

## **Africa APPG submission to IDC inquiry on responses to the Ebola Crisis (September 2015)**

### **Background summary**

1. The Africa APPG welcomes the IDC's follow up inquiry on the Ebola response. The Africa APPG's evidence is based on the ongoing inquiry that the APPG originally started in October 2014 regarding community led approaches to health systems strengthening and lessons from the Ebola outbreak. The final report is in draft form and due for release in mid-November 2015.
2. During a series of Africa APPG events focused on the West African Ebola crisis, it became apparent that the initial Ebola response was undermined by and often perpetuated a culture of mistrust between the affected communities and the response efforts from governments and partners. Consequently, the Africa APPG commissioned a report with researchers from Polygeia, a student-run global health think tank, to further explore the weaknesses in community engagement exposed by the Ebola outbreak and to examine the lessons and policy implications for community engagement in health crises and for systems strengthening.
3. Research was undertaken through a mixture of literature reviews, 31 written submissions in response to a call for evidence in addition to 7 evidence gathering meetings in Parliament. A central component of the report was evidence collected during field research commissioned to Restless Development in Sierra Leone and PHDI in Liberia. Researchers carried out 23 qualitative interviews with community leaders using questionnaires designed to elicit the health needs of communities.
4. The report suggests that the lack of trust and confidence in state-based institutions and outside groups stems from decades of warfare, socio-economic ruin, and the inability of the governments to deliver basic services. Primary evidence shows community leaders champion the inclusion of localised initiatives, however, due to the complexity of coordinating international aid, especially during a crisis, the support of bottom-up capabilities is often overlooked by governments and donors. This submission focuses on the importance of community mobilisation and community-led interventions in the Ebola response.
5. The Africa APPG calls for DFID and the wider development and humanitarian sectors to put community ownership at the centre of response efforts during health crises, and more broadly of health systems, as a critical component of health systems strengthening.

### **About the Africa APPG**

6. The Africa APPG brings together parliamentarians interested in the positive development of the African continent to further learning and understanding of African and pan-African matters. The Royal African Society provides the full-time support of a Policy & Research Co-ordinator based in UK Parliament.
7. The APPG was established in 2003 by Sir Hugh Bayley and Lord Lea of Crondall and is one of the largest and most active All Party Groups in Parliament, with 195 Members from both Houses and across all Parties. The Group is chaired by Chi Onwurah MP and Lord Chidzey as co-Chair from the Lords.

### **Initial response: the need for earlier community involvement**

8. Figure 1 shows the outbreak in four phases. Initially in phase 1, fear grew in communities fuelled by misinformation and lack of understanding of preventative measures. Once the disease was identified, MSF and national governments responded the earliest with little buy-in from the international community. During stage 2 as the number of cases grew rapidly and WHO and Europe and the USA recognised the threat of spread, resistance at the local rural level increased partly due

to poor communication of the situation by responders. In stage 3 the number of infections per week plateaus and falls with the response focus moving away from care of the infected to contact tracing and community engagement was instrumental in this stage according to Dr Nabarro, UN Special Envoy for Ebola. Stage 4 shows the effort to get cases to zero and to stay at zero. Communities are still playing a key role in contact tracing and hidden cases.

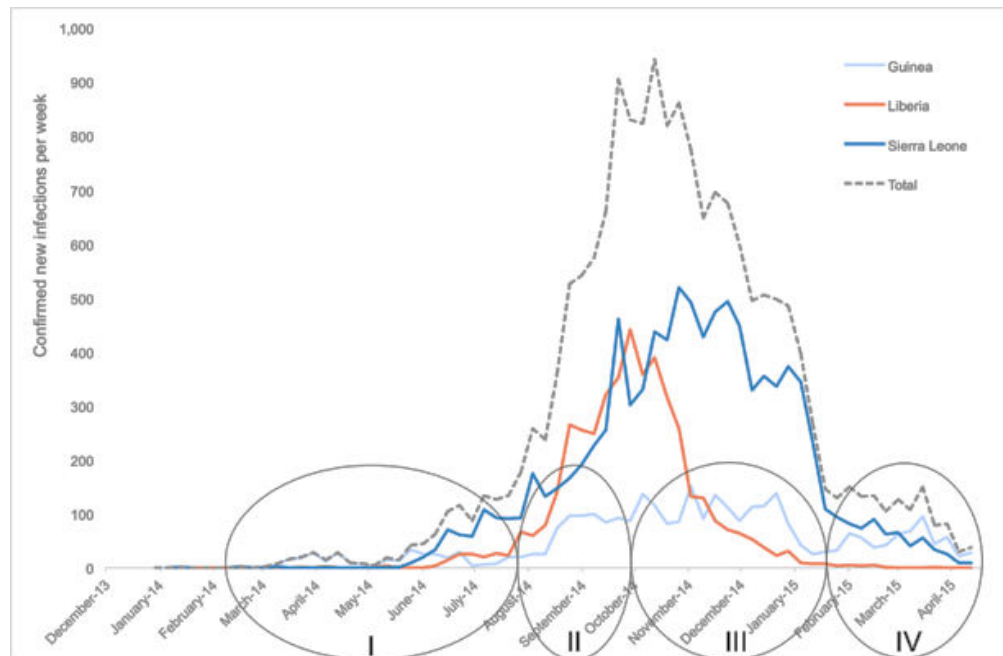


Figure 1- Four stages of the West African Ebola crisis

9. Like other international responders, the UK's initial response to the Ebola outbreak has been criticised as overly authoritarian and unwilling to engage with local concerns. For example, the response initially was supply-focused with concentration on the number of beds available and some UK actors viewed cultural practices as something to work against, rather than with, declaring for example that Sierra Leoneans must "put aside tradition, culture and whatever family rites they have". The training of local safe burial teams and providing protocols for safer home care are two examples of key local demands which were, at least initially, unmet by Ebola responders.
10. As the response progressed, the disadvantages of this approach were recognised, and programmes incorporating community engagement were developed and supported. In the international community, the UK has been lauded for its support of programs that focus on community engagement, however, this support has largely been confined to targeted, vertical programs.
11. Future response efforts should consult communities during the design stages of health programmes and facilitate community dialogue throughout, in order to empower communities towards community ownership of the response.

**Demand creation: Education and awareness through working with not on communities**

12. The initial response did not place enough emphasis on demand creation through social mobilisation instead the approach was supply-focused which prioritised service delivery and resourcing. Early health awareness campaigns and attempts at demand creation focused on raising awareness about Ebola, informing people of the signs, symptoms and care-seeking strategies. However, they were impersonal – for example, staff's use of megaphones from their vehicles has been criticised as intimidating– and were met with suspicion and in some cases hostility. By supplementing models of

treatment and prevention with sustained engagement with communities, the social and cultural acceptability of infection control measures can be improved.

13. Community-led approaches to health typically differ from standard practice insofar as they regard communities as co-partners in the provision of health information and services rather than as passive beneficiaries. From the practical experience of the current Ebola response it has been recognised that facilitating social mobilisation and behaviour change must be weighted equally with the medical/epidemiological response. By paying attention to both demand and supply sides of health, reciprocal strengthening can take place as increased community engagement and ownership of health systems also improves perceptions of service providers and builds community trust.

**Communities as agents change: the importance of community empowerment & ownership**

14. In addition to demand creation, community-led approaches to health place a significant emphasis upon community members as agents of change which involves empowering communities to take ownership of health systems. Although many NGOs operate at the local community level, our respondents highlighted that their activities are not always in line with community priorities or seeking to empower local actors.

*“Most organisations do not plan with communities before implementing programmes, we want to see programmes that are owned by communities.”*

Ismail Foday, Senior Section Chief (Kailahun District, Sierra Leone)

*“Community structures were not empowered to manage a post-Ebola situation. It is important to build capacity and empower community structure so that they can serve as first line of support... There has to be a sense of ownership”*

Lawrence Flomo, Senior High School Teacher and Secretary of the Fiamma Community Association (Fiamma Community, Liberia)

15. Successful community mobilisation involves supporting the efforts of local leadership and existing organisational structures such as youth and women’s groups, valuing local knowledge and expertise. All of the community leaders agreed that more discussion and coordination between local and community groups and structures with national and international organisations would improve health provision in their respective districts. The mobilisation of such community based organisations can draw on the greater social legitimacy afforded to insiders and further facilitate local level ownership.

**Social legitimacy & trust: working with local leadership and organisational structures**

16. Although ‘community trust’ is a difficult variable to quantify in health interventions it plays a vital role in determining their social legitimacy and consequently, their success. Organisations working on the ground have highlighted the reduced social legitimacy of temporary actors in contrast to those who have spent time listening to the daily challenges communities face and understood the complex nature of the problems. Local actors, such as Samuel Borbor Vandi, an NGO worker in Kailahun District, Sierra Leone, have emphasised the importance of time spent with communities to comprehend the issues at stake:

*“Most agencies do not spend a lot of time in communities, particularly vulnerable communities, so it has been difficult for them to know the real issues posing threat to the lives of community people”*

17. Traditional leaders were seen by many as key components of the Ebola response especially around the acceptance and legitimising the response work of external organisations and health workers. Lawrence Flomo, secretary of the Fiamma Community Association, Liberia, specified some of the various

roles of traditional leaders within communities: *“The elders of the community played advisory roles. They also mobilised funding from well-to-do community members. They used letter campaigns to buy disinfectants for those who lacked them.”*

18. In addition, it has been argued that top-down and bottom-up approaches are not mutually exclusive and can act in synergy to promote community-engaged health systems strengthening. Laverack and Labonte have suggested a theoretical framework for the ways in which traditional top-down health promotion programmes can support and run parallel to community empowerment initiatives<sup>1</sup>. Moreover, Paul Richards of Nyala University has highlighted the effectiveness of top-down approaches in cases such as quarantine and many have noted the value of directives from religious leaders, as well as the establishment of by-laws by Paramount chiefs in Sierra Leone in the outbreak. It may be the case that top-down initiatives are helpful in controlling a panic-stricken situation, and where they are used, they should utilise existing social and community structures.

*“The Paramount Chiefs, helped a lot in sensitising their people across all communities and chiefdoms. They enforced the bye-laws and monitored its implementation closely. They worked with DERC, DHMT and organisations.”*

Manjo Lamin, Health Officer (Kailahun District, Sierra Leone)

19. The UK government was the first partner to identify and support large-scale social mobilisation by working with community structures in Sierra Leone through funding SMAC with an initial investment of £3.1 million-

20. Case Study: Social Mobilisation Action Consortium (SMAC)

- The SMAC is a group of five agencies – Restless Development, GOAL, FOCUS 1000, BBC Media Action and the Centres for Disease Control and Prevention (CDC) – working within the Ministry of Health & Sanitation National Social Mobilisation Pillar. Together they have over 33 years on-the-ground experience in Sierra Leone, which is supplemented by their anthropological research with Njala University.
- Through the consortium model, SMAC was able to combine the technical and social expertise of different agencies.
- SMAC’s Community-Led Ebola Action (CLEA) and Dialogue, Reflection, Action-planning, Facilitation, Tracking change (DRAFT) approaches aim to empower communities to analyse the outbreak and take responsibility for tackling it.
- They have worked through 36 radio stations, 3550 religious leaders, 2558 community mobilisers and countless Ebola survivors, engaging existing community structures to reach 70 percent of district communities in Sierra Leone.
- SMAC aimed to achieve “tangible behaviour change towards safe burials, early treatment, and social acceptance of Ebola Survivors”.
- The SMAC response was notable for its community-led approach. An Oxfam report called it “a turning point in tackling Ebola in Sierra Leone ... [that] led to huge uptake of positive practices during the Ebola outbreak and has the potential to be used in building health systems after Ebola.”

21. As a leader in the Ebola response, the UK should ensure the crucial role of community engagement in health crisis response is built into every element of future response efforts from the start with community ownership being the priority in recovery efforts.

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<sup>1</sup> Labonte and Laverack’s framework for community empowerment goals within health highlight nine operational domains: participation, leadership, organisational structures, problem assessment, resource mobilisation, asking why, links with others, role of the outside agents and programme management.

### **Harnessing local knowledge & expertise: building a sustainable and local health workforce**

22. Community empowerment also involves the development of an effective community health workforce, with the resources needed to protect themselves. While the UK and international responders have helped address the shortage of health workers and lack of health resources, a sustainable, localised solution is needed.
23. As members of the community, 'informal' health practitioners are well placed to understand the needs and concerns of local people and are often trusted over external medical groups in the first instance of sickness. Additionally, health clinics are logistically and economically unviable for many of the poorest communities and instead informal health practitioners mix traditional healing with biomedical apparatus. Part of the appeal of such practitioners is that they treat their patients holistically, they are perceived to be attentive to material, economic and spiritual needs as much as a physical illness.
24. International donors have attempted to address the chronic shortage of health workers in Liberia, Sierra Leone and Guinea by training informal community health workers (CHWs). CHWs have been cited as a central need for a localised response, as they *"act as an important link between formal health structures and primary care provision... [assisting] in tracking patients and [encouraging] communities to participate in preventative activities"* As non-professional CHWs are steeped in the sociocultural context of their respective settings, they are granted a form of social legitimacy not often extended to foreign medical workers.
25. The WHO strongly recommends that CHWs be supervised through formal health institutions in a respective country. However, CHW training courses offered by different organisations vary drastically in content, length and methodology. Training has been found to be inconsistent, with little or no competency assessments or in-service training to review content (refresher training) or learn new material. An Oxfam report has recommended that donors develop retention and professionalisation schemes for the CHWs trained during the crisis to ensure the long term impact of the training provided. However, this needs complementing with a strong referral system. Providing accessible training for high-level specialists is an urgent priority.
26. Whilst there was a key role for various community surveillance approaches the findings generally favour building local health capacity within the community as it allows for a more cooperative approach to providing medical care. Rather than focusing on surveillance programs where the sick have to be sought out and reported, a focus on demand creation with corresponding local capacity building would encourage the infected and their families to seek care for themselves. Case-taking at health facilities would still allow for epidemiological surveillance and enable governments and international organisations to monitor disease trajectory and support preparedness initiatives.
27. Reconstruction efforts should prioritise sustainability, by promoting the training and employment of community health workers in the national workforce and formalised support systems. They should also prioritise community ownership in health service provision by working within existing community structures including traditional leaders and health workers to avoid creating parallel health systems.

### **Community resilience: holistic responses**

28. The effects of the Ebola outbreak at the community level cannot be overstated. Community leaders from all the included counties and districts cited the collective trauma and devastation felt by the communities as a result of the illness and deaths from Ebola. Many of the leaders emphasised the knock on effects of the disease including displacement of families, loss of business, interrupted

harvests, closure of schools and the loss of valued traditional practices such as burials and handshakes. These have had a deep impact on communities and a sense of community belonging.

29. Many of the community leaders noted that beyond Ebola itself there were many repercussions for health in their communities. Dr Sesay, remarked: *“Ebola killed a lot of people because of the denial attached to it at the beginning, but the main thing that killed people is the fear to go to hospital for other illnesses that could have been cured quickly.”*
30. As such, community resilience must be planned for in future responses to health crisis- by working with the community in the initial stages of response a more holistic understanding of community needs can underpin response design and implementation.

### **Strengthening the evidence base for the role of community in health: working with anthropologists**

31. Community-led approaches to health involve recognising that as experts in themselves communities possess the local experience, knowledge and perspectives required to ensure that health interventions are appropriate, inclusive and relevant to context.

*“Organisations [should] spend more time to discuss with community people regarding the issues that affect them and involve them in developing the design of the project”*

Samuel Borbor Vandi, NGO worker (Kailahun District, Sierra Leone)

32. The inclusion of social science expertise was especially crucial given the breakdown of trust between communities and health systems. Ignorance of and disrespect for local practices in many cases hampered response efforts, according to the Institute of Development Studies (IDS). Working with anthropologists can enable health promoters to distinguish between situations where behaviour change is needed and where it is not. Where health-promoting practices already exist in communities, efforts can be made to support them and incorporate them into programme design. Better integration of social and clinical expertise in the future will help develop responses that are well-suited to both the disease and the local context.
33. The UK took a notably multidisciplinary approach to high-level policymaking, including a social scientist and a social science sub-group in the Scientific Advisory Group in Emergencies (SAGE), as well as directly consulting regional experts. Additionally, the UK has established the Ebola Research Anthropology Platform, an international network of anthropologists with expertise in West Africa and medical anthropology. The platform is coordinated by academics from London School of Hygiene & Tropical Medicine (LSHTM), IDS, Sussex and Exeter and funded by the Wellcome Trust and DFID. The platform drove DFID’s investment into the Social Mobilisation Action Consortium (SMAC) and has fed directly into the UK’s response at the community level with anthropologists working with leaders from ‘resisting’ villages.
34. However, Tomori (2015)<sup>2</sup> documents how international research institutions are dominated by donor country scientists, with African scientists side-lined. Donors should instead support African research capacity building and create collaborative relationships to avoid the need to “parachute in” foreign academics in a future crisis, an ambition set out in the African Union Agenda 2063. A present example is the cooperation between the USA and the African Union to establish the African Centres for Disease Control and Prevention. The UK has taken a leading role in this area, working through the

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<sup>2</sup> Tomori O. Will Africa’s future epidemic ride on forgotten lessons from the Ebola epidemic? BMC Med [Internet] 2015 Jan [cited 2015 May 20];13:116. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=4432500&tool=pmcentrez&rendertype=abstrac>

Medical Research Council, the Wellcome Trust, the Newton Fund, and bilateral partnerships between universities.

35. The Government should expand its use of multidisciplinary expertise in global health decision-making, by working with the academic sector in both the UK and abroad to build capacity in anthropology and other social sciences. In addition it should support further research to widen the evidence base on effective strategies for supporting community engagement in health crisis response and more broadly in health systems strengthening.

**Coordination: The need to strengthen multi-stakeholder partnerships**

36. Several actors have raised concerns over the lack of coordination between agencies in the response, with doubts over competence suggested to contribute to mistrust and resistance.

*“We want support in terms of coordination, so as to avoid duplication. We need to know what all organisations are doing so as to avoid duplication of Ebola response intervention.”*

Ibrahim Fofanah, Regional Coordinator CCACCO (Port Loko District, Sierra Leone)

37. UNMEER was set up as a coordinating body to remedy these problems during the outbreak. The consortium NGO model also provided an effective means of cooperation. In the short term, the international community must improve its capacity to respond to global health emergencies. Arguably, a single body is needed with responsibility for initiating and organising the response, in order to ensure timely and coordinated action. In the long term, however, national governments are best placed to coordinate emergency responses.
38. The Government, not-for-profit, academic and others in the health sector should scale up support of collaborative approaches to health crisis response and health systems strengthening and support efforts to improve coordination of global health emergency responses.

**Supporting national Governments to achieve Universal Health Care**

39. Yet, unlike international NGOs, national governments are accountable to their citizens. During the Ebola outbreak, the response was found to be most effective “when international partners supported the governments’ leadership, strategies and plans rather than pushing their own”.
40. Ultimately, the only way to prevent another outbreak is to strengthen national health systems, with the ultimate goal of universal health coverage as highlighted in the proposed goal 3.8 of the SDGs: *“[To] achieve universal health coverage (UHC), including financial risk protection, access to quality essential health care services, and access to safe, effective, quality, and affordable essential medicines and vaccines for all”*
41. The IDC has previously criticised DFID focusing on high-profile diseases and rapid results at the expense of wider health systems strengthening. Moreover, IMF policies have been identified as a barrier to health systems strengthening, by prioritising short-term deficit reduction over health systems investment.
42. As DFID has already noted, the UK is in a strong position to influence an international drive towards universal health coverage through health systems strengthening, given the expertise contained in the NHS. Additionally, in terms of financing, UHC, ActionAid, Christian Aid, Oxfam and Save the Children have urged the UK to back G77 calls for global tax standards to move from the OECD to the UN. This is necessary to support the African Union’s target of achieving self-reliance by 2063.

43. Such bolstering of national government capacity need not replace NGOs but must underpin their work. DFID should avoid supporting initiatives which undermine Government legitimacy in providing national public services. Instead, the UK Government should refocus its efforts to support the goals of Universal Health Coverage and self-reliance for developing countries and recognise the critical role of community ownership of health systems in achieving this goal.