LESSONS FROM EBOLA AFFECTED COMMUNITIES: Being prepared for future health crises

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The Ebola crisis in West Africa demonstrated clearly how vulnerable the region was to rampant disease. Robust health systems, available at the point of need, were simply not there. There was little ability among the populations to pay. In the circumstances the responses from community health workers, local health systems and the people themselves were, in many cases, remarkable and totally selfless.

The Republic of Guinea, Sierra Leone and Liberia share not only common borders, but deep cultural, language and ethnic affinities. The borders themselves barely exist for the local populations that straddle them. In the mountainous rainforest regions of the interior, there are minimal transport networks and non-existent utilities such as mains water, sanitation and electricity. Communities in remote villages are virtually inaccessible.

Congratulations are due to Polygeia in drawing together written and verbal evidence on the responses to the Ebola health crisis from well over 200 sources. Their extensive analysis of the community engagement in the response to Ebola alongside national, international, and health aid agencies intervention in this report provides important guidance for the future.

Lord Chidgey,
Co-Chair Africa All-Party Parliamentary Group
ACRONYMS AND ABBREVIATIONS

APPG  All-Party Parliamentary Group
ACAPS  Assessment Capacities Project
AFRO  (World Health Organization) African Region Office
ASEOWA  African Union Support to Ebola Outbreak in West Africa
AMREF  African Medical and Research Foundation
AU  African Union
CDC  Centers for Disease Control and Prevention
CEBS  Community Evidence-Based Surveillance
CHW  Community Health Worker
CLEA  Community-Led Ebola Action
CWC  Community Watch Committee
DERC  District Emergency Response Centre (Sierra Leone)
DFID  Department for International Development
DHMT  District Health Management Team (Sierra Leone)
EBOLA/EVD  Ebola Virus Disease
ETU  Ebola Treatment Unit
FGM  Female Genital Mutilation
FHCl  Free Healthcare Initiative
HIV/AIDS  Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
HSS  Health Systems Strengthening
IDC  International Development Committee
IDS  Institute of Development Studies
IFRC  International Federation of Red Cross
IHR  International Health Recommendations
IOM  Institutional Organisation for Migration
IRC  International Rescue Committee
LSHTM  London School of Hygiene and Tropical Medicine
MNCH  Maternal Neonatal and Child Health
MOH  Ministry of Health
MoHS-HED  MOH Health Education Department (Sierra Leone)
MSF  Médecines Sans Frontières
NGO  Non-Governmental Organisation
NHS  National Health Service
OECD  Organisation for Economic Co-Operation and Development
PHU  Public Health Unit
PPE  Personal Protective Equipment
PRA  Participatory Rural Appraisal
SAGE  Scientific Advisory Group in Emergencies
SMAC  Social Mobilisation Action Consortium
UK  United Kingdom
UN  United Nations
UNFP  United Nations Population Fund
UNICEF  United Nations Children’s Fund
UNMEER  UN Mission for Ebola Emergency Response
US  United States of America
USAID  United States Agency for International Development
WHO  World Health Organization
EXECUTIVE SUMMARY

By January 20th 2016, an Ebola epidemic in West Africa had killed 11,316 people. It had begun over two years before in Guinea and exposed under-resourced and over-burdened health systems in the affected countries. The international response was weak. However the UK played a key role by providing Sierra Leone with £427m worth of medical, technical and logistical support largely through the Department for International Development. These funds were given to the Sierra Leone government, front-line NGOs and other vital actors and used to support a range of research.

At Westminster between October 2014 and May 2015 the Africa All Party Parliamentary Group organised a series of panel discussions on the international response to Ebola. Panellists who had worked in the Ebola-affected communities stressed repeatedly that the response was being hindered by fear and a lack of trust between national actors, international actors and affected communities. Consequently the APPG, together with Polygeia, launched an enquiry into attempts to engage the affected communities in the response (1). This report reviews the evidence submitted by key informants through interviews and a literature review. It reflects the lessons learned from the Ebola outbreak and explores the importance of trust between governments, health workers and communities and the importance of local ownership of health systems.

A diverse range of actors were involved in the response in West Africa. They often had different priorities and strategies and not every strategy was successful. In the early stages mistrust of and resistance to responders was indicative of a lack of community engagement. This report analyses the engagement by different groups in the community including women, young people and community leaders and highlights the crucial role they played in creating successful strategies to control Ebola. To ensure the voices of affected communities were represented in the report, 23 key informants were interviewed. In Sierra Leone these were conducted by Restless Development, and in Liberia by Public Health & Development Initiative (PHDI).

This report finds that response efforts were most effective when communities demanded assistance at the local level. It therefore advocates that although a top down approach (nationall and internationally) may always be necessary in a health crisis such as an Ebola outbreak, it is only effective when the affected communities trust that response. The report acknowledges that the need to react rapidly in a health crisis makes it almost impossible to consult communities immediately. However the key lesson in ensuring preparedness for future health crises is that health systems should be developed horizontally, local ownership should be prioritised and investment made at community level. Such approaches foster trust and create demand for health services. Communities should be consulted about their needs and local facilities and systems developed to provide permanent services which local people trust and access and which can respond effectively during a crisis.

The chief finding of the report is that efforts to curb the outbreak of Ebola in West Africa were most effective when local leaders of affected communities led the demand for assistance from their governments and the international actors, and played an essential leadership role in the management of that assistance.
The chief recommendation of this report is that the UK government and non-governmental organisations should give higher priority to community ownership of health. This would strengthen local health systems and enable them to respond more effectively to a crisis. The conclusions of this report will help guide a UK response to future epidemics and, in the long term, help reconstruct and strengthen health systems in poor countries.

A summary of this report and its recommendations was included as written evidence to the House of Commons International Development Committee; Ebola: Responses to a public health emergency (2).
INTRODUCTION

The Africa All-Party Parliamentary Group commissioned researchers from Polygeia, a student-run global health think tank, to explore the experiences of communities affected by the 2014 - 2015 Ebola crisis in Sierra Leone, Liberia and Guinea. The researchers also examined the role of affected communities in the response to the outbreak and learned lessons for community engagement in health crises and more broadly the implications for strengthening health systems in West Africa.

Chapter One explores the response and the effectiveness of national health systems of countries affected by the Ebola outbreak in the context of their socio-political and historical factors.

Chapter Two examines evidence of community mobilisation and community-led interventions in the Ebola crisis and evaluates their importance.

Chapter Three focuses on how the UK can influence, strengthen and improve the response of communities and national health systems to health crises.

The report includes evidence from 31 written submissions in response to a call for evidence; the findings of 5 meetings held by the Africa APPG to discuss the Ebola response including the role of the media, pharmaceutical companies and community actors, the impacts on economies, food security, women and community resilience; and a review of the literature on Ebola outbreaks. 19 parliamentarians were involved in the process. To ensure the voices of affected communities were represented, the Africa APPG and Polygeia worked with Restless Development, a youth-led development agency, in Sierra Leone and Public Health & Development Initiative Liberia (PHDI) in Liberia. Researchers conducted 23 key informant interviews with community leaders in rural and urban areas to gain insights into the response of their communities in the Ebola response.

The role of communities in the response to a health crisis such as Ebola is complex and multifaceted. This report uses a broad definition of community to include any group of people who are linked by social ties and common perspectives, and engage in joint actions. Communities vary hugely within and between these countries so it is difficult to generalise their response to the crisis. However, this report aims to draw out central themes and lessons from the Ebola outbreak, which could improve community engagement and effectiveness in response to a health crisis in the short term and in the longer term contribute to a stronger health system.
1 WHAT WEAKNESSES HAS THE EBOLA OUTBREAK EXPOSED

The Ebola Virus Disease (Ebola) was first identified in the Democratic Republic of Congo (then Zaire) and South Sudan (then Sudan) in 1976 and named after the Ebola River in northern Congo. It is believed to be zoonotic which means it normally exists in animals but can be transmitted to people. Once in the body, rapid viral replication affecting immune cells and blood vessels triggers systemic inflammation and a drop in blood pressure. This can lead to death from shock and multiple organ failure (3). Ebola is also passed between people through direct contact with the blood or other bodily fluids or the secretions of an infected person. On average, it takes 8 to 10 days for symptoms to appear and is often confused with cholera and malaria, making early diagnosis difficult (4,5). Treatment consists of intensive care, oral rehydration salts and intravenous fluids. At present, candidate vaccines are in clinical trials with planned submission for licensure by the end of 2017 (6).

In the 40 years since its discovery there have been 26 Ebola outbreaks in 12 countries. The case fatality rate for each outbreak ranges between 25% and 90% with approximately 2361 cases and 1548 deaths prior to the 2014 - 2015 West African Ebola outbreak (5). Countries in equatorial Africa have experienced the most Ebola outbreaks: seven in the Democratic Republic of Congo and five in Uganda. In contrast to the recent West Africa Ebola outbreak, all previous outbreaks were controlled in periods ranging from three weeks to three months. This is partly attributable to the preparedness of health systems. According to the World Health Organisation (7):

“Clinicians in equatorial Africa have good reasons to suspect Ebola when a “mysterious” disease occurs, and this favours early detection. Laboratory capacity is in place. Staff know where to send patient samples for rapid and reliable diagnosis. Health systems are familiar with Ebola and much better prepared. For example, hospitals in Kinshasa, the capital of the Democratic Republic of Congo, have isolation wards, and staff are trained in procedures for infection prevention and control. Governments know the importance of treating a confirmed Ebola case as a national emergency.”

West African countries, having never experienced an Ebola outbreak, were poorly prepared for this disease at every level, leading to the initial rapid and undetected spread in what was to become the largest and deadliest Ebola outbreak in history.
1.1 THE WEST AFRICAN EBOLA OUTBREAK

In December 2013, an 18-month-old boy in Melindou, a village in Guinea, became the first case in the West Africa Ebola outbreak. There is evidence that he may have been infected by contact with bats (8). Family members quickly developed similar symptoms, as did funeral attendees and several traditional healers and hospital staff who had treated them in nearby Gueckedou. Over the following three months transmission chains carried the virus cycle of exposure, cases, deaths and funerals to several cities, including the capital, Conakry, and many more villages and rural districts (9).

Initial investigations by the Meliandou health centre, and later by staff from Médecins Sans Frontières (MSF), suspected cholera which is endemic in the region, but without conclusive evidence. In March 2014, a larger investigation began which included the Ministry of Health, World Health Organisation (WHO), WHO Regional Office for Africa (AFRO) and Médecins Sans Frontières (MSF) staff and the Ebola virus was identified as the causative agent. In June, MSF warned that Ebola was “out of control” and called for the “massive deployment of resources” as the disease continued to penetrate local communities in south-eastern Guinea and began to spread in neighbouring Sierra Leone and Liberia. On August 8th, as the disease was entering its deadliest phase, the WHO declared a Public Health Emergency of International Concern (PHEIC). During the following months, Ebola intensified in both rural and urban areas, with cases reported in Nigeria, a country of almost 200 million people, and Senegal.

In autumn 2014, two leading doctors, Dr Samuel Brisbane of Liberia and Dr Sheikh Umar Khan of Sierra-Leone, succumbed to the disease (10), and several healthcare workers returning to the UK, Spain and US were diagnosed as infected (11–13). The US-based Center for Disease Control warned of up to 1.4 million cases in West Africa by January 2015 (13). Local and international press began to speculate on the potential catastrophic consequences. This spurred the international response to further action, but it also created an image of Africa that created panic and fear.

Transmission peaked during October 2014 with approximately 900 new infections per week (see figure 1 and box 1). The plateauing and eventual decline of the incidence of the virus coincided with a surge in local and international responses. Although direct correlation between specific responses (medical, social or political) and the reduction in cases is yet to be made.

At present – 2nd February 2016 – The West African Ebola outbreak was declared to have ended on 14th January, however there has already been re-emergence in Sierra Leone (14). There have been, in total, 28,638 confirmed probable and suspected cases worldwide and 11,316 deaths. All but 36 cases and 15 deaths have occurred in Guinea, Liberia and Sierra Leone. The geographical distribution of these cases is shown in Figure 2 (15).
Stage 1
- An unidentified disease spreading through Guinea, Sierra Leone and Liberia. Lassa fever, Ebola or Cholera?
- MSF and national governments responded the earliest, with little initial buy-in from the international community
- Growing fear in communities fuelled by misinformation and lack of understanding of preventative measures

Stage 2
- Most rapid increase in infections during the outbreak
- The threat of spread to Europe and North America was realised
- In September, the WHO announced that the Ebola outbreak was an “event of international concern” and began scaling up the response
- Large degrees of resistance were displayed by the communities

Stage 3
- Number of infections per week plateaus and falls
- Continued support from the international community, with the focus moving away from care of the infected to contact tracing
- Community engagement is instrumental in this stage

Stage 4
- Decrease in infections, outbreak declared over in Jan 2016, but re-emergence likely
- Support needs to continue to ensure that we get to zero cases
- Communities play key role in contact tracing and hidden cases

Figure 1 & Box 1: Stages of the West African Ebola crisis (1-4) by the number of confirmed new Ebola cases by week. (adapted from presentation by Dr Nabarro, UN Special Envoy for Ebola (16) & European Centre for Disease Prevention and Control report (17))
Figure 2: Geographical distribution of total confirmed cases in Guinea, Liberia, and Sierra Leone as of 01 November 2015 (15).

Confirmed Cases
- 1 - 5
- 6 - 20
- 21 - 100
- 101 - 500
- 501 - 4000
- No cases reported
1.1.1 LASTING IMPACT ON COMMUNITIES

The appalling suffering, enormous death toll and the catastrophic impact on affected communities cannot be overstated. All the community leaders interviewed for this report cited the collective trauma felt by the communities.

Beyond the immediate horror and loss of life, the Ebola crisis brought the usual routines of daily life to a halt: restricted population movement, interrupted harvests, lead to the closure of markets and restricted regional and international trade. Economic activity in the region was reduced, reversing recent economic gains in Sierra Leone, Guinea, and Liberia. The United Nations Development Group (UNDG) predicted a loss of GDP of up to 9.6% ($315m USD) in Guinea, 8.0% ($292m USD) in Sierra Leone and 18.7% ($245m USD) in Liberia (18). This economic impact will continue to have a considerable effect on employment and household livelihoods in the region. The region is predominantly rural and those communities which rely on subsistence farming are particularly exposed to an economic collapse (see case study below).

This regional economic decline also caused a widespread crisis of food security, affecting hundreds of thousands of people in each country (19). In some areas there has been a slow economic recovery in recent months but household income remains low, food production has fallen and higher food prices have hit already poor communities (20). The World Food Programme (WFP) found that in many communities in Sierra Leone, Liberia and Guinea, transport issues are a key factor in reducing food security (21).

Routine healthcare services have also been disrupted in the region. The vast majority of healthcare workers were diverted to combat the Ebola outbreak and hundreds have died from it. The International Rescue Committee (IRC) reports that as of January 2014, “65% of health care worker infections occurred among staff employed in non-Ebola care facilities”. The most common cause was exposure because employees lacked personal protective equipment (PPE) (22). Many people avoided health services altogether because they feared infection (15). This had adverse effects on all major health programmes including TB, HIV, malaria and nutrition programmes and routine vaccinations. The knock-on effects will be catastrophic (23). For example, in many areas routine measles vaccination rates have fallen by at least 25%. This could result in tens of thousands of additional measles cases leading to between 500 to 4,000 deaths (24).

Ebola has disproportionately affected women. In the outbreak’s early stages, women were more likely to be exposed to the virus than men due to their care-giving role in families. This gender disparity continues in the knock-on effects of Ebola; a disproportionate number of women in Sierra Leone, Liberia and Guinea are employed in sectors most affected by the outbreak such as informal services and agriculture (18,25).

Education has also been badly affected. Schools were closed in parts of Sierra Leone, Liberia, and Guinea for up to six or even eight months. Five million children were affected (26). Loss of household income may also mean more children will drop out of school in the longer term. Finally, some studies show an increase in teen pregnancy and child labour during this period (18,27).
Case Studies: The impact of the Ebola outbreak on communities

“We are hungry”
Gelengasiasu Town lost eighteen people to Ebola. “The whole community was destroyed. Our houses spoiled. Human beings warm houses – with the deaths nobody was inside the houses” Folokula Gayn, the general town chief, explains. “Our rice harvest did not happen” Gayn continues. “We are hungry; there is no way to even harvest rice”. Jackson Miller, from a market town in neighbouring county Gounwolaila, shares a similar story. “We have moved from town to our farms, disturbed our businesses and interrupted our farming. We are a market town”.

Interviews from Gelengasiasu Town, Gbarpolu County, Liberia and Kpayeakwelle, Gou Gounwolaila County, Liberia.

“A witch flight fell”
“It started with a story that a witch flight (plane) fell, so that is why people were dying”. Ibrahim Fonah, a 32 year old from Port Loko Town, describes one of the many rumours that spread through communities during the early stages of the outbreak. Dr Sesay, a medical officer shares the impact of fear and denial on health in the district. “Clinic attendance has been low … a lot of other people died not from Ebola, but from the fear to go to hospital when they are sick. Health service delivery has been seriously hampered, a lot of gains made in healthcare have been lost as well.”

Interviews from Port Loko Town, Port Loko District, Sierra Leone

“Children are fending for themselves”
“Schools were closed, hospitals closed, pregnant women were not taken care of, health practitioners were afraid and children died of simple ailments. Businesses were affected as parents were not going to work” Ruth Johnson from Lakpazee explains. High School teacher, Lawrence Flomo, describes the impact on families in Fiam Community. “Records show over five family heads [have died from Ebola]. Some children have been orphaned. Some children are fending for themselves. There are also orphans that were brought from other communities to Fiam”.  

Interviews from Lakpazee and Fiam Community, District 9, Liberia
1.2 THE RESPONSE

Box 2: Key tools of the Ebola response and their challenges

Quarantine
- Stopping an Ebola epidemic means prompt identification and isolation of infected people. Ebola-infected patients must be quarantined to prevent it spreading.
- Many people have highlighted the methods, extent and safety of some quarantine policies (189,190). The World Bank highlighted the insufficient supply of food and other necessities to some quarantined individuals (191). In some cases, families broke quarantine in order to buy food (192).

Contact tracing
- The identification and follow-up of persons who may have had contact with an infected person (193). All potential contacts of suspected, probable and confirmed Ebola cases need to be systematically identified and put under observation for 21 days (the maximum incubation period of the Ebola virus) (193). Efficient tracing required a list of contacts and their location. In Sierra Leone only 20-30% of the contacts in the Ministry of Health’s database were usable, others were too vague for outsiders to identify (194).
- Many people do not have permanent addresses. There was opposition to some of the tracers (194).

Travel restrictions
- Governments of the most affected countries imposed travel restrictions with the aim of preventing the spread of Ebola (73). However, this sometimes slowed down and inhibited response workers.

Safe burial
- Ebola-infected dead bodies are extremely infectious; transmission through ceremonial body washing was common. Governments of all three Ebola-affected countries decided to provide safe burials for everyone who died. Liberia also instituted cremation (195).
- This required huge resources (burial teams, vehicles and personal protective equipment), coordination (with swab teams, laboratories, contact tracers) and planning (graves marked and families informed).
- The deployment of burial teams and the engagement of communities to ensure safe burials lead to a reduction in unsafe burials and potential transmission.

Social mobilisation and community engagement
- Supporting communities to identify and implement behaviour change to keep them and their communities safe was key.
- Encourage people to come forward if they were sick. Patients and families needed the confidence to know that they would be cared for.

Expansion of treatment infrastructure
- Care needed to be effective, to create high survival rates, and safe, so that Ebola was not transmitted to health workers.
1.2.1 NATIONAL RESPONSE

Guinea, Liberia and Sierra Leone had declared the Ebola virus disease epidemic as a national health emergency by mid-August 2014 and established National Task Forces. The respective National Ebola Outbreak Response Plans were subsequently developed; the aims of which were collectively agreed at the WHO Accra Ministerial meeting in July 2014 (28):

1. Ensure effective coordination of the outbreak response activities at all levels.
2. Strengthen early detection, investigation, reporting, active surveillance, and diagnostic capacity.
3. Institute prompt and effective case management and psychosocial support while protecting the health of health-care workers involved.
4. Create public awareness about Ebola, the risk factors for its transmission as well as the factors that do not entail any risk, and its prevention and control among the people.

A key component of the national response was to set up, with international support, coordinating mechanisms to contain the spread of the disease.

In Sierra Leone, the Government created a National Ebola Response Centre (NERC) that, together with the United Nations Mission for Ebola Emergency Response (UNMEER), served as a command and control structure for many partners in the Ebola response. The NERC oversaw 15 District Ebola Response Centres (DERCs) with a feedback loop between the NERC and the DERCs. These DERCs also coordinated with the district health management teams for technical aspects of the response, and were joined by national and international partners. According to Stephen Gaojia (29), Sierra Leone Incident Manager for Ebola:

“We believe a decentralised response is going to be critical to get us to zero in the shortest possible time.”

Liberia and Guinea set up similar decentralised national structures but the information flows and local-level structures varied among the countries (30). An example of this decentralised coordination can be seen in figure 3, which shows the social mobilisation pillars and sub-committees developed in Sierra Leone, Guinea and Liberia during the outbreak.

The enormity of the required response to Ebola meant the governments of Guinea, Liberia and Sierra Leone quickly called for an international response effort. Foreign Minister Samaur W. Kamara of Sierra Leone in September 2014 said (31):

“Based on the knowledge we had, based on the advice we were given by our international partners, we mobilised to meet this unfamiliar threat. But the staff, equipment, medicines and systems we had were inadequate and this slowed our effective response.”
Figure 3: Social Mobilisation pillars and sub-committees developed in Guinea, Liberia, and Sierra Leone: an example of decentralised coordination in the Ebola response (30).

Liberia’s Social Mobilization Pillar
National-Level Coordination Structure for EVD Response (Current)

Chair: Health Promotion Division MOHSW
Co-Chair: UNICEF

- MOH + CDC: Media Support and Documentation
- MOH + UNICEF: Message and Materials Development
- MOH + WHO + Crusaders for Peace: Mobilization and Field Support
- MOH + Liberia + CSOs + RBHS: Interpersonal Communication Training
- MOH + JHU/CCP: Research, M&E

Sierra Leone’s Social Mobilization Pillar*
National Emergency Management System (Ebola)

District SM Committees
- Western (Urban)
  - Bo
  - Bombali
  - Bonthe
  - Kailahun
  - Kambia
- Western (Rural)
  - Kenema
  - Koinadugu
  - Kono
  - Monyamba
  - Port Loko
  - Pujehun
  - Tonkolili
- Media Group
- Faith Based Organization Group
- Youth and Adolescent Group
- C at Household-Level Group
- IPC with Healthcare Workers Group
- Special Needs Group (same as subcommittee 5)

Guinea’s Social Mobilization Pillar

National Coordination Against Ebola

- Surveillance
- Communications
- Patient Care
- Sanitation
- Research
  - Rumor Management
  - Public Relations
  - Social Mobilization
  - Prevention Communications
1.2.1 INTERNATIONAL RESPONSE

By 14th October 2015, the international community (over 50 nations and many donor organisations) had mobilised over $8.2bn USD to finance the Ebola response (32). The top five highest contributing donors included the US which gave $2.1bn USD, the UK $687m USD, the World Bank $1.6bn USD, the European Commission $955m USD and the African Development Bank $525m USD (33) (see figure 4).

It is difficult to estimate how many health workers were involved in the response. The World Bank and the African Development Bank estimate that more than 39,000 health workers took part alongside equally large numbers of surveillance and community mobilisation staff (34). Thousands of response workers were trained, including 4,500 frontline workers at the Institutional Organisation for Migration’s (IOM) National Ebola Training Academy in Sierra Leone. In April 2015, the World Bank estimated that more than 1300 foreign medical personnel were taking part including more than 850 volunteers from other African countries (through the African Union Support to the Ebola Outbreak in West Africa (ASEOWA). Approximately 1,000 WHO and nearly 200 UNMEER personnel supported these health workers mainly in logistic and coordination roles.

This was a considerable mobilisation of resources but there has been widespread criticism of the time lag between the outbreak and the response. Six months into the crisis, only 30 medical response teams were on the ground. Most of the health workers and support teams and the financial and equipment/facility investment arrived mid-way through the crisis (35). Table 1 shows the allocation of funding ($6.6bn USD) from 46 contributing partners between September 2014 and May 2015 as reported by UNMEER, stratified by country, recipient category, and purpose.

### Table 1: Allocation of disbursed funds by country, recipient category, and purpose (36)

<table>
<thead>
<tr>
<th>Country</th>
<th>Allocation (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guinea</td>
<td>13%</td>
</tr>
<tr>
<td>Sierra Leone</td>
<td>20%</td>
</tr>
<tr>
<td>Ebola-affected country</td>
<td>28%</td>
</tr>
<tr>
<td>Liberia</td>
<td>31%</td>
</tr>
<tr>
<td>Other country</td>
<td>1%</td>
</tr>
<tr>
<td>Unspecified</td>
<td>7%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recipient</th>
<th>Allocation (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affected countries (Multi-lateral)</td>
<td>33%</td>
</tr>
<tr>
<td>Affected countries (Bilateral)</td>
<td>14%</td>
</tr>
<tr>
<td>International NGOs</td>
<td>12%</td>
</tr>
<tr>
<td>International Organisations</td>
<td>23%</td>
</tr>
<tr>
<td>Research institutions, Regional &amp; local NGOs</td>
<td>31%</td>
</tr>
<tr>
<td>Other recipients</td>
<td>13%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Allocation (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response</td>
<td>71%</td>
</tr>
<tr>
<td>Recovery</td>
<td>9%</td>
</tr>
<tr>
<td>Research and Development</td>
<td>4%</td>
</tr>
<tr>
<td>Other</td>
<td>16%</td>
</tr>
</tbody>
</table>
With its 450-year connection to Sierra Leone, the UK government took the lead, committing over £427m to support the battle against Ebola. Its links included Sierra Leoneans working for DFID, links to NGOs, an existing partnership with Njala University and collaborations such as the King's College Hospital Sierra Leone Partnership. Table 2 shows some of the key projects in the UK Ebola response.

### MEDICAL AND TECHNICAL SUPPORT

DFID funded the construction of 6 treatment centres, around 200 community care units and supported over 1,400 treatment and isolation beds - more than half the beds available for Ebola patients in Sierra Leone (37). In addition to this, DFID focused much of its resource allocation on improving safe burials, supporting a total of 140 burial teams, and expanding social mobilisation efforts to educate and equip communities with the knowledge and tools to tackle Ebola. Their review, ‘Reducing Transmission of Ebola in Sierra Leone Through Changing Behaviours and Practices’ reports an increase in community knowledge of Ebola from 39% to 69%, reduction in stigma from 94% to 41% and an average of 97% of burials being classified as safe and dignified medical burials (38).

<table>
<thead>
<tr>
<th>Project Title</th>
<th>Budget</th>
<th>Start Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Support to Respond to the Ebola Virus Disease in 2014 (Urgent Needs)</td>
<td>£79.41m</td>
<td>Jul-14</td>
</tr>
<tr>
<td>Sierra Leone Kerry Town Ebola Treatment Facility</td>
<td>£89.10m</td>
<td>Sep-14</td>
</tr>
<tr>
<td>Ebola Treatment Centres in Sierra Leone</td>
<td>£45.90m</td>
<td>Oct-14</td>
</tr>
<tr>
<td>Ebola Care Units in Sierra Leone</td>
<td>£43.40m</td>
<td>Oct-14</td>
</tr>
<tr>
<td>UK Response to Ebola Crisis Through Support for UNMEER and the Wider UN System</td>
<td>£22.13m</td>
<td>Oct-14</td>
</tr>
<tr>
<td>UK Support to Ebola Crisis Through Support for the Joint Inter Agency Task Force (JIATF)</td>
<td>£33.44m</td>
<td>Oct-14</td>
</tr>
<tr>
<td>UK Response to Ebola Crisis Through Establishing Laboratories</td>
<td>£12.15m</td>
<td>Nov-14</td>
</tr>
<tr>
<td>Ebola Central Health Care Supply Chain Platform</td>
<td>£7.20m</td>
<td>Nov-14</td>
</tr>
<tr>
<td>Match Funding for Ebola Response</td>
<td>£6.20m</td>
<td>Dec-14</td>
</tr>
<tr>
<td>Regional Preparedness</td>
<td>£19.20m</td>
<td>Jan-15</td>
</tr>
<tr>
<td>Transition from Ebola Response to Early Recovery</td>
<td>£54.0m</td>
<td>Mar-15</td>
</tr>
<tr>
<td>Ebola Vaccines Insurance</td>
<td>£1.10m</td>
<td>Apr-15</td>
</tr>
</tbody>
</table>
These projects faced many challenges. One such challenge was deciding where to prioritise the resource allocation. High risk groups included communities geographically related to others with known Ebola cases; communities with attitudes and practices known to increase Ebola transmission risk; as well as vulnerable or marginalised groups, such as women and young people (38). DFID also faces the challenge of ensuring that the use of donor contributions and other forms of received capital are verified, especially as programmes draw to a close. Nonetheless, the primary challenge DFID faces in terms of funding resources is a temporal one: whether to prioritise short-term or long-term interests. Unpredictable spikes in the demand for resources to tackle health emergencies, make it more difficult for DFID to adequately fund the more sustainable, longer term goals necessary for health systems strengthening (38).

The UK also provided human resources through NHS volunteers. Over 150 NHS Staff travelled to Sierra Leone, with salaries covered by the NHS and Public Health England and in addition deployed over 100 staff to run three new laboratories in Sierra Leone. This reduced the turnaround time for samples from 4-5 days to less than 24 hours (39). However, problems with backfilling in the NHS prevented more staff contributing. There were reports that more than ten times as many staff volunteered as were able to go to Sierra Leone (39,40). Some have argued that the UK’s West African diaspora healthcare professionals could have been utilised further, especially considering their unique position to shape culturally appropriate and socially legitimate response programmes (41) (see box 3).

The IDC has recommended in its recent report on the Ebola response that DFID fund a formal structure to facilitate more volunteering by NHS staff (40). However, as highlighted by Health Poverty Action, sending large Western teams of health workers has questionable benefit when compared to the long-term strengthening of local health systems (42,43).

1.2.3.2 LOGISTICAL SUPPORT

The UK provided emergency food, equipment, and logistical support to the Sierra Leonean government’s Ebola response. It also financed Small and Medium Enterprises (SMEs), and psychosocial and social protection for children. DFID also funded health promotion radio programmes in eight local languages, in part through working with BBC Media Action (44).
The UK has also been at the forefront of academic research into Ebola including epidemiological, anthropological, social and economic research critical to understanding the underlying causes of the Ebola outbreak and informing response and recovery programmes. DFID co-funds vital research on Ebola, including clinical trials which have led to the development of promising vaccine candidates (6,45).

Box 3: The UK’s African diaspora in the Ebola response and health systems strengthening

Examples of UK’s African Diaspora involvement in the Ebola Response:
- Sierra Leone UK Diaspora Ebola Taskforce (SLUKDET) has been involved in negotiations with Public Health England, the NHS and DfID to recruit volunteers. They also delivered cultural awareness training to NHS and international volunteers prior to their deployment (172).
- SLWT have worked with local grassroots organisations to provide protective raincoats to 750 commercial motorbike riders, as well as PPE and hand-washing facilities and protective raincoats (173).
- EngAyde has provided protection and care for Ebola children and psycho-social support for Ebola affected families and local health care workers (174).

The wider role of the African Diaspora in African development:
- Remittances to Africa outweigh Western Aid to the continent, accounting for an average of 5 per cent of GDP and 27 per cent of exports (197,198).
- Members of the African diaspora have contributed significant financial capital to African countries in investment capital and the purchase of goods and services from the continent (175).
- Many professionals from the diaspora temporarily or permanently return to their country of origin. This brain circulation and return migration strengthens knowledge production in African countries (177).
1.2.3.4 RESTRICTIONS ON TRAVEL

The UK government and 39 other nations restricted direct flights to the region and quarantined all returning health workers. These measures have been described as disproportionate and without scientific justification and may have deterred other international health workers (46,47). The WHO raised concerns that they could “cause economic hardship, and could consequently increase the uncontrolled migration of people from affected countries, raising the risk of international spread of Ebola” (48). Fears of such an overreaction contributed to the WHO’s decision to delay putting out an international alert.

1.3 UNDERLYING CHALLENGES: HEALTH SYSTEMS AND INFRASTRUCTURE

The Ebola outbreak in West Africa was centered on a region with a shared recent history of weak health systems, transnational civil war and internationally led post-conflict reconstruction efforts. This legacy of conflict and shortcomings in the reconstruction efforts are key to understanding many of the weaknesses exposed by the outbreak.

“The health system became seriously exposed by Ebola, because when it came it killed a lot of health workers and community people … the basic principles of prevention and hygiene were lacking.”

Samuel Borbor Vandi, NGO worker (Kailahun District, Sierra Leone)
1.3.1 HEALTH SYSTEMS IN GUINEA, LIBERIA AND SIERRA LEONE

Some health systems in West Africa, such as those in Nigeria and Senegal, have the capacity to control Ebola epidemics (49,50). Sierra Leone, Guinea and Liberia have all made some progress in strengthening their health systems, particularly by providing services for child and maternal health and HIV/AIDS. However, crucial problems in the health systems of these three countries were re-exposed by the Ebola epidemic (50–53).

1.3.1.1 GAPS IN HEALTH FINANCING AND GOVERNANCE

The WHO’s estimate of minimum spending to provide basic lifesaving health services per person per year is $44 USD (54). The governments of all three Ebola-affected countries spend significantly less than this, as shown in table 3. All three countries receive aid for health from donor countries and agencies, however much of the funds provided are for specific disease programmes, such as HIV/AIDS, malaria and TB (55,56). Spending on health per person per year has increased in the region and has more than doubled in Guinea and Liberia between 2006 and 2012. However, spending is still well below what is needed to fund a functioning health system. The resulting gap in funds for essential services is manifested in out-of-pocket expenditure. Sierra Leone and Guinea have more than triple the WHO recommended proportion of spending on health by out-of-pocket expenditure (55). This makes it more likely that poorer people will be pushed further into poverty as a result of paying for their health needs.

<table>
<thead>
<tr>
<th></th>
<th>GUINEA</th>
<th>SIERRA LEONE</th>
<th>LIBERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expenditure per person per year spent on health (USD)</td>
<td>$9</td>
<td>$16</td>
<td>$20</td>
</tr>
<tr>
<td>Estimated Proportion of total health funding from out-of-pocket expenditure</td>
<td>66%</td>
<td>76%</td>
<td>21%</td>
</tr>
<tr>
<td>Amount of External support for health per annum (USD)</td>
<td>$46m</td>
<td>$93m</td>
<td>$89m</td>
</tr>
</tbody>
</table>

Strong governance is needed to enable effective health systems strengthening. In all three Ebola-affected countries, there have been attempts at health systems reform, such as the notable Free Health Care Initiative in Sierra Leone. Governance experts, however, have highlighted the absence of accountability mechanisms and conflicting policies. The trickle down effects of delayed decisions at national level are key barriers to the development of health systems in all three countries (58–60).
1.3.1.2 CHRONIC SHORTAGE OF HEALTH WORKERS

Strong governance is needed to enable effective health systems strengthening. In all three Ebola-affected countries, there have been attempts at health systems reform, such as the notable Free Health Care Initiative in Sierra Leone. Governance experts, however, have highlighted the absence of accountability mechanisms and conflicting policies. The trickle down effects of delayed decisions at national level are key barriers to the development of health systems in all three countries (58–60).

Health worker absenteeism is also a significant problem, particularly in rural or remote areas and with those who work in lower-level health facilities (66). However, national rates of absenteeism are quite low in Sierra Leone – at less than 2% in 2014. A ReBUILD research consortium attributes this to the introduction of the Free Health Care Initiative (FHCI) in April 2010 which included fee exemptions for healthcare workers (67).

**Box 4: Health workforce prior to the Ebola outbreak (64,65)**

<table>
<thead>
<tr>
<th>Country</th>
<th>Health worker per</th>
<th>Public health institute</th>
<th>Health expenditure per capita</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guinea</td>
<td>1 health worker per 1,597 people</td>
<td>1 public health institute with limited capacity</td>
<td>$25 USD</td>
</tr>
<tr>
<td>Liberia</td>
<td>1 health worker per 3,472 people</td>
<td>“Emergency Human Resources Plan” (2007) designed to rebuild its health workforce and double the number of nurses but had limited overall success</td>
<td>$44 USD</td>
</tr>
<tr>
<td>Sierra Leone</td>
<td>1 health worker per 5,319 people</td>
<td>10,917 nurses and midwives in the country</td>
<td>$96 USD</td>
</tr>
</tbody>
</table>

Liberia

- 1 health worker per 3,472 people
- “Emergency Human Resources Plan” (2007) designed to rebuild its health workforce and double the number of nurses but had limited overall success
- $44 USD health expenditure per capita (10% of GDP)

Guinea

- 1 health worker per 1,597 people
- 1 public health institute with limited capacity
- $25 USD health expenditure per capita (4.7% of GDP)

Sierra Leone

- 1 health worker per 5,319 people
- 10,917 nurses and midwives in the country
- $96 USD health expenditure per capita (11.8% of GDP)
Compounding the human resource crisis is a lack of healthcare facilities. Community mobilisation is often fraught with geospatial complications in disconnected urban slums (68) and vast rural areas (69) hindering the efficient distribution of goods.

Sierra Leone, Guinea and Liberia have all made some improvements to the delivery of services in recent years. For example, the Free Health Care Initiative in Sierra Leone, mentioned in the previous section, removed user fees from public maternal and child health services. However, Sierra Leone still has some of the highest rates of maternal and child deaths worldwide and the health system still fails to deliver most of the WHO’s ‘building blocks’ of good health service delivery, as summarised in Box 5. The Ebola outbreak has revealed the inability of many communities to mobilise resources from both national and international sources, such as medical equipment, trained health workers, and supplies for quarantined Ebola victims (40,42).

“[We need] training and posting of qualified health staff, logistics support, construction and rehabilitation of health facilities (PHUs), and more drugs. It has to do a lot with resources.”

Dr Tom Sesay, Acting District Medical Officer (Port Loko District, Sierra Leone).

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**Box 5:**
Characteristics of good health service delivery, adapted from WHO building blocks (70).

- **Comprehensive:** A comprehensive range of health services is provided, appropriate to the needs of the target population.
- **Accessible:** Services are directly and permanently accessible with no undue barriers of cost, language, culture, or geography.
- **Continuous:** Service delivery across the network of services, health conditions and levels of care.
- **High quality:** Services are effective, safe, centred on patient’s needs.
- **Person-centred:** Services are organised around the person, not the disease or the financing.
- **Coordinated:** Across types of provider, types of care, levels of service delivery, and for both routine and emergency preparedness.
- **Efficient:** To achieve the core elements described above with a minimum wastage of resources.
Poor service delivery has been a significant challenge to community mobilisation and community-led efforts in the Ebola response. It is well documented that in Sierra Leone the inability of health institutions to keep up with the demand for Ebola treatment led to patients seeking out understaffed community health clinics not integrated into the broader health system.

Lack of resources is not a purely economic issue. When clinicians or technology are missing because of inadequate ancillary health services (71,72), trust in health services is eroded. In an extreme example, in Nimba county and Bomi county, Liberia, families in some communities were boarded up in their homes without food or water because there was no medical care or isolation facilities (73). This fostered fear, resentment and stigmatisation in the affected communities, presenting patients with what felt like a death sentence. Similarly, the lack of consistent food delivery to quarantined patients in Monrovia resulted in feeling of exclusion from their communities (74). Many of the rural responses in our interviews described the absence of medical services, the attempts to carry sick people for miles on stretchers and the desperate lack of medicinal drugs. The Ebola Response Anthropology Platform (ERAP) suggested that provision of a “solidarity kit” to quarantined patients – including a charged phone, mobile credit, and food – could mitigate the isolating consequences of quarantine (75).

The sparse healthcare available was underscored by fragile physical infrastructure, according to evidence submitted by The Malaria Consortium (76). An adequate level of general infrastructure is essential for the effective coordination of public health strategies. For example, an outreach campaign is unlikely to be successful when schools are closed, households have little access to the media, literacy levels are low and there are not enough clinicians to convey a particular message (77,49,78,79). The success of community mobilisation efforts is crucially dependent on adequate resourcing and the continued development of infrastructure.

“We talked to people in quarantined homes and counselled them, because most people in quarantined homes are heart broken.”

Mrs Mariatu Songo Kanu, Religious Leader (Port Loko District, Sierra Leone).
1.3.2 RURAL, PERI-URBAN AND URBAN CHALLENGES

In the past, Ebola outbreaks have been limited to rural and geographically isolated communities but this outbreak saw a rapid and extensive spread into urban and peri-urban areas.

Previous rural outbreaks, for example in Uganda, have typically been quickly contained; partly because of natural geographical restrictions but also because of social support and resilience of the affected communities. Infection is usually limited to family members who are intimately involved in the care of the sick and the dead (68). However, the rural environment in Sierra Leone is different, with significant and complex movements of people between rural regions and across great distances. A study by Professor Paul Richards and others at Njala University found that the direction and size of movement between villages was influenced by inter-family relationships, some pre-existing the recent civil war. People travel along trade routes to markets for education, marriages and funerals.

Some of these ties span large distances and cross national borders. This was particularly important in the spread of Ebola between Kisi-speaking communities of Sierra Leone, Guinea and Liberia. Without a detailed knowledge of the local communities and their travel patterns, the spread of Ebola across rural regions would be difficult to anticipate (80).

For the first time since Ebola was discovered, cities, large and small, were affected. West Africa, like the rest of the continent, is experiencing unprecedented urban growth, with rates of urbanisation amongst the highest in the world (81). Such growth has resulted in peri-urban sprawl characterised by informal settlements. For example, 97% of Sierra Leone's urban residents live in informal settlements. These peri-urban areas pose a great challenge for infection control as they typically have poor infrastructure and hygiene, little governmental influence and great heterogeneity (82).

This is well illustrated by the Ugandan outbreaks between 2000 and 2012; the largest outbreaks were where Ebola spread to the overcrowded, peri-urban settlements of internally displaced persons and Gulu municipality, the main town in the area. Other outbreaks in rural regions were much smaller and more easily contained (68). The Institute of Development Studies (IDS) notes that the introduction of agricultural practice into urban areas makes future zoonotic outbreaks more likely (82).
1.3.3 LEGACIES OF WAR AND RECONSTRUCTION

Sierra Leone and Liberia suffered from political instability and vicious civil wars in the 1990s that killed over 300,000 people and maimed many more. Guinea also suffered from dictatorship and its violent aftermath. Millions were displaced between 1989 and 2004 (83). In addition to death, wounding and distress, these conflicts devastated infrastructure and led to long periods of political instability. One major legacy of the recent conflicts in these countries is the remoteness of the state in many communities. Whilst there have been significant development and progress in towns since the end of civil wars and conflict in the region, the state has not delivered basic necessities in health facilities, transport, education and governance in many rural areas (84,85). In all three countries there is widespread distrust of political leaders and the legacies of civil unrest are evident in the current Ebola crisis.

In Guinea and Liberia, conspiracy theories hampered government public health efforts during the Ebola outbreak. In Sierra Leone, in communities alienated from the central state, a rumour spread that Ebola was a ruse to depopulate an area known to be the heartland of the political opposition (86). Furthermore, in Sierra Leone, a combination of refugees from the civil war and lack of rural development post civil war caused a mass exodus into cities. In packed slums and increasingly overcrowded urban districts with poor infrastructure, Ebola spread rapidly.

At the Peacebuilding Commission’s (PBC) Special Meeting on Ebola, held in New York in April 2015, the PBC chair called on the international community to maintain a commitment to Liberia, Sierra Leone and Guinea to ensure that progress on peacebuilding was sustained. The meeting highlighted the importance of material and psychosocial support for survivors in a country still dealing with the effects of broken relationships and the violence of the civil war (87).

“We just came from war and saw a silent war. Almost everybody is traumatised”

Rose Taylor,
Acting Speaker for the Perry Town General Women Organisation (Perry Town, Liberia)
1.4 SUMMARY

The West African Ebola outbreak of 2014-2015 is the largest and longest Ebola outbreak in history. It resulted in a huge loss of life and its social, economic, and political knock on effects will be felt for years. The worst affected countries, Liberia, Sierra Leone and Guinea, have suffered civil war that has underscored the difficulties of the Ebola response. Enormous progress has been made through the Ebola response, and the UK can be commended for its substantial medical and humanitarian support, notably to Sierra Leone through DFID. Ebola drew global attention to the challenges of generating an effective health crisis response. It is critical to consider the role of communities in the recent Ebola epidemic and to examine the lessons for community engagement in health crises and strengthening health systems.
2 HOW IMPORTANT ARE COMMUNITY-LED APPROACHES TO HEALTH?

West African countries that had strong health systems, such as Nigeria, were able to control the Ebola outbreak. Those that did not, namely Liberia, Sierra Leone and Guinea, were the worst affected. The effects of civil unrest and authoritarian rule in Liberia, Sierra Leone and Guinea are manifested in a lack of development, mistrust in governments and official institutions, especially in rural areas. Furthermore, healthcare systems in these countries— if present— were incapable of controlling the outbreak.

2.1 WHAT IS A ‘COMMUNITY-LED’ APPROACH?

Ebola is a particularly vicious disease, both fatal and easily spread. Controlling it in any circumstances is difficult. Conventional, top-down, almost military-style approaches to an Ebola outbreak may seem appropriate but there was no structure or capacity in place to deal with an Ebola outbreak.

There is great heterogeneity in community leadership and structures across West Africa. For example, in 1896 the British administration divided Sierra Leone into 149 chiefdoms, each with a Paramount Chief as the sole local authority. The chiefs and their sub-chiefs are elected from the ruling families by the Tribal Authority, a group of local notables (88,89). As ruling families compete for election, the number of ruling families within a chiefdom can impact the level of corruption and consequently trust within a community, as well as the level of community participation in civil society organisations and forums managed by those in power (88).

During the war, many chiefs fled or were killed, but in many rural areas the chiefdoms continued informally allowing governance even when the state collapsed. Today, the authority of chiefs is much stronger in rural communities than in urban communities where central governance is more strongly felt and post-war Paramount Chiefs can be seen more as moral leaders than authoritative decision-makers (89). There are also geographical differences in community structures and leadership, with Southern provinces permitting female Paramount Chiefs, while Northern provinces do not (90).

In 2004, the World Bank sponsored the creation of elected local councils to liaise with the central government in determining expenditure in rural areas (88). However, there is tension between government and traditional leadership, with the National Council of Paramount Chiefs advocating for the withdrawal of Paramount Chiefs from the Parliament, and the creation of a new independent body to manage tradition-related matters (90). Moreover, in Sierra Leone, like Liberia and Guinea, the vast majority of the population identify as religions, with Christian, Muslim and traditional religious leaders having great influence in their different communities (91).

The community leaders interviewed for this report reflect the diversity in community leadership and structures, with interviews with Paramount Chiefs, religious leaders, health workers and civil society organisation leaders. They all spoke of the collective traumatisation of their communities following the horrifying illness and rapid death caused
by the Ebola virus. Many emphasised the knock-on effects of the disease: displacement of families, loss of business, interrupted harvests, closure of schools and the ban on traditional social actions such as washing bodies for burial and even handshakes. These bans have had a deep impact on communities and their sense of belonging. However, the resilience and resourcefulness of many communities in this outbreak highlights that they must have a central role in such a crisis, educating citizens and strengthening health systems. Community-led approaches to health regard communities as co-partners in the provision of health information and services. Table 4 has been adapted from Restless Development’s summary of the key features of community-led approaches to health education and awareness. It shows how they differ from standard practice (63). A typical community-led health education programme uses respected, trusted and trained community members to raise awareness and promote behaviour change.
<table>
<thead>
<tr>
<th>UNIT OF ANALYSIS</th>
<th>TYPICAL HEALTH EDUCATION/ INFORMATION APPROACHES</th>
<th>COMMUNITY-LED APPROACHES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Individuals</td>
<td>Communities and families</td>
</tr>
<tr>
<td>CORE ACTIVITIES</td>
<td>Educating communities</td>
<td>Listening to communities</td>
</tr>
<tr>
<td></td>
<td>Disseminating key information</td>
<td>Empowering communities to</td>
</tr>
<tr>
<td></td>
<td></td>
<td>be agents of change</td>
</tr>
<tr>
<td>COMMUNICATIONS APPROACH</td>
<td>One-way information dissemination</td>
<td>Two-way sharing of expert</td>
</tr>
<tr>
<td></td>
<td>Health educators are the 'experts'</td>
<td>knowledge between community</td>
</tr>
<tr>
<td></td>
<td></td>
<td>members and external groups</td>
</tr>
<tr>
<td>EMPHASIS</td>
<td>Top-down approaches</td>
<td>Bottom-up approaches</td>
</tr>
<tr>
<td></td>
<td>Sharing biomedical facts, correcting erroneous</td>
<td>Appreciative of other ways</td>
</tr>
<tr>
<td></td>
<td>local beliefs</td>
<td>of understanding illness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>and to hold multiple</td>
</tr>
<tr>
<td></td>
<td></td>
<td>framings for disease at</td>
</tr>
<tr>
<td></td>
<td></td>
<td>the same time</td>
</tr>
<tr>
<td>FACILITATION STYLE</td>
<td>Teaching, preaching</td>
<td>Listening, learning</td>
</tr>
<tr>
<td></td>
<td>House-to-house</td>
<td>Community-wide</td>
</tr>
<tr>
<td>METHODS AND TOOLS</td>
<td>Information, Education &amp; Communications (IEC)</td>
<td>Participatory Rural</td>
</tr>
<tr>
<td></td>
<td>materials</td>
<td>Appraisal (PRA) tools to</td>
</tr>
<tr>
<td></td>
<td></td>
<td>enable communities to</td>
</tr>
<tr>
<td></td>
<td></td>
<td>analyse their own situation</td>
</tr>
<tr>
<td>TYPICAL ASSUMPTIONS</td>
<td>'Traditional' beliefs and behaviours are the</td>
<td>Communities have responses</td>
</tr>
<tr>
<td></td>
<td>problem to be changed or solved</td>
<td>that are both health-lowering</td>
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<td>Communities must be convinced to use health</td>
<td>and health enhancing</td>
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<td></td>
<td>services</td>
<td>Health services must adapt</td>
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<td>to meet the needs of</td>
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<td></td>
<td></td>
<td>communities</td>
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<td>KEY MOTIVATIONS FOR CHANGE</td>
<td>Awareness of biomedical facts</td>
<td>Urgency to protect each</td>
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<td></td>
<td>Rational understanding of transmission</td>
<td>other, social solidarity,</td>
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<td></td>
<td>routes</td>
<td>cooperation and mutual</td>
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<td></td>
<td>Self-preservation</td>
<td>support</td>
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<td>Hope with early treatment</td>
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<td></td>
<td></td>
<td>Trust in health authorities</td>
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<td>DESIRED OUTCOMES</td>
<td>Individuals seek external health services</td>
<td>Communities feel</td>
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<td></td>
<td>and follow the rules</td>
<td>empowered to protect</td>
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<td></td>
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<td>themselves using local</td>
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<td>resources</td>
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<td>Two-way dialogue results</td>
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<td>in better use of health</td>
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<td>community needs</td>
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2.2 THE ROLE OF COMMUNITIES IN THE RESPONSE: BUILDING TRUST AND LEGITIMACY

2.2.1 INITIAL PUBLIC MOBILISATION CAMPAIGNS: RESISTANCE AND FEAR

In the early stages of the West African Ebola outbreak, information and education were vital to counter misinformation. Rumours about the cause of deaths (92) or even denial of the existence of the virus impeded efforts to involve communities in the effort to control the epidemic (72). Consequently, attempts to educate communities about the virus faced challenges.

The delivery methods of the warnings about Ebola were impersonal and often evoked hostility. The message omitted family and community responsibilities (22), as well as practical concerns such as the food supply which was badly affected by movement restrictions, curfews and quarantines (93).

Initial campaigns focused on raising awareness about Ebola, informing people of the signs, symptoms and how to seek help but there was little effort to build the capacity of local journalists to spread accurate information and raise awareness (79,80). Another unintended consequence of the approach of the Government and international agencies was the effect of the dramatic, highly-stigmatising and fear-inducing messages such as “Ebola kills,” “There is no cure for Ebola” and “Don’t touch”. This deterred people from seeking care (96) and Ebola Treatment Units (ETUs), were initially seen as “black holes”. Family members disappeared into them and were never seen again (74).

The international agencies have also been criticised for simply paying the local media large amounts of money to disseminate messages rather than using local media outlets as partners in health education and awareness. According to the Ebola Response Anthropology Platform (ERAP) these campaigns followed purely clinical and epidemiological frameworks. They did not consider the social context (97). The methods used to deliver the messages about Ebola were described as intimidating. A typical example was the initial health awareness campaign in Lofa county, Liberia. Predominantly rural Lofa borders Guinea and Sierra Leone (98) and people move across these borders at will. It had one of the highest cumulative incidences of Ebola (93). Officials drove around the district shouting messages through megaphones. This appeared to cause resistance. For example, in July 2014, a group of UNICEF-supported animators were chased away and their vehicle damaged by community members (101). Box 6 gives examples of other similar occurrences across West Africa (97).

Fear and mistrust surrounded the isolation units. When people died the public health authorities took bodies for immediate burial but families demanded that traditional religious rituals for burial be followed. This led to clashes with families hiding the bodies of the deceased from health officials (22). The International Growth Centre’s surveyed 78 communities in Monrovia, Liberia, and found that a “high distrust in government” was associated with low levels of compliance with preventative
health measures such as the ban on public gatherings, travel restrictions and safe burials by health workers (104). As discussed in Chapter One, this mistrust of government bodies and NGOs is due partly to mistrust created by the recent civil war and partly due to the challenges underlying weak health systems.

Box 6: Examples of hostility towards healthcare workers

In July 2014, the Red Cross were forced to suspend Ebola operations in Guinea as a group of staff were attacked by “locals wielding knives” (199, 200). MSF and other charities also reported similar attacks on their staff (199–201).

In September 2014, health workers came under attack while trying to bury the bodies of five Ebola victims in Sierra Leone (202).

In October 2014, a riot erupted in eastern Sierra Leone when health workers tried to take a blood sample from a 90-year-old woman suspected of having Ebola, resulting in the death of two people (203).

In Monrovia, Liberia, the West Point slum has 750,000 people living in a square mile. The Government set up an isolation centre and there were reports of a woman and her six children, with no Ebola symptoms, were forced into this centre. All were contaminated and died (204).

17 Ebola patients are said to have fled from the West Point Isolation Centre, some freed by their families. It was reported that they believed Ebola was hoax and demanded an end to quarantine. “There’s no Ebola” they shouted (205).

Table 5:

<table>
<thead>
<tr>
<th>RELIGIOUS LANDSCAPE</th>
<th>GUINEA</th>
<th>LIBERIA</th>
<th>SIERRA LEONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>MUSLIM</td>
<td>70-85%</td>
<td>12-20%</td>
<td>45-78%</td>
</tr>
<tr>
<td>CHRISTIAN</td>
<td>4-10%</td>
<td>40-85%</td>
<td>11-27%</td>
</tr>
<tr>
<td>ETHNORELIGIONIST</td>
<td>5-25%</td>
<td>4-40%</td>
<td>2-40%</td>
</tr>
</tbody>
</table>

Note: many communities combine traditional religious adherence to Christianity and Islam

2.2.2 COMMUNITY GROUPS: RISING TO THE CHALLENGE

2.2.2.1 RELIGIOUS LEADERS & ORGANISATIONS: DIALOGUE AND HOPE

The majority of people in Guinea, Sierra Leone and Liberia identify with a religion as summarised in Table 5 below. As such, religious groups are one of the key community structures and a source of support for many.
In the 1980s, the Islamic Action Group and the Christian Action Group in Sierra Leone were mobilised to eradicate polio and during the Ebola crisis, this network of religious leaders was rejuvenated by FOCUS 1000, a Freetown-based NGO. Together, these groups developed ways to use the Quran and the Bible to promote behaviour change, safe burial practices and community surveillance (105). In the quote below, one of our key informants, Reverend Victor Tommy Kaynboi, describes his involvement in the initiative.

The WHO and UNICEF also made efforts to engage religious and community leaders in a response to the outbreak, for example, in Liberia they met with the leaders of the Muslim Council of Liberia and the Council of Churches (106).

Many religious groups run radio stations that are trusted by community members and their weekly programmes help spread news and messages across communities (107). During the Ebola outbreak UNICEF collaborated with local stations such as Crusaders for Peace and Hott FM which broadcast Liberian “hip co” artists such as The Deng, SoulFresh and FA who sang Ebola awareness songs (108). The role of survivors was recognised and awareness campaigns spread their stories shifting the message from fear to one of hope. They encouraged patients to seek early treatment (101,109). For example, BBC Media Action produced “Kick Ebola Nar Salone” (Kick Ebola Out of Sierra Leone). This message was aired by 35 local partner stations across the country. They also carried an interview with a nurse who had survived Ebola. She had avoided transmitting the virus by isolating herself and being tested shortly after falling ill (110). In addition to awareness messaging, listeners were encouraged to phone in and raise concerns and questions (111).

Moreover, religious leaders and communities provided practical as well as psycho-social support to those affected by the outbreak. The Sierra Leone Inter-Religious Council and the Islamic and Christian Action Group has branches in all 149 chiefdoms, with networks that reach the community level. External actors worked with these networks. For example World Vision’s Channel of Hope programme equipped pastors and imams to address hopelessness, fear and stigma in communities, as well as health education (112). Religious groups were also a source of technical and medical support. The Christian Health Association of Liberia (CHAL) in collaboration with partners distributed medical supplies, such as Personal Protective Equipment (PPE), gowns and buckets across south-east Liberia. CHAL also trained nearly 80 healthcare providers in the appropriate use of the equipment and preventative measures (113).
“The religious leaders met, and we decided that a pastor should go to the mosque, and an imam to the church. So that when the pastor goes to the church, the Muslims will really understand the importance of the fight against this Ebola, and when the imam goes to the church, the Christians will say “wow”, if the imam is here, then we really need to take this fight serious.

I was sent to the mosque with an entourage to talk to Muslims about the prevention of Ebola. We listened to the sermon and prayed together... When I first entered, people were moving away from me. But when the time came for me to speak, my message was that “Ebola is not here for Muslims or Christians, but Ebola is here for everybody, it’s only when we join our hands, we can win against Ebola”. Immediately after my message, people started saying “Yes, now we are getting the message”.”

Reverend Victor Tommy Kaynboi
form the Pujehun District, Sierra Leone.
‘Community trust’ is difficult to quantify but it plays a vital role in determining the social legitimacy of health interventions in communities and, consequently, their success. Informants and organisations working on the ground point out that temporary actors from outside the community do not have the social legitimacy of those who have spent time listening to communities and their daily challenges (114).

"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”

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

‘Informal’ health practitioners, such as traditional healers, are often trusted more than external medical groups. Frequently they will be the first people that communities turn to, especially when health clinics are far away and too expensive for many of the poorest communities.

In such areas, informal health practitioners mix traditional healing with biomedical apparatus. They are perceived to be attentive to material, economic and spiritual needs as much as a physical illness (115). Sandy Taimeh, an Imam from Kailahun District, Sierra Leone describes the role traditional healers play in his community:

“Most times our local people go first to traditional healers, sometimes the traditional medicine works. We have had cases where someone got sick, and he was taken to the government hospital, his family was told that it was not a hospital sickness, and that they should take it to the traditional healers. We also have had cases in which some went to the traditional healer, and the healer told his family that he should go to the government hospital for treatment, because they could not handle it. So it happens like that in our locality. That is why community people keep the traditional healers close by.”

Sandy Taimeh, Imam (Kailahun District, Sierra Leone)

The trust invested in some traditional healers within communities in contrast to the ambivalence felt towards formal health authorities partially explains their role as first contacts when an individual becomes sick (116). Richard Mallett of the Overseas Development Institute’s Secure Livelihoods Research Consortium (SLRC) has suggested, traditional healers were “largely ignored by the state and the international community” in early response efforts(117).

Consequently, in the early stages of the epidemic, traditional healers were also key sources of disease transmission as they treated the sick and subsequently became infected themselves. Health Poverty Action reported that in Bombali District, Sierra Leone, one in five people believed that traditional healers could cure Ebola and many turned to Secret Societies, instead of medical teams, for specific healing and burial rituals (42).

Later in the response, efforts to work with traditional healers involved peer education to discourage attempts to treat Ebola cases and training to enable traditional healers to refer the sick to health facilities (118).
For example, in Sierra Leone, Health Poverty Action worked with the District Health Management Team (DHMT) and the District Council in Bombali District to engage with 150 traditional healers about Ebola and equip them with the knowledge and tools to refer people to health facilities. Alternative incomes were also provided for traditional healers and incentives given to them for reporting suspected Ebola cases (42,118).

2.2.2.3 LOCAL LEADERS: ENFORCING THE BYE-LAWS

Community members usually turn to local leaders first for advice and support. This gives these leaders a critical role as points of contact, educators and role models who can demonstrate safe behaviour (119,120). As previously mentioned, Sierra Leone has a Paramount chieftaincy system. The important role of Paramount Chiefs was noted by many respondents in Sierra Leone.

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

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

Paramount Chiefs and other local authorities helped encourage behaviour change through bye-laws and associated fines. These bye-laws and directives supported work on the ground to discourage unsafe practices such as unsafe burials and unnecessary contact with suspected cases. This was particularly important in regions far from main cities where central governance is less felt (119).

“Religious leaders gave Ebola sensitisation messages in their sermon, because I made it compulsory... We warned [the secret societies] to stop their practices during this Ebola crisis and obey the bye-laws.”

Adekalie Miller II, Paramount Chief (Port Loko District, Sierra Leone)

Professor Paul Richards, among others, has highlighted the effectiveness of bye-laws and directives from authoritative figures within the community in cases such as quarantine. (120). Glen Laverack, Technical Officer at the WHO, and Ronald Labonté, Canada Research Chair in Globalisation and Health Equity at the Institute of Population Health, argue that top-down and bottom-up approaches are not mutually exclusive. They suggest a theoretical framework in which the two can act in synergy to promote community engagement, which includes community leaders acting as the primary decision makers in the health programmes that will affect their community (121).

The Ebola outbreak has demonstrated the significant influence that respected and trusted local leaders have on their communities and the crucial role they can therefore play in strengthening health systems.
**Case Study: Bye-laws in Pujehun District, Sierra Leone during the Ebola outbreak**

“We upheld the bye-laws of Ebola: don’t touch, no hand shaking, no public gathering, we closed the church and mosque for a whole month. No secret societies were allowed during this Ebola period and it was a very strong bye-law. Traditional leaders upheld and enforced the bye-laws very strongly.”

Chief John Mohamed Kai Kai, Quarter Head Chief

“All social and economic activities were halted. Most valued traditional practices like burials, handshakes and societies were all halted. The whole of Pujehun district was under curfew and movement was restricted in adherence to the bye-laws.”

Rebecca Kallon, NGO worker

“The [District Emergency Response Centre] tried to put things together and enforce the bye-laws. However, before the government set bye-laws, we already had our own, and the DERC just came in to re-enforce it.”

Musa Sesay, District Social Mobilisation Coordinator on Ebola

### YOUNG PEOPLE

The ‘Ebola Generation’, the young people of the three worst affected countries, played an important role and their positive contribution to community engagement in the crisis has been increasingly recognised (63).

“It was difficult for [the youth] to accept initially, they wanted to revolt against any health worker who went out to talk to them about Ebola. However, when the District Health Management Team took a diplomatic move to calm them down and communicate key information on Ebola, backed by the physical examples of the dangers of Ebola, they then came on board to give support. They also raise awareness.”

Musa Sesay, District Social Mobilisation Coordinator on Ebola (Pujehun District, Sierra Leone)

In many instances, young people have spontaneously responded to the Ebola epidemic by forming their own groups to conduct door-to-door awareness campaigns (72), taking part in contact tracing and running community screening checkpoints (1,122).

“Local youth groups communicated a lot of messages on Ebola, and supported the bye-laws, burial teams and surveillance teams as well.”

Samuel Borbor Vandi, NGO Worker (Kailahun District, Sierra Leone)
Examples of youth involvement include: YouthAid-Liberia (YAL) which implemented a community engagement initiative on the awareness of preventative measures on Ebola in local communities (123); the Federation of Liberian Youth which organised community training (72); and the Youth Leadership Forum in Freetown which was organised by Restless Development to engage young leaders from across Sierra Leone (100).

A report by Save the Children, World Vision International, Plan International and UNICEF links Sierra Leone's closure of schools following the outbreak to increased child labour and exploitation, violence in the home and community as well as teenage pregnancy (124). The disruption of education when schools closed led to the development of programmes such as “Reading for Breakfast”, community reading clubs and Book Chains, where community-based organisations were provided with books (125).

In Sierra Leone nearly half of the population is under 18. The Ebola epidemic has highlighted the capacity and resourcefulness of groups. But how can health systems and response efforts engage them and meet their needs? Post-Ebola reconstruction efforts should seek to reflect their abilities and achievements as well as their needs as part of a health strategy aimed at facilitating community ownership (124).
Case Study: Strengthening local partnerships

NAYMOTE - Partners for Democratic Development, a local civil society organisation, strengthened partnerships between youth leaders and local government leaders and promoted the involvement of disabled people and women in Liberia’s Ebola response. For example, the NAYMOTE Ebola Awareness Call Centre disseminated health messages from the Ministry of Health and Social Welfare and the Ministry of Information. It also encouraged feedback from contacts in the villages and this contributed to the development of community awareness forums for local leaders across Liberia. These forums shared concerns from their communities and developed strategies to address them.

The call centre and forums have been complemented by Mobile Awareness Outreach initiatives, such as the Bus Project, which has used talk shows, meetings, art and drama to recruit over 150 young people as voluntary Ebola communicators (206).

NAYMOTE partnered with local NGOs and the Community Development and Research Agency (CODRA) in Bong county, the Gender Peace Network Liberia in Grand Gedeh county and the Youth in Technology and Arts Network (YOTAN) in Lofa county. These organisations mobilised young people to support response efforts. One respondent, a NGO worker, describes the contribution of young people to the Ebola response efforts: “In addition to participating in response activities, young people have assumed greater responsibility in the general activities of their communities”. For example, the percentage of girls who collect water for their households increased following the outbreak as the percentage of adult women who collected water fell. However, this has left many young girls vulnerable to sexual assault (207).

2.2.2.5 WOMEN’S GROUPS

From the early stages of the epidemic women played key roles as caregivers in their families and at health facilities. They also had specific roles in traditional burial practices (126–128). Many formed groups to fill gaps they identified in the response to the epidemic, such as raising awareness (1,72), assuming responsibility for orphans (126) and providing basic resources, such as food, to quarantined families (129).

Two District Health Sisters highlighted the importance of women in the crisis:

“Women’s groups supported the Ebola response by doing radio talks and going to communities to talk to other women about their role in protecting their family and homes from Ebola. They also gave out buckets and soap for hand washing.”

Sister Cobbie, District Health Sister (Kailahun District, Sierra Leone)
“Local women’s groups have been very active during this Ebola campaign; they have been included at every level.”

Sister Hawa Kallon, District Health Sister (Port Loko District, Sierra Leone)

Grassroots organisations such as the Liberia Women Media Action Committee, Grand Kru Women’s Development Association and the Women in Peacebuilding Network played a key role in mobilising women during the crisis. Many of these organisations are made up of members of communities with experience of working on peace-building post-conflict projects. More than 70 NGOs like these in Liberia have received funding from USAID through The Ebola Community Action Platform (ECAP), a large social mobilisation project developed by Mercy Corps in 2014 (130). However, greater funding for women’s grassroots groups is still needed (131).

An assessment of the gender aspects of Ebola by the Ministry of Social Welfare, Gender and Children’s Affairs, UN Women Sierra Leone, OXFAM Sierra Leone and Statistics Sierra Leone concluded that it was only when community care centres involved women that Sierra Leone started seeing a reduction in Ebola (128). The UK government pushed for a focus on women and girls in the response (132) and UNMEER collaborated with UN Women to engage women in all aspects of the response (133).

The UN has also supported a ‘data revolution’ to help create a framework to disaggregate and analyse data (134). A 2010 World Bank report found that around 63% of education, health and water projects which incorporated gender considerations delivered substantial outcomes for women, compared to 22% of the projects which did not (135).
2.3 LOCALISED APPROACHES: COMMUNITY, ENGAGEMENT AND CONSULTATION

In May 2015, Liberia was first declared free of the Ebola virus transmission, with Sierra Leone and Guinea approaching zero cases in the following months. The WHO and DFID have identified community engagement as one of the factors that contributed to the comparatively fast control of Ebola in Liberia (109), and subsequently in Sierra Leone and Guinea (136). Actors reported increased acceptance of Ebola Treatment Units (ETUs) and safe burials once communities’ legitimate concerns were addressed and the community was involved in the planning and design of the health programmes (22,137).

Trusting relationships between health providers and communities require dialogue in which each party shares their concerns and ideas with the joint aim of strengthening health systems. Many of the community members interviewed described the value of dialogue.

One example of such an approach is summarised in Box 11. It describes MSF’s project in Foya which helped to reduce the number of Ebola cases by December 2014, contributing to the containment of Ebola in Lofa county (111).

“When they interact with the community they will know the community’s problems and we will know what steps to take in order to improve the community health care system”

Bendu Charles,
Business Woman and Secretary of Women United for Peace and Love (Montserrado County, Liberia)
Restless Development workers saw greater acceptance of safe burials after communities’ concerns were taken into consideration. They reported an average 9% increase in the number of communities conducting safe burials following the implementation of the Community-Led Ebola Action (CLEA) method in over 10,000 communities in Sierra Leone (1). The CLEA process involved community leaders, elders and young people, identifying risks associated with traditional burial practices and agreeing on a safe and dignified burial method (138). Other successful approaches included training trusted community members on how to conduct medically safe burials which involved family members in the preparations (111).

In exceptional cases, anthropologists were able to work with community and health workers to agree on a plan of action (139). For example, in Kissi, Guinea, local tradition did not permit a deceased pregnant woman to be buried with her foetus. A team of anthropologists, funded by WHO, were able to work with the community to organise a reparation ritual as well as allow a safe burial. The role of anthropologists in outbreaks and health systems strengthening is further discussed in Chapter Three.

Evidence suggests that the later, more localised approaches to public awareness and safe burials contributed to a decline in cases. For example, in Lofa County, behaviour change was encouraged through door-to-door campaigns and education programmes in churches and mosques (detailed in 2.2.2.1). Simulation studies show that the increase in Ebola Treatment Units (ETUs) alone would have been insufficient to stop the disease outbreak (140). However, the
added effects of social mobilisation on behaviour change, as measured by changes in population compliance with control measures, explain the rapid decline in Ebola cases in Lofa county from September 2014, as shown in Figure 5 (140), which was closely followed by a decline in cases across Liberia by late October (109).

The experience of Lofa County illustrates the need for social mobilisation as well as a medical/epidemiological response. Treatment units and behaviour change through education both contributed to the fall in the number of Ebola cases (1). Health systems generally can be strengthened by addressing both the demand and supply sides of health.
2.4 AVOIDING PARALLEL SYSTEMS: UTILISING EXISTING STRUCTURES

When outside experts and helpers arrive in an emergency situation that is foreign and unfamiliar to them, it is self-evident that they should work within existing structures – political and social. They should explain to communities what they are doing and why and also aim to empower local actors and community members by seeking their guidance and input. Many NGOs operated at community level but our respondents highlighted a gap between their activities and the communities’ priorities.

As discussed in 1.2.1, the governments of Sierra Leone, Liberia and Guinea set up decentralised national structures to control the Ebola outbreak, including social mobilisation pillars with sub-committees (see figure 3 in 1.2.1). In Sierra Leone, for example, suspected cases were reported to District Task Forces, made up of District Authorities and partners which included District Medical Health Teams, WHO, MSF, World Vision, UNFPA and Save the Children (141). Suspected cases were investigated at this level and, where necessary, contacts were traced and treated. These District Task Forces were chaired by the Social Mobilisation Action Consortium (SMAC), working within the Ministry of Health and Sanitation, and UNICEF (142).

In Guinea, UNFPA, UNICEF and WHO established over 2000 Community Watch Committees (CWCs) or “comité de veille” across the country (143). USAID described these as the “backbone of the UNICEF communication for development strategy” (144). Composed of voluntary and locally-elected community members, the CWCs were designed to monitor Ebola in their communities and report cases to surveillance committees at the prefectural district level. This should have ensured that patients with Ebola symptoms were collected and brought to transit centres (145).

“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 Fiama Community Association (Fiama Community, Liberia)
However, it is now estimated that only a quarter of CWCs were functional. Instead they were poorly resourced with poor communication between local officials, health facilities, NGOs, community-based organisations, local community members and other stakeholders (143,145).

Moreover, local health authorities have argued that CWCs bypassed them and created a parallel response structure. This fostered distrust (146). Secondly, Third World Health Aid reported that CWC members tended to be selected by the Guinean government that gave them substantial payments. This was particularly problematic because many communities felt payments like these caused social disruption (74). Finally, the CWCs failed to be representative of all sub-prefectures and had no women or young members (147).

The poor relationship between community leaders and other stakeholders is demonstrated by Paramount Chief Adekalie Miller II’s comments:

“Most local NGOs just come around to loiter, move up and down, they operate in a very tight space in such a way that we don’t know their office and their mandate. But the issues have been sent to the Senior District Officer and the District Council, that we do not have the opportunity to interact with them”

Paramount Chief Adekalie Miller II, (Port Loko District, Sierra Leone)

An Ebola Response Anthropology Platform (ERAP) report noted that where community members had face-to-face interaction with government or NGO workers, levels of trust were higher. Outreach by government was most effective when it engaged community leadership and respected community members (104).
Case Study: Utilising existing community structures

The Community Event-Based Surveillance (CEBS) programme was developed in October 2014 by the International Rescue Committee (IRC) in Sierra Leone's Bo District Health Management Team (DHMT) and Centres for Disease Control and Prevention (CDC). The CEBS consist of community surveillance supervisors and community health monitors. Community surveillance supervisors are local people selected by CEBS, the DHMT and other partners operating in the District. Similarly, CEBS implementation teams work with local community health officers and Paramount Chiefs to identify potential community health monitors, usually teachers, farmers or others who know their community well. These community health monitors were trained to detect signs of Ebola. They reported suspected cases to the local chiefdom surveillance supervisors who investigated the reports and contacted the local community health officers if a case was found.

A CEBS pilot in two chiefdoms in Bo District, Sierra Leone, showed a high level of acceptance by team members as well as community members. This is likely due to the IRC choosing to work with existing social structures and socially legitimate actors. They engaged the Paramount Chiefs and local inhabitants and did not create a new parallel system from the outside, which risked bypassing or undermining existing community efforts. The IRC has since trained over 7000 community health monitors and 128 surveillance supervisors across Sierra Leone. Between March and mid-June 2014, over 3400 cases and deaths were reported.

The long-term sustainability of programmes like the CEBS programme described in the case study, however, is questionable. Community health monitors and supervisors were financially compensated for time off work but are no longer on the Ministry of Health and Sanitation (MoHS) payroll, unlike most other healthcare workers. Furthermore, Doctors of the World noted that the involvement of the DHMT members in the work of the District Emergency Response Centre (DERC) was at the expense of the DHMT’s core activities, which are fundamental to the maintenance of a functional health system. These activities include the coordination, training and support of staff working in peripheral health units (PHUs), organising the supply of medications and vaccines, as well as engaging with communities in public health activities and education.

While it is often necessary for responses to a health emergency to supersede routine health activities, neglecting ‘background’ health challenges can have a devastating effect on the health of the population and preparedness for future outbreaks. For example, in February 2015, a Doctors of the World situation analysis concluded that there was a public health emergency affecting the...
The Ebola epidemic in West Africa has highlighted the importance of developing sustainable health systems in the region that belong to communities and respond to their needs. Communities need, and demand, better health care and stronger health systems with increased and improved resources and services. Successful community mobilisation means working within existing organisational structures, valuing local knowledge and incorporating that expertise to build accessible local health systems.

Systems that facilitate the mobilisation of trained community members and workers in emergency responses must be in place without hampering essential health activities. Moreover, adequate health education and trusting relationships between community members and health authorities would negate the need for such intensive surveillance programmes. Equipping community members with the tools to recognise symptoms and access health services, as well as addressing issues of fear and mistrust, encourages engagement with health services and is more sustainable than emergency surveillance efforts. Epidemiological surveillance, through recording and reporting cases at health facilities, would enable governments and international bodies to monitor disease trajectory and support preparedness initiatives.

2.5 SUMMARY

The Ebola epidemic in West Africa has highlighted the importance of developing sustainable health systems in the region that belong to communities and respond to their needs. Communities need, and demand, better health care and stronger health systems with increased and improved resources and services. Successful community mobilisation means working within existing organisational structures, valuing local knowledge and incorporating that expertise to build accessible local health systems.
3 HOW CAN THE UK AND INTERNATIONAL DONORS BEST SUPPORT COMMUNITY-LED APPROACHES TO HEALTH SYSTEMS STRENGTHENING?

3.1 PUTTING COMMUNITY AT THE CENTRE OF FUTURE HEALTH PROGRAMMES

The UK has a rich history of supporting programmes which focus on community engagement. Examples include the programme for improving Reproductive, Maternal, Newborn and Child Health (RMNCH) in Sierra Leone (123) and the Partnership for Reviving Routine Immunisation in Northern Nigeria: Maternal Newborn and Child Health Initiative (PRRINN-MNCH) (124). However, like other international actors in the crisis, the UK’s initial response to the Ebola outbreak has been criticised as authoritarian (85,150,151). Many UK actors in the crisis were not educated about traditional beliefs and practices and so were unable to work with communities.

During the crisis some traditional beliefs involved practices such as mourning by holding the dead body of a relative and washing and dressing it in preparation for burial which allowed the disease to spread. However, in the rush to save lives foreign aid workers frequently ignored these aspects and some even tried (largely unsuccessfully) to tell Sierra Leoneans that they must “put aside tradition, culture and whatever family rites they have” (42,150,152).

This resulted in resistance, and at times hostility, towards the Ebola responders (153). The WHO recognised in April 2015 that “inadequate engagement with affected communities and families” was a “significant obstacle to an effective response”(106). In future national and international strategies for sudden disease outbreaks should include programmes – formal or informal – that enable the communities to instruct outside actors about their history, social structure, culture and manners.

During the epidemic some organisations developed strategies which specifically incorporated community engagement. The Social Mobilisation Action Consortium (SMAC) initiative, as previously mentioned (142) was notable for its community-led approach. The key features are summarised in Box 7. An Oxfam report called it “a turning point in tackling Ebola in Sierra Leone ... [that] led to a huge uptake of positive practices during the Ebola outbreak and has the potential to be used in building health systems after Ebola.” (6).
• The UK government was the first partner to identify and support large-scale social mobilisation in Sierra Leone through funding SMAC with an initial investment of £3.1 million.

• 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). It works within the MoHS 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 (142).

• 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 the Dialogue, Reflection, Action-planning, Facilitation, Tracking change (DRAFT) aim to help 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% of district communities in Sierra Leone.

• SMAC aimed to achieve “tangible behaviour change towards safe burials, early treatment, and social acceptance of Ebola survivors” (142).

**Box 7: Social mobilisation action consortium (SMAC)**

Communities affected by Ebola have demonstrated remarkable resilience and adaptability. In addition to traditional authorities in communities, such as Chiefs and religious leaders, young people and women’s groups have demonstrated their capacity to play a significant role (2.2.2.4 and 2.2.2.5). The UK should continue to support grassroots organisations and groups that empower women and young people and promote their engagement with forging new health systems that will respond to their needs. Supporting such organisations is aligned to the aim of supporting a holistic approach to health emergency responses, addressing both medical and non-medical needs.

In addition to the examples discussed in 2.2, SMAC has demonstrated how working within existing community structures and engaging socially legitimate actors can promote community ownership of health messages. The case study below illustrates the various roles local community members can play in response efforts.
Case Study: Community members in Kailahun District, Sierra Leone

The Ebola outbreak had a devastating effect on the Kailahun District, with the death of many health workers and community members. In July 2015, Restless Development conducted five key informant interviews in Kailahun District, Sierra Leone. Samuel Borbor Vandi, a NGO worker from the district describes the impact of the outbreak. “The Ebola crisis halted schools, social activities, business and [the] movement of people. People were not going to health facilities because of fear and many people lost their homes and loved ones”.

Several community members and organisations were involved in bringing the outbreak under control. The key informants described how the District Ebola Response Centre (DERC) coordinated the activities of the district councils and NGOs who worked together to draw up response strategies.

Traditional leaders helped to establish and enforce bye-laws, halting secret societies and discouraging traditional healing, while religious leaders and women’s groups played a key role in sensitising communities and providing psycho-social support.

The key informants praise the increased training in Infection Prevention and Control practices and Sister Cobbie, a 48 year old District Health Sister, notes that the improvements in the “hygiene habits of nurses and also community people”.

Senior Section Chief, Ismail Foday, believes that community groups are stakeholders in health and praises their greater involvement in health since the Ebola crisis. He explains that coordination and communication between stakeholders “helps to develop resources, ideas and strategies that will help us work together and succeed”.

3.2 EARLIER COMMUNITY CONSULTATION: FOSTERING OWNERSHIP

Community-led approaches to health emphasise that the members of communities are themselves agents of change. This means that communities must take ownership of health systems (63). All community members interviewed said they wanted greater consultation and ownership of the programmes that are run in their communities.

“Most organisations do not plan with communities before implementing programmes. We want to see programmes that are owned by communities to reduce their poverty situation.”

Ismail Foday, Senior Section Chief (Kailahun District, Sierra Leone)
Effective community engagement not only means social mobilisation during a crisis, but also means spending time with communities, listening to them and co-learning:

“...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...organisations need to spend more time to discuss with community people regarding issues that affects them, and involve them in developing the design of the project.”

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

Engaging with communities at the earliest possible stage of health programme planning and implementation prior to health emergencies can increase the

effectiveness of response strategies in the event of an epidemic (60,71). A key advantage of incorporating communities at the design stage is that it allows programmes to be based on existing community structures and practices as communities define them with appropriate leaders identified. Facilitating community dialogue at all stages of health programming, with equal emphasis on social mobilisation and behaviour change alongside service delivery and resourcing, can allow for the reciprocal strengthening of both the demand and supply sides of health.

While health emergencies require a rapid response, working with communities to establish and strengthen health systems takes time and requires a long-term strategy. This means fostering resilient partnerships between communities and health providers. Social scientists can play a key role in overcoming barriers such as poor understanding of community perspectives and insufficient tailoring of programmes to distinct local contexts.

### 3.3 RECOGNISING COMMUNITIES AS EXPERTS IN THEMSELVES

Health awareness should be viewed as a dialogue, the two-way sharing of expert knowledge between community members and external groups. As experts in themselves, communities possess the local experience, knowledge and perspectives required to ensure that health interventions are appropriate, inclusive and relevant to the context (60). By working with, rather than on communities, health providers are able to facilitate practicable adaptations to community practices and foster trust in health intervention (154). The IDS argues that ignorance of, and disrespect for, local structures and practices have hampered response efforts in many cases (60).

Perceptions of the role of culture have varied in the Ebola response. There has been a growing international recognition that as the disease spread, a decline in transmission rates required collaborative approaches to behaviour change. In the context of the Ebola epidemic, the importance of community knowledge was demonstrated by innovative infection control strategies which communities employed to harmonise biomedical interventions...
with traditional rituals (60). For example, during Uganda’s Ebola outbreak in 2000, local people in Gulu classified Ebola as gemo, a bad spirit. The gemo is traditionally dealt with by isolating the patient, even for a month after they no longer have symptoms. But the patient is also properly fed and cared for. Another example of the tradition is that community members must stay in their homes and avoid sexual relations. Family members are also encouraged to refrain from quarrelling and conflict, avoiding much of the stigmatisation and social breakdown seen in many communities affected by the outbreak (155). This is just one example of community-led good practice.

Another example comes from Masindi, Uganda where an Ebola patient arrived having escaped from a hospital in Gulu. The community imposed isolation of all 73 members of her extended family to contain the disease within this family. As a result, there was only one Ebola case from the general population of 314,000 people (68). Similarly, many religious traditions have teachings with characteristics of good infection control (105,156). 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.

The African Diaspora Healthcare Professionals for Better Health in Africa recommends that “the UK adopt a strategy which ensures that all healthcare programmes designed to support African countries have some elements of health education and literacy that utilises traditional and religious networks”. This would help bridge the gap between the communities and medical responders (41). Effective engagement of religious and traditional groups could also facilitate faster, more organised and culturally appropriate responses to outbreaks, as well as promoting community engagement in health systems. Such an engagement would require an understanding of religious demography as well as the roles and relationships within and between communities, moving from an exclusively medico-epidemiological framework for disease responses to working towards the integration of social understanding and clinical expertise (157).

The UK took a notably multidisciplinary approach to high-level policymaking and included a social scientist and a social science sub-group in the Scientific Advisory Group in Emergencies (SAGE) (60). They also consulted regional experts directly (158). The UK has also established The Ebola Research Anthropology Platform (ERAP), an international network of anthropologists with expertise in West Africa and medical anthropology. The platform is coordinated by academics at The London School of Hygiene & Tropical Medicine (LSHTM), IDS, Sussex and Exeter Universities and funded by the Wellcome Trust and DFID and fed directly into the UK’s response at the community level with anthropologists working with leaders from ‘resisting’ villages (132). While the WHO has included anthropologists in its response teams since 2005 (159), they remain a small contingent. Social scientists accounted for just 1.6% of professional staff in 2013 (160). The organisation said it had learned lessons from the outbreak and committed to “develop multidisciplinary approaches to community engagement, informed by anthropology and other social sciences” (106). Oxfam is also trialling the use of anthropology in other emergencies (161).
Professor Oyewale Tomori, president of the Nigerian Academy of Science, has documented the predominance of donor country scientists in international research institutions; African scientists tend to be side-lined (50). Donors should support African research capacity building and create collaborative relationships that will avoid the need to “parachute in” foreign academics in a future crisis. This ambition is set out in the African Union Agenda 2063 (23,136).

A current example is the cooperation between the USA and the African Union to establish African Centres for Disease Control and Prevention. The UK has taken a leading role in this, working through the Medical Research Council, the Wellcome Trust, the Newton Fund, and bilateral partnerships between universities in the UK and Africa (39).

The UK 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 strengthening health systems.

### 3.4 Harnessing Local Resources: Building a Sustainable and Local Health Workforce

Community empowerment requires the development of an effective community health workforce, with the resources needed to protect themselves from health threats. 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. Reconstruction efforts should prioritise sustainability, by promoting the training and employment of community health workers in the national workforce and formalised support systems.

Community health workers (CHWs) have been cited as crucial actors in a localised response. 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” (79). As they are steeped in the sociocultural context of their respective settings, CHWs are granted a form of social legitimacy which is not often extended to foreign medical workers (72,114,162). In their submitted evidence, ReBUILD, COUNTDOWN and REACHOUT, three multi-country research consortia, note that CHWs and maternal health promoters, many of whom are female Traditional Birth Attendants who have been retrained, can be characterised as the ‘backbone’ of the health system at the community level. If properly supported, they argue, these workers could constitute a key bridging structure between the community and health facilities (163).

The WHO strongly recommends that CHWs be supervised through formal national health institutions (162). However, one of the important challenges in training CHWs is the lack of standardised curriculum, accountability and support structures. Some level of
decentralisation is required, given that these workers are spread across the county and are constantly on the move. A diversity of training programmes across a given region can be tailored to the realities of Ebola in each particular area. However, CHW training courses offered by different organisations vary widely 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 the learning of new information (164).

There was a very great risk of infection spreading amongst CHWs at local clinics because they did not establish standard operating procedures or manage patient flows. (165). Restless Development praised the development of Sierra Leone’s Standard Operating Procedures for Ebola Social Mobilisation and Community Engagement by Ministry of Health and Sanitation – Health Education Department (MoHS-HED) and UNMEER (100). In their framework for achieving and sustaining zero new Ebola cases (166), the WHO has prioritised the full implementation of standard operating procedures through increased and improved supervision, reporting and systematic feedback.

At the Recife Global Forum for Human Resources for Health in 2013, several health development partners, including DFID, made a commitment to harmonise their actions supporting CHWs and frontline health workers (167). However, current efforts to support CHW initiatives are largely still operating through fragmented systems. An Oxfam report recommended that donors develop retention and professionalisation schemes for the CHWs trained during the crisis to ensure a long term impact from the training provided (168). However, this needs complementing with a strong referral system. Providing accessible training for high-level specialists is an urgent priority (79). Health systems should prioritise sustainability by promoting the training, support and employment of CHW within a national standard of training and operating procedures.

### 3.5 COORDINATION: THE NEED TO STRENGTHEN MULTI-STAKEHOLDER PARTNERSHIPS

#### 3.5.1 COORDINATING NATIONAL STAKEHOLDERS

In June 2015 the WHO (169) produced a report on support for recovery and resilience plans in Ebola affected countries. It recognised that Sierra Leone, Liberia and Guinea all have national structures in place for the coordination of health responses. At a national level, Sierra Leone has a Health Sector Coordination Committee (HSCC), chaired by the Minister of Health, which acts as a consultative and strategic decision making body, while the Health Sector Steering Group (HSSG), chaired by the chief medical officer, coordinates most health programmes, donors and health implementing partners. District Health Medical Teams (DHMT) and local councils coordinate activities at the district and community levels(169). The report found that the feedback loops between the HSCC, HSSG and sub-groups were weak and many of the DHMTs, and local councils failed to meet regularly. They are not fully functional. The importance of
coordination between stakeholders was raised by some of the community leaders we interviewed:

“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)

Governments and partners need to commit to strengthening the coordination of stakeholders under the leadership of the respective Ministries of Health. They need to build the capacities of districts and communities to feedback to national bodies and also to promote local ownership of health systems. A recent Harvard-LSHTM report has proposed the establishment of a forum for representatives of affected communities to ensure that stakeholders can be held accountable for the effectiveness of their response efforts (170). The WHO argues that nationwide adoption of strong systems and structures created for the Ebola crisis demonstrated good coordination, feedback, timeliness and information flow. Such systems can also strengthen national coordination of health systems.

### 3.5.2 COORDINATING INTERNATIONAL STAKEHOLDERS

The failure of the international community to offer a timely and well-coordinated response to the Ebola epidemic has been well-documented. It indicted an urgent need for a comprehensive global strategy for health emergencies when the need for medical assistance outstrips national capacities (170). Effective coordination would be central to such a strategy to avoid the duplication of efforts and clarify areas of responsibility.

The WHO report also highlighted the poorly coordinated response between neighbouring countries, as well as between international donors. In 2014, the International Development Committee (IDC) of the UK Parliament noted that until recently DFID had no protocol for coordination between bilateral country offices and centrally managed programmes (152). Similarly, Dan Cohen, a special advisor to Sierra Leone’s President Ernest Bai Karoma, highlights that a clear command structure was not in place during the epidemic before UNMEER was set up. Responders often found themselves embroiled in institutional conflicts over the direction of the response (130). UNMEER has also faced criticism as a body operating outside established channels of communication and thereby complicating coordination efforts (170). We welcome the calls by Harvard-LSHTM for the creation of a dedicated outbreak response centre at the WHO with the capacity to mobilise necessary laboratory, epidemiological, clinical, communications, and logistical responses (170).

This is in keeping with the recommendations from the Commission on a Global Health Risk Framework for the Future, which suggests the creation of a new Centre for Health Emergency Preparedness and Response, an independent WHO centre which
would work alongside to lead outbreak preparedness and response. To this end, the report recommends a global investment of $4.5bn USD to upgrade public health infrastructure and capabilities in developing countries, build on research and development in infectious diseases and strengthen the WHO (171). The UK government should support such efforts to improve national and international coordination efforts as part of both emergency preparedness strategy and health systems strengthening.

### 3.5.2.1 Partnerships with Diaspora Groups

Save the Children has pointed out that the current NHS employment of 27 Sierra Leonean doctors and 103 nurses amounts to a subsidy to the UK of up to £22.4m based on the cost of training the equivalent number of doctors and nurses in the UK. Save the Children urged the Government to review the use of migrant health workers in the NHS (57). Similarly, Health Poverty Action argues that wealthy countries should provide restitution to the countries whose health systems they have “undermined” (114). Strengthening health systems in developing countries, as well as investing in the development of other sectors such as education and infrastructure, may reduce the rate of loss of professionals from developing countries.

Finally, the Ebola crisis has highlighted the unique role that the African diaspora in Western countries can play in health and development. The African Diaspora Healthcare Professionals for Better Health in Africa Initiative has highlighted the potential role of the West African diaspora as a valuable resource for shaping culturally appropriate and socially legitimate response programmes and strengthening local health systems (41). For example, the Sierra Leone UK Diaspora Ebola Taskforce negotiated with Public Health England, the NHS and DFID to facilitate recruitment of NHS volunteers during the outbreak. They also delivered cultural awareness training to NHS and international volunteers prior to their deployment (172). Many diaspora groups, such as the Sierra Leone War Trust (SLWT), worked with local grassroots organisations to provide ground support such as protective raincoats for commercial motorbike riders, personal protective equipment and hand-washing facilities (173). EngAyde has provided protection and care for Ebola orphans and psycho-social support for Ebola affected families and local health care workers (174).

More generally, members of the African diaspora have remitted significant capital to African countries, some for investment, some to support their families and for goods and services from the continent (175). For example, in 2013 migrant remittances to Liberia accounted for 19.7% of Liberia’s GDP (176). Many professionals from the diaspora temporarily or permanently return to their country of origin and this strengthens links between the UK and Africa (177). Several other developing countries, notably the Philippines, have seen financial benefits from Filipino trained nurses and physicians who work abroad and thereby remit significant amounts of foreign currency (178). The UK government should enable the diaspora to live and work “here and there” and try to mitigate the negative impacts of emigration on countries with weak health systems.
Unlike international NGOs, national governments are accountable to their citizens. A 2015 report by the Tony Blair Africa Governance Initiative (AGI) concluded that the Ebola outbreak was “a systems problem” and the role of international partners in such situations is to support “governments’ leadership, strategies and plans rather than pushing their own”(179). In line with this, the WHO and partners have been supporting the national governments of priority countries in reviewing their level of readiness (180) and have prioritised the coordination of responses under national leadership (166).

Ultimately, the only way to prevent another outbreak of Ebola is to strengthen national health systems, and ultimately provide universal health coverage as highlighted in goal 3.8 of the SDGs (181).

“[To] achieve universal health coverage, 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”

The International Development Committee (IDC) has criticised DFID in the past for focusing on high-profile diseases and rapid results at the expense of wider health systems strengthening (79). However, as both the IDC and DFID have noted, the UK and its National Health Service are in a strong position to give valuable advice to national governments in the international drive towards universal health coverage through health systems strengthening. (182)

The UK and international donors need to ensure governments in poorer countries are supported in strengthening their own public services and not pulled in different directions by the various donors and international institutions. For example, the African Union suggests that 25% of African budgets should be spent on health system strengthening. However, according to a 2010 WHO report IMF policies have been a barrier to health systems strengthening, by prioritising short-term deficit reduction over health systems investment (183,184).

A group of British NGOs including ActionAid, Christian Aid, Oxfam and Save the Children have urged the UK to back G77 calls for global tax standards to come under the management of an intergovernmental body in the UN, as the current system is dominated by the Organisation for Economic Cooperation and Development (OECD) and favours wealthier countries. (185). A global tax system under UN management will give developing countries the greater influence in determining global tax rules needed for them to develop sustainably. The ability of African countries to be able to collect the tax owed to them in order to invest in vital public services is necessary to support the African Union’s target of achieving self-reliance by 2063 (186) and movement away from traditional donor-recipient relationship.

Of growing importance is the role NGOs can play in partnering with community and civil society groups in holding their local and national governments to account and ensure these funds are being spent correctly and transparently. Such bolstering of national government capacity need not replace NGOs but must underpin their work. Conversely, 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. Moreover, Health Poverty Action argues that UK policies on “trade, tax, migration, human rights and debt” can undermine UK policies on global health and development, and so they should be better coordinated with each other (187).

### 3.7 CONCLUSION

In Dr Margaret Chan’s reflections on the Ebola crises at the 2015 Princeton-Fung Global Forum in Ireland, she concluded “the first priority must be to get well-functioning health systems in place, especially in fragile or vulnerable countries” (188).

On 14 January 2016, the WHO declared West Africa to be Ebola free. However, within the same week there were reports of new cases. The Ebola crisis continues to highlight the crucial role of communities in the establishment of health systems that are resilient and can mitigate the impact of future disease outbreaks. As a critical component of health systems strengthening, the UK government and non-governmental organisations should give higher priority to the promotion of community ownership of response efforts during health crises, and more broadly of health systems.
4 RECOMMENDATIONS

The chief finding of the report is that efforts to curb the outbreak of Ebola in West Africa were most effective when local leaders of affected communities led the demand for assistance from their governments and the international actors and played an essential leadership role in the management of that assistance.

The chief recommendation of this report is that the UK government and non-governmental organisations should give higher priority to community ownership of health. This would strengthen local health systems and enable them to respond more effectively to a crisis. The conclusions of this report will help guide a UK response to future epidemics and, in the long term, help reconstruct and strengthen health systems in poor countries. In support of this we recommend the following:

4.1 RECOMMENDATIONS FOR UK GOVERNMENT

1. 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.

2. The UK can build on its strengths in the research, design and implementation of health systems strengthening across academic, government and not-for-profit sectors to support community-led health systems strengthening in developing countries.

3. The 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.

4. The Government should reassess the current system through which NHS staff volunteer abroad, with efforts made to ensure that only the appropriate staff are deployed and in a timely manner.

5. The Government should enact a review on its use of migrant workers from countries with weak health systems and should consider providing restitution to the countries worst affected by the UK’s employment of their professionals.

6. The Government should build on its relationships with diaspora groups in the UK, involving them in programme planning and policymaking.

7. 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.

8. The Government should support efforts to improve coordination of global health emergency responses and harmonisation of health system strengthening efforts, encouraging other donors to do the same.

9. The Government should expand its use of multidisciplinary expertise in global health decision-making, by working with the academic sector in the UK and abroad to build capacity in anthropology and other social sciences.

10. The Government 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.
4.2 RECOMMENDATIONS FOR UK ACTORS

1. Response efforts and health programmes should prioritise working within existing community structures to avoid creating parallel systems, including both faith and non-faith community leaders in response efforts.

2. In order to empower communities towards community ownership of health services, communities should be consulted before the design stages of health programmes and community dialogue and involvement facilitated throughout the design.

3. Response efforts and health programmes should prioritise sustainability, by promoting the training and employment of community health workers in the national workforce.

4. Response efforts should be aware of the need for increased support of vulnerable groups and ensure the funding of grassroots organisations for women and young people is a priority.

5. Health workers should be trained in the social factors that affect health, so that they can engage the most vulnerable members in communities and promote a holistic approach to health systems strengthening.
REFERENCES


20. Food and Agriculture Organization of the United Na-


52. Njala University Sierra Leone. Ebola Emergency Preparedness Responses for Community-Based Health Planning and Service (CHPS) in Sierra Leone.

53. Doctors of the World. Response to Africa APPG inquiry: Beyond Ebola: rebuilding health services in Moyamba, Sierra Leone [Internet]. 2015. Available from: http://b.3cdn.net/droftheworld/54befeb29ddee73fa1_s4m62058i.pdf


76. Malaria Consortium. Response to Africa APPG inquiry. 2015;


82. Waldman L. Urbanisation, the Peri-urban Growth and Zoonotic Disease: IDS Practice Paper in Brief 22 [Internet]. 2015. Available from: http://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/5855/ID563Online.pdf?sequence=1


86. Mark M. Fear and ignorance as ebola “out of control” in parts of west Africa. The Guardian. 2014.


100. Restless Development. Written evidence on community-led health systems & the Ebola outbreak – Submission. 2015; (June):1–18.


111. Wilkinson a., Leach M. Briefing: Ebola-myths, reali-


125. Foboi M. Ebola has shackled my education and my future - but we can fight back. A world at School. 2014.


131. Collaboration of grassroots organizations. Local groups in Guinea Liberia and Sierra Leone. A Call to Fund in-country grassroots Organizations Addressing the Effects of Ebola. [Internet]. 2015 [cited 2015 Aug 15]. Available from: https://docs.google.com/forms/d/11s1kZbW-CvnR4GXqVshbudh8Wt-wOC6zU-NEjsfM0cM/viewform


133. UN Women. UN Women Action To Confront The Ebola Crisis. [Internet]. 2015. Available from: http://www.unwomen.org/~/media/headquarters/attachments/sections/library/publications/2015/un women action to confront the ebola crisis.pdf


144. USAID. West Africa - Ebola Outbreak - Fact Sheet #10 [Internet]. 2014. Available from: https://www.usaid.gov/ebola/fy15/fs10

145. Amref Health Africa. Ebola Response in Guinea History of Amref Health Africa and West Africa Capacity Amref Health Africa’s Situational Analysis. 2015;


149. Beyond Ebola: Rebuilding Health Services in Moyamba, Sierra Leone.


155. CDC. Cultural Contexts of Ebola in Northern Uganda.


163. ReBUILD Countdown and Reachout. Response to Africa APPG inquiry: Call for written evidence on community led health [Internet]. 2015. Available from: http://b.3cdn.net/droftheworld/54befeb29ddee73fa1_s4m62058i.pdf

164. One Million Community Health Workers Campaign. The Current State of CHW Training Programs in Sub-Saharan Africa and South Asia: What We Know, What We Don’t Know, and What We Need to Do. [Internet]. 2014 [cited 2015 Jul 31]. Available from: http://1millionhealthworkers.org/files/2013/01/1mCHW_mPowering_LitReview_Formatted.compressed.pdf


174. EngAyde: an online-platform aimed at brokering information and giving guidance on taking action for Ebola. [Internet]. Available from: http://www.engayde.org


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