



# Prioritising Community Engagement to Strengthen Health Systems in Ebola Recovery

***‘My biggest fear is that the health sector is not improved.’***

George Caulae, New Kru Town, Liberia, February 2015

This short paper outlines **priorities for successful and sustainable community-based health systems:**

1. Community engagement is crucial for getting to zero on Ebola. The governments of Sierra Leone, Liberia and Guinea must continue to prioritise and resource this. We must ensure that lessons are learned and embedded for future Ebola outbreaks.
2. Community health systems need to be built from the grassroots up, enabling communities to identify and manage their own health needs. This can be done by mobilising and equipping a broad range of influential groups who can engage communities, including religious leaders, women’s groups, youth leaders, traditional healers, traditional leaders and community health workers (CHWs). Governments need to provide structures at the district level to enable this.
3. Extensive, resourced and integrated CHW programmes are important. The funding requests put forward by governments to build and formalise the work of CHWs should be considered affordable, cost-effective and a priority area for support by donors.
4. Accountability to communities and capacity at district level need to be significantly strengthened to empower communities and increase the likelihood that the large amount of funds pledged at the conference are spent effectively.

It also provides **specific recommendations for the Ebola Recovery Pledging Conference, July 2015.**

# Priorities for successful and sustainable community-based health systems

## 1. Community engagement to get to zero – and for future Ebola outbreaks

**‘We went into a security approach. We put the army there. We put the security people there. We closed the borders... Now I know that people’s ownership, community participation, works better in a case like this. I think that experience will stay with us.’**

Ellen Johnson Sirleaf, President of Liberia, 11 March 2015<sup>1</sup>

Whilst enormous progress has been made, there are still new Ebola cases occurring in Sierra Leone and Guinea, and sadly also again in Liberia. We know that when the region is declared Ebola free, evidence from earlier outbreaks indicates that another outbreak is likely; there is a 30 percent probability that Ebola will re-emerge within one year, and a 50 percent probability within two years.<sup>2</sup> It is vital that we learn the lessons from earlier outbreaks and our most recent response.

Community engagement is now widely recognised as a critical component of responding to Ebola, it is medically essential, not just a ‘nice to have’. This was not always recognised though. At the outset of the response, there was a disproportionate focus from governments, the UN and donors on the ‘hardware’ of treatment (construction of medical facilities, provision of equipment, medicines and health workers), with too little on the ‘software’ of prevention (social mobilisation, empowering communities). The majority of public messaging campaigns consisted largely of telling people how to protect themselves. Such messaging was important, but it was impersonal, top down and did not address people’s fears. As time went on it became clear it was not enough.

## 2. Building community health – from the grassroots up

**‘We love our community. We love development work. Our community should not be a laughing stock. I want my community to be a role model. We want to transform our community. We want to protect our people, our friends, from sickness’<sup>3</sup>**

Community leader in John Thorpe, Freetown, May 2015

Involving community perspectives in health provision is critical to understand the barriers to healthcare and how it can be improved. One way of doing this is through the mobilisation of Social Mobilisers – volunteer community members who engage communities to manage their own health.

A turning point in tackling Ebola in Sierra Leone came with the development and use of community-led approaches such as Community Led Ebola Action (CLEA) and Dialogue, Reflection, Action-planning, Facilitation, Tracking change (DRAFT).<sup>4</sup> These methodologies, developed by the Social Mobilisation Action Consortium (SMAC) and used by a range of agencies, are premised on participatory techniques to engage communities. The idea is to go beyond one-way conversations to triggering attitudinal change and guide action. The approaches engage influential groups and figures such as religious leaders (local Imams and pastors), local leaders (mammy queens and chiefs), women’s groups, youth groups, traditional birth attendants, teachers and traditional healers. In so doing, the ownership and sense of responsibility to prevent and respond to Ebola is shifted onto communities,

households and individuals, rather than being retained solely by the official 'response workers'.

This led to huge uptake of positive practices during the Ebola outbreak and has the potential to be used in building health systems after Ebola. The CLEA approach, for example, has supported over 10,000 communities in Sierra Leone to develop and implement action plans focussing on preventative behaviours such as screening visitors, and reactive steps such as alerting health authorities when community members display Ebola symptoms or have died.<sup>5</sup> In essence, community-led approaches continue to create demand in a service that was considered, at the beginning of the outbreak, to be foreign, unwanted and threatening. There are important lessons here for how communities can be engaged with health systems relating to other diseases, as well as the Ebola recovery.

Agencies implementing community-led approaches typically include the following elements in their work:

- Social Mobilisers are selected from the same local area as those they are engaging with and are provided significant training in behaviour change communication techniques as well as the latest information on Ebola. This means they are trusted, "They [the Social Mobilisers] are the sons and daughters of our community, they are sons of the soil, they will not falsify messages."<sup>6</sup> It also meant they can speak in their local language.
- Social Mobilisers discuss and deal with the very real fears that people have about Ebola treatment. For example, many believed that if they got into an ambulance, "They would spray you with chlorine and you would die right there." Or that if people were taken to an Ebola Treatment Unit, "Families would not know what happened to them, they would die in another town, the bodies would not come back."<sup>7</sup>
- Consistent information is provided at community level through a range of sources, including Social Mobilisers 'on the ground', religious leaders in their sermons and local media including radio and social media. This consistency continuously and reciprocally strengthens the credibility of these sources, leading to greater trust in the information being provided.
- Planning is shifted from regional/district level to the micro level of the village or even the household. In this way, each individual community's understanding of the issues related to the intervention are understood and a community response designed.
- Existing community structures are engaged and recognition is built that these structures, and the individuals within them, work differently in each community.
- Feedback is provided to communities, especially regarding decisions that affect them relating to the treatment of the sick and deceased.
- Social Mobilisation volunteers are not taken for granted. Their expenses are reimbursed, and phone credit or transport is provided for them to do their work, for example.

The principles and techniques that have proven so valuable in these community-led approaches during the Ebola response now need to be used in building health systems. We know these approaches work in Ebola response, now we need to adapt and apply them in building health systems that deal with a variety of health needs beyond Ebola.

Various agencies are experimenting with how to do this. One such programme can be found in Koinadugu, Sierra Leone where NGOs have started a three month process of consultation in a bid to engage communities in what they can do to improve the health services.<sup>8</sup> Initial discussions will cover what the community thinks of the services of the Peripheral Health Unit (PHU), what they trust and distrust and therefore when they use it and when they do not. Depending on the nature and severity of the problem, it may be rectified within the community itself, or raised in a second series of conversations between community members and staff from the PHU, or taken to the level of the District Health Management

Committee. This process will help to resolve some problems and can assist communities to understand where the blockages are and who is responsible for them. The idea is to increase the ability of the community to take responsibility for what they can do themselves and push for change where others are responsible.

**Recognising the key role that women, youth and vulnerable and marginalised groups can play**

Engaging communities requires engaging with all parts of that community; it means recognising capacities and strengths as well as ensuring inclusion and specific targeting where necessary. People are different and there is no one-size-fits-all approach. Efforts should be made to ensure people with a visual or hearing disability can communicate effectively in discussion processes, for example, and that the health needs of those with disabilities are recognised. Young people have shown innovation, high levels of civic responsibility and determination during the Ebola response yet have often been marginalised.

Gender roles in the Ebola-affected countries mean that women are the primary caregivers; they have responsibility for family health that should not be overlooked. Women have reported that men did not always convey critical information on Ebola prevention and treatment to women, exposing households and communities to greater risk.<sup>9</sup> However, women were frequently sidelined in the Ebola response due to pre-existing gender norms that privilege men.<sup>10</sup>

Effective community engagement requires the direct involvement of young people and trusted and respected female community members and must actively include those with disabilities.

Focusing on this ‘software’ approach – engaging communities, building understanding and increasing community ownership – can be perceived to be harder than ‘hardware’ elements of providing more health centres, medicines and medical staff. It is explorative, experimental and time consuming and the impact can be difficult to quantify. But we must remember the lesson learned from the Ebola response and maintain a strong focus in this area.

*Governments needs to ensure that they provide resources at the district level for co-ordination of those working with communities, as well as providing feedback mechanisms for communities and support to empower them.*

### 3. Developing effective CHW programmes

‘We want CHWs to stay’<sup>11</sup>

Male respondent in Port Loko, Sierra Leone

The Ebola response has shown that CHWs also have a key role in influencing health behaviours. While Social Mobilisers focus on facilitating discussion, working with larger groups and encouraging communities to lead their own response, CHWs focus on teaching and clinical case management. Both roles are crucial in the recovery.

#### CHWs – bringing treatment to the community



Justina Bangura, Ebola survivor

Justina Bangura, from New Kru Town, Montserrado, Liberia, became ill but was too scared to go to an Ebola Treatment Unit (ETU). She said: ‘I won’t go there, they will kill me.’ Patricia, a CHW told her about the advantages of going to the ETU but faced opposition from Justina’s family, ‘My family drove her away from the house but she kept coming back. When I agreed, my family were angry.’

‘Whilst I was away, Patricia kept visiting my family to let them know what was happening and to encourage them. She would contact me and encourage me. Now I am so happy that the CHW was there because she encouraged me to go and today I am alive. If it hadn’t been for Patricia, I’d have died...and this is what the whole family are saying.’<sup>12</sup>

Mechanisms must be found quickly to retain the increased number of CHWs that have been trained in recent months.<sup>13</sup> Ebola-affected governments have recognised the key role of CHWs. The Government of Liberia, for example, is revising a Community Health Services Policy and Plan, which aims to standardise and professionalise the CHW cadre. This includes;<sup>14</sup>

- CHWs carrying out preventative, curative and promotive healthcare for communities further than 5kms away from a PHU;
- CHWs carrying out surveillance for diseases such as yellow fever, malaria, cholera, lassa fever and rabies as well as Ebola;
- Creating standardised training packages and incentive schemes, aiming to pay \$70 per month, as well as providing non-monetary incentives such as continuous learning and skills development;
- Providing CHWs with uniforms to formalise their role;
- Having a ratio of 1 CHW for every 200–500 people;
- Providing supervision for CHWs with a ratio of 1 CHW supervisor to every 5–10 CHWs.

The Government of Sierra Leone has similar plans; the Directorate of Primary Health Care is working up a package of measures to support the ongoing work of CHWs post Ebola.<sup>15</sup>

These programmes should be prioritised for support by donors at the Pledging Conference because:

- They are cost effective. It has been estimated that providing 1 CHW for every 650 rural inhabitants would cost \$13.7m in Liberia, \$22.8m in Sierra Leone and \$48m in Guinea per year, a total of \$84.5m.<sup>16</sup> This is a small amount compared to the \$3.5bn already spent on responding to Ebola<sup>17</sup> and given the potentially huge possible health and socio-economic benefits, including savings on curative treatments;
- Frontloading preventative care is effective. Getting the number of adequately resourced PHUs and hospitals up to required levels will take time. While development of all parts of the health sector in parallel is important, there is a strong case for frontloading the work of the CHWs to maximise preventative health and reduce the load on other parts of the health system.

*The funding requests put forward by governments to build and formalise the work of CHWs should be considered affordable, cost-effective and priority areas for support by donors.*

#### **4. Strengthening accountability at the community level**

**‘We do not know how much money has been allocated to the local PHU to meet our needs. We do really want to know. There is widespread fear among the community towards government and its agencies.’**

Town Chief in Port Loko, who lost two wives to Ebola<sup>18</sup>

Holding governments and NGOs to account to deliver and support health services is key. But while accountability structures exist in theory and in law, they are often dysfunctional. In Sierra Leone, for example, the Local Government Act of 2004 provides for a democratic system of accountability at the local level. However, elections for the chairs of District Councils and Ward Development Committees are heavily influenced by political parties and Village Development Committees often lack the information required to have impact and their views are not taken seriously.

There is a need to build a culture of public governance and accountability in the health system. The systems that exist should be strengthened to ensure they are less politicised. Communities need to be empowered to know their rights and develop the skills to advocate for them. They need to be supported by programmes that build their capacity to negotiate, participate, advocate, monitor and network according to their needs.

Increased capacity and resources are required in local government at the district level to build effective health systems with genuine community participation. Local government authorities need to be able to rely on timely disbursement of funds and long-term investment and also have the authority to make decisions; this was a real problem in the Ebola response.<sup>19</sup> District-level health teams need to be empowered and resourced to carry out effective monitoring and supervision of health centres and facilities and strengthen communication with communities. This requires skill-strengthening, increased transportation and resources and, in some cases, political will.

*Governments, donors and all actors need to actively support local accountability and capacity at district level to increase community empowerment and the likelihood that the large amount of funds pledged at the conference are spent effectively.*

## **Recommendations for the International Ebola Recovery Conference, July 2015:**

It is positive that post-Ebola national health recovery plans contain some measures for community engagement in the formal health system. The pledging conference provides a major opportunity to support and strengthen this, with long-term benefits for affected populations.

### **Community engagement**

Governments, donors and other actors should:

- Work together to ensure community engagement is a fundamental element of disease response and health systems strengthening, designing strategies with community engagement at their centre not their periphery;
- Prioritise funding for programmes that mobilise influential groups to include communities in the design, implementation and monitoring of health approaches;
- Involve communities in the selection of Social Mobilisers trusted by them;
- Strengthen district level co-ordination and support for those mobilised through community engagement programmes;
- Reduce barriers and strengthen women's engagement and leadership in the health system, including in their role as Social Mobilisers and CHWs.
- Give special attention to ensuring the inclusion of marginalised and vulnerable groups in community engagement processes.

### **CHW schemes**

Governments should:

- Fully develop retention plans for CHWs, involving training, regular adequate payments, support structures and active monitoring;
- Increase investment in district-level health management capacity to ensure strong and well-resourced management and oversight of CHW programmes.

Donors should:

- Fully fund CHW professionalisation schemes as set out by the governments of Sierra Leone, Guinea and Liberia.

### **Accountability**

Governments, supported by donors and other actors should:

- Make public the funds they are providing for community health at national and district level. In Sierra Leone, use the Open Data Portal set up by the Government to do this;<sup>20</sup>
- Strengthen community-based structures of accountability to provide apolitical platforms for community engagement;
- Provide financial and other support for programmes designed to strengthen the capacity of communities to advocate for their needs and hold service providers to account for effective health care delivery.

Governments should:

- Establish monitoring, reporting, evaluation, learning and review systems;
- Provide audit trails to detail the provision of finances to sector specific areas; publishing figures for sectors alone is not adequate.

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- <sup>16</sup> Awoko (2015) 'Sierra Leone News: Pres. Koroma to launch Open Data Portal' <http://awoko.org/2015/05/12/sierra-leone-news-pres-koroma-to-launch-open-data-portal/> provides information on the Open Data Portal. The web link is here: <http://sierraleone.opendataforafrica.org/>, the financial parts are to be developed shortly.

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