All Party Parliamentary Group on Africa: Community led health systems and the Ebola outbreak

Joint written evidence from ReBUILD, COUNTDOWN and REACHOUT

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Introduction

We would like to thank the All Party Parliamentary Group on Africa for the opportunity to submit evidence to this very timely enquiry into Ebola in West Africa.

We represent three multi-country research consortia which bring together a wealth of experience on health system strengthening internationally. We are drawn from government, academia civil society, and the private sector. Some of us are, or have been, working on the Ebola-response in Sierra Leone or Liberia.

Communities play a largely unrecognised, unrewarded and unsupported role in health systems around the world. There are many families and community structures (such as governance arrangements and schools) which perform tasks which are central to good health. Yet they are rarely factored into health system planning and their views tend not to influence policy and practice in this area.

Close-to-community providers of health care (such as community health workers (CHWs)) live and work within their communities, visiting people in their homes and workplaces every day, they can have a vital role in informing realistic healthcare policies that deliver results at community level. However even when their health promotion and delivery activities are recognised, for example in some CHW initiatives, they are often working in sub-optimal circumstances and are poorly linked to, and managed by formal health programmes. This has led to a disconnect between healthcare policy and the workers delivering healthcare services directly to individuals, families, and communities.

This disconnect has resulted in loss of motivation and problems with health worker retention and ultimately an additional disconnect between service users in the community and health facilities resulting in a decrease in service utilisation. In Ebola-affected countries this is exacerbated by poor infrastructure, inadequate skilled health workforce which was further depleted by loss of health care workers to the illness, health systems which were already struggling and unresponsive in a post-conflict context, and Ebola-stigma against front-line workers.

The recent call for more of a focus on people centred health systems[i] and the devastating effects of Ebola in West Africa have brought communities to the forefront of the attention of decision makers. This is to be welcomed. But we would like to see this translated into tangible changes in the way that health systems are conceptualised and supported. This requires better learning from the Ebola response, opportunities to strengthen the sharing of lessons across affected settings, greater acknowledgement of community action in health systems research, and health systems policy and financing which explicitly supports these hard working and often extremely courageous citizens.

Main messages

- ✓ Community structures and close-to-community providers of health care have the potential to improve health system functioning and health outcomes in Ebola-affected countries and beyond. They are vital to rebuilding trust between communities and health systems. Yet their (potential) role and responsibilities are poorly understood and supported. There is an urgent need to gather more information which can better integrate their work into the larger health system. This is a body of research that the UK Government should support.
- ✓ There is much that we can learn from the response to Ebola. Yet platforms and information sharing mechanisms are inadequate. The UK Government could play a key role in financing multi-stakeholder platforms to this end.
- ✓ Community-level health work is reliant on the robustness of the overall health system. In Ebola-effected countries (which were also post-conflict settings) the overall system had critical weaknesses. Efforts to strengthen the whole system under the leadership of national government are sorely needed.
- ✓ The lack of appropriately trained, remunerated, and incentivised health workers is of particular concern to Ebola-affected countries.
- ✓ Improving health needs to be a multi-sectoral endeavour. Infrastructure, telecommunications networks, and roads as well as urban regeneration are also important to the response.
- ✓ A body of evidence on both community action on health and system strengthening post-conflict and crisis already exist and should not be overlooked as we rebuild in the post-Ebola era.
- ✓ It is our recommendation that the UK Government develop a strategy that specifically addresses the role of communities and CHWs in supporting better health.

The role of communities in response to health crises and in health systems at the local level

Many commentators on the Ebola response have pointed to the crucial role of community members – in extending health messaging to the hard to reach, dispelling myths, providing frontline health services, supporting safe burial, transporting the sick to health facilities and supporting initiatives

such as quarantine. In both Liberia and Sierra Leone there was initially resistance to Ebola interventions from communities who had low levels of trust in the health system. Misinformation from third parties such as traditional health providers, the formal media and online sources sowed further confusion in a panicked populous. Reaching out to communities to dispel mistrust was a priority in both countries and active community members were key to the identification of sick people and linking these patients to health services.

The community response, whilst laudable, was hampered by a lack of adequate health and other infrastructure in Liberia and Sierra Leone which limited what they could achieve. In Sierra Leone there is an urgent need to improve the health infrastructure and staffing, particularly in rural areas which are often remote and removed from central decision making. However, alongside this it will be important to recognise and nurture those mechanisms within the formal system that recognise, reward, and support community actors.

If community members have low-levels of knowledge about Ebola and ill-health more generally it is difficult for them to make informed decisions about care. When there are no accessible roads it is challenging to take sick community members to facilities. When there are too few health care centres the distance travelled is multiplied. Support to communities needs to be part of an integrated response to health system strengthening more generally.

Given that communities are often the first to respond in emergencies, planning for future outbreaks and health-related crises needs to involve them from the outset. In Sierra Leone at the outset of the Ebola outbreak this engagement was a little ad hoc. We have learnt that early engagement with a variety of community structures and stakeholders such as health management committees, ward development committees and paramount chiefs and religious leaders is needed. Continued engagement with communities will be vital as we move forward and close-to-community providers have a critical role to play in rebuilding trust between communities and health systems.

Promoting and enabling community engagement and ownership of health and health systems

Within the community there were a variety of institutions and individuals who mobilised as part of the Ebola-response. Pre-existing community-level institutions, systems and structures can be harnessed in support of better health. These include traditional governance arrangements and actors (such as paramount chiefs in Sierra Leone). Community systems and structures are dynamic and can change, this has already been seen with many communities and society leaders in Sierra Leone choosing not to implement female genital mutilation during the Ebola epidemic. There is cautious optimism amongst some actors that the practice will be stopped or at least reduced.[ii]

When thinking through the various roles of these actors we need to be clear who they are and adopt different approaches accordingly. Different actors will have particular relationships with the health system at different levels. In Sierra Leone, for example, the system is decentralised on paper but in reality there can be a gap between national level governance and what actually happens in the community. In addition where donors support particular districts and communities a lack of coordination among funders can manifest itself as poor communication among the different parts of the health system. At the international level there is a need to strengthen regulations related to health emergencies to recognise the role of communities.

Community systems and structures need support and strengthening as does their link to government services. In Sierra Leone capacity building is needed for all health workers (including doctors). Traditional governance structures and institutions such as schools could also be sites

through which improved health knowledge and information could benefit the community. Greater responsibility for health at the community level must be accompanied by greater say by communities in health-related decision making. In Sierra Leone in 2012 a pilot project assessed community monitoring of health services.[iii] This model could be revisited post-Ebola.

Community health workers are one way of linking community systems and formal health services. Some have described CHWs as change agents, functioning as social and cultural intermediaries between the existing health system and the community.[iv] As change agents, they are strategically placed to facilitate community participation, stimulate critical thinking and act as a catalyst to social action to address the social and cultural determinants poor health status. At the micro-level, CHWs are in a unique position to observe and understand many of the socio-cultural and gender factors that influence health and healthcare use within households and communities. This is due to their sociocultural embeddedness and frequent contact with individuals in their household and community settings, as compared with relatively infrequent and brief consultations in health facilities away from their social context.

Ebola has highlighted the links between gender and infectious disease: women and girls' roles as carers within households and communities means they may be especially vulnerable to infection. Gendered social norms about who take on which types of work, can also render men vulnerable – the self-named 'burial boys' are also very vulnerable to infection as they bury the bodies of the deceased. Close-to –community health providers and CHWs are strategically placed to understand the ways in which different groups are vulnerable to disease and (with appropriate help from health systems) support communities.

In Sierra Leone there are 14,000 CHWs who could be characterised as the 'backbone' of the health system at the community level and also many maternal health promoters (who are Traditional Birth Attendants who have been retrained). Yet CHWs and maternal health promoters are not officially health workers (with clearly defined roles and management). These workers could constitute a key bridging structure between the community and health facilities if properly supported. They could also be used as champions for health education to go out into the communities on a regular basis with the right health messages to dispel incorrect beliefs. However, if they are neglected and ignored there is the possibility that they will become demotivated. In other settings we have seen community health workers joining the informal sector and using their skills and knowledge to raise an income – the outcomes of this are not always positive.

Motivation and retention of community health workers: What does the literature say?

A recent systematic review[v] of how interventions can better support community health workers has pointed to the need to ensure a balanced workload, in line with expectations and incentives. CHWs around the world often report about the negative effects of high workloads, for example increased loss to follow-up of patients. In addition, a lack of clarity regarding CHW roles often leads to unrealistic expectations from people in the community or health system, resulting in demotivation of CHWs.

CHWs must be supported and a mix of financial and non-financial incentives, paid or delivered at a predictable time, generally enhances CHW motivation and thereby performance. Supervision is essential for CHW motivation. Performance appraisal generally leads to enhanced motivation and attitudes. Continuous training also results in better motivation and job satisfaction for CHWs.

The use of standard operating procedures and programmatic guidelines is helpful, especially in settings using task shifting. CHWs' role to facilitate community monitoring of health programmes in their areas can empower communities and at the same time satisfy CHWs.

In many CHW programmes, community support, selection, and monitoring are associated with increased CHW motivation and self-esteem. Recognition by other health staff leads to enhanced recognition from the community, leading to greater CHW motivation and self-esteem. Sufficient resources and logistics, including transport and CHW kits, and the use of job-aids (simple tools used to support treatment decision-making) increase motivation and competencies of CHWs respectively.

Adapted from Improving the performance of community health workers: What can be learned from the literature? Maryse Kok, http://www.chwcentral.org/blog/improving-performance-community-health-workers-what-can-be-learned-literature

UK policies, resourcing and programming

As far as we are aware the Department for International Development does not currently have an official policy on the role of communities in health systems. Their 2013 Health Position Paper[vi] includes a section on building and maintaining a strong community interface. However this is framed mainly in relation to overcoming barriers that limit demand for services (lack of financial resources or discriminatory social norms that mean some people, for example women, have limited access to services). Important as this is, it does not recognise the growing role of community members, in various guises, in the delivery of health promotion, preventative and curative services.

In November 2013, after the Third Global Forum on Human Resources for Health in Brazil, the Global Health Workforce Alliance, government leaders, donors, health workers, and civil society announced their commitment to align with country objectives and harmonize their actions supporting community health workers and frontline health workers (FLHWs) in a joint agreement.[vii] DFID is a signatory of this agreement – signalling their support for this vital area of work. Two years on from the agreement it would be heartening to see this commitment translated into concrete policy. We (REACHOUT) have benefitted from DFID funding for research on the financing of community health worker interventions and have no doubt about their interest in this area.

Platforms for generating policy-relevant evidence with local research partners, and for communicating among researchers, policy makers and practitioners, are crucial to the sharing of learning about what works, under what circumstances when it comes to responding to health crises in diverse settings. The financing that our three research consortia have received from the UK Department of International Development (either directly or via the EU), and their focus on research uptake and the translation of evidence and research expertise which decision makers can use, has enabled us to generate and share robust relevant evidence collaboratively, including coming together to write this document. We would like to see more of this type of financing and are particularly concerned that this learning can occur in post-conflict and fragile settings in which health systems are often under strain.

There is no doubt a great deal that can be learned from Liberia, Guinea and Sierra Leone about the role of communities in the health system and in response to health emergencies. Within ReBUILD we have tried to share lessons from the 2001 outbreak in Northern Uganda.[viii] The UK Government could play a role in supporting countries to systematically gather together guidelines and learning from their experiences to inform other countries' responses. Information gathering of this type was possible in Uganda because the health system was more robustly resourced and staffed. However given how many health sector stakeholders have lost their lives to Ebola in Sierra Leone and Liberia

outside assistance may be welcomed. In addition bilateral donors can continue to champion health sector investments in recipient countries to ensure that health remains at the forefront of political agendas.

Challenges and gaps in responding to the Ebola crisis in rural and interior areas

Earlier in our submission we have covered some of the system and infrastructural weaknesses which hindered the Ebola response in rural areas of Sierra Leone. One very prominent gap, specific to rural areas in Sierra Leone, is the lack of trained health workers. Every intervention is calling upon the same small pool of trained health workers to support their cause, creating rapidly changing responsibilities for staff (in addition to their regular non-Ebola related tasks). This is not such an issue in urban areas, where there are much higher levels of trained staff and many unemployed staff from training institutes (temporarily closed) who could be called upon to support Ebola-related activities.

In addition even before Ebola there were challenges relating to attraction and retention of health workers in rural and hard to reach areas. On the whole the majority of the health workforce had limited or no training on infection prevention control and lacked the enablers to practice it. In Sierra Leone the majority of the health workers at the forefront of the Ebola response are the mid-level to low-level cadres (or the many unemployed health workers). It is worrying that many local doctors (for other underlying issues) were not at the forefront of the response.

We would like to ensure that urban areas are also a focus of this enquiry.[ix]

It is well established that there is a global trend towards urbanisation and cities are growing due to an increase of existing urban populations, as well as migration. The World Health Organization estimates that by 2050, 70 per cent of the world's population will be living in towns and cities and one in three urban dwellers will live in slums – a total of one billion people worldwide.[x] Furthermore, with an increasing proportion of the world's people living in urban settings, the health conditions of people in densely populated, largely informal residential areas within and adjacent to the main metropolitan complexes deserves particular attention. Cities, it is argued, also intensify certain risk factors for ill health and introduce new risks.[xi] In low-income urban settlements, the health environment remains less than adequate, with overcrowded and substandard housing, patchy provision of water and sanitation, and poor access to affordable quality food or safe spaces for recreation.[xii] These urban and peri-urban settlements, especially informal settlements have their own important community structures which may be different from the traditional and rural communities. Furthermore, it is important to acknowledge that urban and rural areas are interconnected with a flow of people and trade and in-country migration and return.

In Liberia it was easier to quarantine homes in the rural areas. But in Monrovia, where 1.5 million people live and there is a high population density, this was more challenging. The county had to be divided into divisions so that management of the Ebola response could go right down to community level in terms of ensuring accurate information, case reporting and care. The second that Ebola reached Freetown it was very difficult to control for similar reasons.

Barriers to successful and sustainable engagement of communities in health crisis responses

There is an old saying among people who work with academics that trying to organise any joint activity is a bit like 'herding cats'.[xiii] We are not sure whether there are other animals that are more unruly than cats but we are clear that difficulties in coordinating the multiplicity of partners and stakeholders involved in the Ebola response is a significant barrier to the engagement of

communities in health crises. This is a challenge that falls on the shoulders of national governments and all stakeholders need to better consider how they support a coordinated response and not undermine it.

Whilst communities are a site of strength and resistance, sometimes certain religious and cultural practices and norms at the community-level hindered their full engagement in the Ebola response. For example in Liberia traditions related to the washing and burial of the dead meant that contaminated water and the close proximity to people who had died of Ebola led to exposure to the virus. Religious customs such as the 'laying on of hands' to the sick is also unadvisable in an outbreak of this kind. These practices are very entrenched, have important cultural meaning, and are difficult to change. Trying to engage with leaders and respect - as far as possible - religious practices (for example, working with local communities to try to ensure burials are as dignified as possible with marked graves, a single body per gravesite, accommodating families attending burials from a safe distance, Christian burials with a coffin, Muslim burials using sticks) while still upholding safe burial practices is key.[xiv] We need to work more with leaders to develop culturally acceptable alternatives to unsafe burial.

It is important to note that entrenched cultural norms and practices are also evident in government institutions and structures. For example in Sierra Leone one District Health Management Team member was involved in the exhumation of a body which potentially undermines progress towards safe burial practices. Those in authority need to set a good example and there should be sanctions when dangerous practices are carried out by those in positions of power/authority.

When communities are very isolated, either geographically, or because road and telecommunications infrastructure is inadequate, it can be difficult for the formal health system to engage them. Isolation can also occur when health information is not translated into local languages which all can understand.

To overcome these challenges we believe that there needs to be a government-led, multi-sectoral response to health crises and that CHWs may have an important role to play in providing the interface between communities and the formal health system. There needs to be engagement with existing trained CHWs. In an emergency context when there is a need to urgently recruit and train contact tracers and others, it is important that existing CHWs are recruited to these positions to maximise existing links to community and to strengthen these CHWs for future health work. There also needs to be greater investment to building trained human resources for health and strengthening quality of services and infection prevention and control at health facilities, along with engagement with community to work towards rebuilding trust in the health system again.

In the rush to recruit and train and with the financial allowances available to contact trainers, existing CHWs were at times bypassed in favour of others in Sierra Leone. This could potentially undermine current CHW programmes and result in reduced motivation.

Policy, strategy and programming models to improve the response

It is vital to identify and adequately support those in-country organisations and systems that are responsible for the Ebola response. Whether these are at community level or at national level in Government.

That the Ebola outbreak became so significant in post-conflict countries is no surprise.[xv] There is a need for more research into health system strengthening in post-conflict and fragile states as well as platforms and mechanisms that enable the sharing of learning across contexts and stakeholders. The

Thematic Working Group on Health Systems in Fragile and Conflict-Affected States[xvi] is one such mechanism. However, greater investment in this area is necessary.

There is a need for effective coordination of efforts between the key players. In Sierra Leone the delayed response further exposed that measures were not put in place after the cholera outbreak in 2012. Lessons must be learnt in country and across the affected countries. There is a need for a tried and tested emergency response system to avoid this happening in the future

Historically there has been a challenge in reforming and implementing human resources for health policies in Sierra Leone.[xvii] There is therefore a an urgent need for concerted effort from all key stakeholders, training institutions, and researchers to ensure that activities needed to strengthen the human resources pillar of the health system are implemented effectively as we plan to move into the post-Ebola reconstruction phase.

Health financing is necessary to put these measures in place it is important that the Abuja declaration target of 15% invested in health is met and that there is sustained external investment in Ebola-affected countries.

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About our research projects

ReBUILD was formed in 2011 and is a Research Programme Consortium funded by the UK Department for International Development. Partners in the UK, Sierra Leone, Uganda, Cambodia and Zimbabwe have come together to explore different approaches to health system development in countries that have been affected by political and social conflict.

http://www.rebuildconsortium.com/

COUNTDOWN was formed in 2014 and is a research consortium funded by the UK Department for International Development. Neglected Tropical Disease (NTD) researchers, policy makers, practitioners and implementation research specialists, from the UK, USA, Cameroon, Liberia and Ghana have come together to generate knowledge about the realities of increasing the reach of NTD treatment, in different contexts.

http://www.countdownonntds.org/

REACHOUT is a healthcare research project supporting and strengthening the vital work of close-to-community providers of health care in Bangladesh, Indonesia, Kenya, Malawi, Mozambique, and Ethiopia. They are funded by the European Union.

http://reachoutconsortium.org/

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[i] See for example http://hsr2014.healthsystemsresearch.org/theme-third-global-symposium-on-health-systems-research-2014-cape-town

[ii] http://www.huffingtonpost.com/2015/01/16/female-genital-mutilation-sierra-leone_n_6481054.html

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[ix] See https://www.ids.ac.uk/publication/urbanisation-the-peri-urban-growth-and-zoonotic-disease

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[xii] K. Hawkins, H. MacGregor, R. Oronje 2014 The health of women and girls in urban areas with a focus on Kenya and South Africa: a review http://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/3202/bitstream?sequence=1

[xiii] See for example http://en.wiktionary.org/wiki/herd_cats

[xiv] http://www.concernusa.org/news/safe-and-dignified-burials-in-sierra-leone-1212

[xv] Fustukian S. and Cavanaugh K. (2014) Ebola emerges in fragile states: another 'wake- up' call for action on health systems in conflict affected states? http://www.healthsystemsglobal.org/GetInvolved/Blog/TabId/155/PostId/35/ebola-emerges-in-fragile-states-another-wake-up-call-for-action-on-health-systems-in-conflict-affected-states.aspx#sthash.yFzwmAkB.dpuf

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