they are supporting, not undermining, community rights, voice and livelihoods (http://www.ids.ac.uk/project/ebola-lessons-for-development).

Many grassroots social groups – formal and informal – have been weakened by the Ebola epidemic. They may need support to take back their space in the public arena. There will be challenges to reach consensus on the channels through which such support could and should go through and the extent to which national states control external international support to the (I)NGO and their grassroots partners. The atmospheres of mistrust are not limited to the relation between national citizens and the state and include also distrust in international organizations or national umbrella organizations based in capital cities. They are linked to legal concepts and principles such as national sovereignty, which are deeply political and shape the public arena.

Atmospheres of mistrust manifest in assumptions about the ignorance of rural or poor populations, matched with suspicions on the side of those marginalised populations that response officials have ulterior motives – a point proved by evidence of misappropriated Ebola funds.

Both national and international officials have all too often dismissed people's fears as 'selfishness' and 'stubbornness' or the result of deeply ingrained 'traditional culture'. But Western health organisations' official recommendations – including on Ebola transmission – have also not been consistent and have left people to come up with their own solutions. For

example, WHO and CDC have given vague and possibly conflicting messages on the sexual transmission of Ebola by survivors.

'Culturalist' assertions and dismissive discourses misdiagnose the problem and limit the scope for meaningful community engagement. An effective response needs to be able to recognise and support local organisation, and to address people's fears and the sources of their distrust.

There is a risk of increasing Ebola 'fatigue', and people want to get back to normal life. In Sierra Leone a recent upsurge in cases was recorded when residents of a fishing community in Freetown scattered to evade quarantine, travelling back to home villages for care. Sierra Leone's District Ebola Response Command (DERC) daily briefings also include a small but persistent number of reports of households hiding sick people, of suspect cases turning to the bush or private healers, and of bodies being washed before calling burial teams.

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?

The UK has played a key role during the Ebola emergency in Sierra Leone. This will need to be scaled back not only for financial sustainability related reasons but to make sure regional, national authorities and civil society organizations have the ownership and the lead in the Ebola response. That said, the UK government can support these efforts and institutions and encourage the establishment of procedures to ensure that coalitions of people from broad sections and levels of society are involved in national and regional policy planning, implementation and evaluation processes. On all jurisdictional levels, the UK should support an 'opening' of institutions to plural forms of knowledge and inclusive dialogue that feeds into policy and planning. Decades of development research practice have shown the benefits of participatory and inclusive approaches to development.

Along these lines, the UK can support the integration of multiple forms of expertise into health systems and emergency planning. In terms of response strategies to localised infectious disease outbreaks and epidemics, emerging evidence the Ebola epidemic and from other infectious disease outbreaks demonstrates that pervasive mistrust can be better addressed in the context of intervention through decentralised but coordinated collaboration between biomedical experts and those with a range of other forms of expertise, including local healers, lay pharmacists, midwives, and members of other specialist groups, and people who have experienced survived infection or have taken on the role of carers of the infected in the context of disease outbreaks.

Networks of local and international social scientists, including but not limited to those based in the UK, USA, and West Africa, have emerged in the context of the West African Ebola crisis and have actively contributed to response efforts. This coming together and engagement has created new spaces for bringing social science intelligence into emergency response operations, and for the inclusion of social scientists on scientific advisory committees. Their contributions to improved programme performance have been recognized at a global leadership level. The UK has also shown leadership in integrating social science contributions into its highest-level decision-making around the Ebola response (for instance, including a social scientist and a social science sub-group in the SAGE Ebola advising the Government Chief Scientist and Chief Medical Officer). This integration of social science expertise into high-level policy making offers a promising model for informing future responses to health

and other crises, and to setting future UK science and policy strategies in this and related fields.

As demonstrated in the context of the West African Ebola epidemic, members of social science networks can rapidly mobilise knowledge and expertise on regional and local norms, histories, and socio-political dynamics, and members often have years of in-depth research experience in local contexts and well established social networks including biomedical experts, officials, lay professionals and lay experts, and community members and leaders, all of which can deepen opportunities to develop, synthesize and apply evidence on the social dimensions of health and emergencies and provide a deep and broad knowledge base in the event of future epidemic outbreaks. These initiatives could be expanded to other global health emergencies while strengthening and maintaining core surge teams of social scientists. These networks should be supported and included in the above and other planning activities, and these networks could most easily be maintained through targeted funding to support web space, administration, workshops, and travel.