

# **Community-Based Ebola Care Centres**

**A formative evaluation**

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Ebola Response Anthropology Platform

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## **EXECUTIVE SUMMARY**

The Ebola outbreak in West Africa differed from others in its unprecedented size and the high proportion of human-to-human transmission occurring in the community. This report presents an analysis of the impact of Community Care Centres (CCCs) on communities in Sierra Leone. Much has been written about the leadership and coordination of the response – or the lack of it. The emphasis of this evaluation is on the views on the development, implementation and relevance of the CCCs from the perspective of the communities next to and near where they were located.

### **Questions**

The key questions explored are divided into two categories: (1) Community engagement with the development and management of the CCC; and (2) Post-Ebola uses of the CCC.

### **Methods**

We visited seven CCCs located across eight chiefdoms in four districts (Maforki, BKM and Koya in Port Loko; Magbema in Kambia; Fiama and Nimiyama in Kono; Tane and Kunike in Tonkolili. In most cases the CCCs are located outside the chiefdom town. As well as visiting the CCC we also collected information in villages three to four miles away from it to explore its impact at a distance.

In each community we conducted discussions on community engagement with elders (male and female), men, women and youths using semi-structured themed question lists. A total of 1,031 participants joined the discussions, of whom more than half (688) participated actively. People who spoke received a card which enabled us to keep track of active participants. This system also allowed people in villages to observe the focus groups and diminished the risk of possible harmful rumours and intrigue surrounding Ebola and the evaluation process.

We also held 78 semi-structured interviews held with Health Authorities, District Medical Officers (DMOs), District Ebola Response Centre (DERC) representatives, implementing partners, CCC staff and Peripheral Health Unit (PHU) staff in Freetown, Port Loko, Kambia, Tonkolili and Kono. Below are findings based on a preliminary analysis of the anonymised data and suggestions from the communities.

### **Findings**

CCCs were conceived during a confusing time of urgent need. Survey findings showed high levels of knowledge on Ebola transmission in communities.<sup>1</sup> Yet unprecedented human-to-human transmission was taking place in communities

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<sup>1</sup> A Knowledge, Attitudes and Practices survey released in September conducted by UNICEF, FOCUS 1000, and Catholic Relief Services prior to DEC funding showed high levels of knowledge about Ebola (<http://ow.ly/Mn8rP>).

and technical expertise on community engagement in Ebola was scarce. It was an extraordinary situation that justified exceptional measurements. Some predictive models warned of potentially millions of new cases, and a key argument for the introduction of the CCC was to respond to a possibility of a system wide shortage of beds. DFID and its international and national partners supported the development of new care centres located in communities to allow local people to come voluntarily to be isolated if they suspected that they had the disease. By the time most CCCs were implemented the facilities were about much more than beds, with CCCs aiming to play a role in contact tracing, community education and case management.

Implementing partners and policies emphasised the need for community ownership and engagement. Ebola-related security incidents also showed the dangers of failing to work with communities. But the evaluation found divergent opinions among partners on community engagement, local ownership and the role and function of the CCCs in the wider health system. These differences reflect different approaches to public health in emergency responses, and different understandings of what is possible in emergencies. Perspectives were also influenced by patterns of Ebola virus disease (EVD) transmission and the timing and availability of EVD facilities and services such as ambulances and treatment units in each district.

The Ebola response used traditional hierarchical political structures to reach communities in consultation with DERCs that were specially set up in parallel to existing district-level state systems. Some of these district-level facilities were still functioning while others had collapsed. Policy makers, implementing partners and authorities expressed concerns about the coordination between these parallel governance systems and structures. Communities were apprehensive about the political decision-making processes on the allocation of land, water resources and jobs. The use of traditional authorities and emergency systems and rules to fight Ebola were accepted, but perceived abuse of power, especially favouritism with regard to employment, was strongly and widely resented. However, staff who worked at the CCCs were both appreciated and commended for their efforts whether they were locals or outsiders. People felt they should be paid well as it was risky work that could damage people's private and professional lives for a long time.

We heard complaints in all districts about human resource management and/or the staff and their competencies from authorities and policy makers. In a number of cases the local CCC recruited staff from the PHU by offering better salaries, thus weakening the PHU by leaving it understaffed. Communities, however, appreciated the free care, the kind attitudes and skills of staff and the food that was provided to patients. Although the restrictions relating to care and case management of family members in the CCC were understood, communities wanted more involvement and closer relations with the staff with regard to care of family members in the CCC.

The CCCs arrived just when the number of ambulances and Ebola Treatment Units (ETUs) increased, reducing the need for holding places of suspected patients.

Some policy actors therefore saw them as redundant from day one. Communities, however, appreciated the care for non-Ebola related health problems that CCCs provided.

Although the outbreak was unique, some of the problems – setting up parallel systems, lack of coordination, exclusion of communities, fear – are familiar from other vertical disease programmes (such as those on HIV) and non-Ebola related emergency health responses. This raises questions about the lessons for ‘Ebola exceptionalism’ for future health systems and community engagement in emergency responses.

There was also a tension between communities’ non-Ebola health-related needs and the objectives of CCCs as an Ebola-specific intervention. This was compounded by the fact that many communities were facing unusually restricted access to ‘normal’ health services. There was some confusion as to whether the CCCs were for Ebola or for all diseases. In one respect, however, they were clearly different: PHUs charged user fees while the CCC was able to provide free care. The vertical, disease-specific approach to Ebola conflicted with the professional sense of duty of medical staff in the CCC. Medical staff and implementing partners saw an urgent need for affordable health care on the ground and some used CCCs as a vehicle to provide this.

Much has been written about the fear and ‘ignorance’ of average citizens in Sierra Leone and in other Ebola-affected countries. This evaluation found that many people of different ages in affected communities have detailed knowledge of case management and transport procedures and accept that some special measures were needed. What is important in relation to people’s compliance with Ebola-specific rules is that they feel that the facilities are safe and that they and their loved ones, living or dead, are treated fairly and with respect.

Procedures around medical burials have been changed to make them more humane. Communities have noticed and appreciated these changes. However, families want to work closely with CCC staff and be more involved in the undertaking – washing, praying and wrapping bodies in white cloth. The employment of young people in burial teams for undertaking and burials is resented. Young people are not seen as able to take on these responsible roles. They are considered by young and old alike to lack important life experience.

Now that the CCCs exist people want the materials and the staff and their new skills to be used to improve public health and educational services in their communities. In each community people have detailed ideas reflecting their specific context and how the CCCs resources could be put to use in the future: improving health education, triage and health care in schools, strengthening PHUs with equipment and tents so that they have more space and staff can do more, and cleaning and repurposing the buildings. What people don’t want to see are the CCCs packed and stored far away until the next big outbreak.

Communities need to be engaged on managing the transition between the response and the recovery phase.

Communities in Sierra Leone had low levels of trust in government authorities and services before Ebola. It is important to reflect on the possible long-term political and public health effects of giving people free health care in an Ebola centre and then taking this away from them. Given the complaints about political favouritism during the process of developing and setting up CCCs, it is essential that the transition and CCC decommissioning processes are transparent and led by trusted people. Who exactly is 'trusted' to lead CCC stocktaking exercises in a local village will depend partly on who is seen as having benefitted from Ebola. It is important to avoid the same leaders being in charge of every decision made and thus being seen as the 'judge, jury, and executioner'.

## Recommendations

### **Rec 1: Ensure that community and civil society organisations own the process and outcome of decommissioning and decontaminating CCCs.**

- Provide clear and comprehensive information on decommissioning and decontamination of the CCCs.
- Organise joint monitoring and evaluation and stocktaking of the response with local committees of trusted people to map out the contributions that have been made to improve transparency, accessibility and Ebola preparedness. Verify land and water usage rights and ownership of the plots where CCCs – or any future community-based facilities – are located. Establish whether there have been abuses and negotiate compensation for this. *These committees can also play a role in informing people about access to the available packages for survivors and other vulnerable people (e.g. orphans and widows).*
- If CCCs have already been shut then these procedures should be adapted but not neglected altogether.

### **Rec 2: Maintain capacity and integrate the reduced CCC workforce in public services**

- Take stock of the volunteer and professional workforce – including traditional authorities – around the CCC. Include villages that hosted the CCC and those that referred cases to it. Identify the Ebola-specific and general skills gained by the workers during the emergency response and their ambitions to continue to provide or otherwise support public services. This should be done by a committee of respected persons together with health and education authorities and representatives of young people. Ensure that this data is made available to District Health Management Teams (DHMTs) and other relevant service providers.
- Encourage DHMT officials to visit communities to discuss ways to improve links between village- and chiefdom-level disease control resources and PHUs and district hospitals.
- Based on these visits, develop chiefdom-level plans to maintain and strengthen the capacities and skills identified. These activities need to be geared towards broader public health concerns and local health priorities, including Ebola.
- Provide certificates of medical clearance and skills certificates to leaving volunteers and professionals.

### **Rec 3: Strengthen primary health care at the community level**

- Maintain and strengthen the capacities and skills of PHU staff as part of a broader strategy to strengthen human resources for health.
- Transfer clean equipment and medicines from the CCC to the PHU as part of investing in health systems and improving triage and outbreak capacity in PHUs.
- Develop national strategies that move towards universal health care at PHUs.

### **Rec 4: Improve engagement with the elderly in culturally appropriate undertaking and burials**

- Identify elders from different backgrounds who want to be engaged in medical undertaking and burials in advisory and practical roles.
- Develop activities with elderly medical burial teams and other experts that address the specific concerns related to undertaking and burials in different cultural and religious contexts in Sierra Leone.

### **Rec 5: Support families and communities to find closure**

- Involve elderly and respected persons in ceremonies and activities that pay proper final respect to people who died during the outbreak and were not buried in their home village.
- Support activities that help families of the diseased to find closure and prepare for the future.

### **Rec 6: Document key lessons and innovations learned during this Ebola response**

- Support the integration of multiple forms of expertise – especially from the social sciences – into health systems and emergency planning.
- Ensure that specific lessons from the Ebola response, transition and recovery are documented and communicated to the relevant authorities at multiple levels to improve their preparedness for future outbreaks.
- Examine the justifications for and impact of ‘Ebola exceptionalism’. Document the lessons for emergency health and vertical disease programmes.



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## List of abbreviations

CCC	Community Care Centre
CDC	Centers for Disease Control and Prevention
DERC	District Ebola Response Committee
DC	District Council
DMO	District Medical Officer
ERAP	Ebola Response Anthropology Platform
ETU	Ebola Treatment Unit
EVD	Ebola virus disease
IRC	International Rescue Committee
PHU	Peripheral Health Unit
INGO	International non-governmental organisation
MoHS	Ministry of Health and Sanitation
NERC	National Ebola Response Committee
NGO	Non-Government Organisation
PC	Paramount Chiefs
WHO	World Health Organisation

## BACKGROUND

An innovative component of the Ebola epidemic control policy in Sierra Leone is triage and isolation in decentralised Community Care Centres (CCCs) or Holding Units, from where transfer to Ebola treatment units (ETUs) is arranged for those diagnosed as Ebola virus disease (EVD) positive. The epidemic is currently waning, and there have been sufficient beds in the ETU for months, yet new micro-epidemics emerge, raising questions about the future role and relevance of the CCC.

This report presents the findings of a formative evaluation conducted by the UK-based Ebola Response Anthropology Platform (ERAP)<sup>2</sup> in February 2015. The team research team, led by Pauline Oosterhoff (IDS) with Esther Yei Mokuwa (Njala) and Annie Wilkinson (IDS), build on the work of many colleagues and anthropologists in ERAP. The preliminary findings have already been shared in order to provide policy makers with insights into options for the use of the CCCs during the bumpy 'road to zero'.<sup>3</sup>

The Ebola crisis has brought new perspectives on the roles of social scientists and anthropology in relation to global health emergency crisis response, post-crisis recovery and the challenge of building resilience to future epidemics. It is now widely recognised that a significant obstacle to an effective response has been inadequate engagement with affected communities and families.<sup>4</sup> Social science and anthropology have been instrumental in pointing out the importance of respect for culture and community engagement with health systems. DFID has strongly supported the role of social science in the Ebola response through the SAGE sub-group, R2HC funding for ERAP and various other important initiatives.

Although the horizontal transmission and virulence of epidemics often decrease over time<sup>5</sup> and research on this Ebola epidemic is still ongoing, community-level dynamics were highly likely to have played a major role in ending the spread of the Ebola epidemic.<sup>6</sup>

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<sup>2</sup> ERAP was established in 2014 by researchers at Institute of Development Studies (IDS), the London School of Hygiene and Tropical Medicine, University of Sussex, University of Exeter and Njala University College Sierra Leone, to draw social and cultural knowledge and advice into the Ebola response ([www.ebola-anthropology.net](http://www.ebola-anthropology.net)).

<sup>3</sup> P. Oosterhoff, A. Wilkinson and E. Yei-Mokuwa (2014) Policy brief on Community-based Ebola Care Centres. Ebola Response Anthropology Platform ([www.ebola-anthropology.net/key\\_messages/policy-briefing-on-community-based-ebola-care-centres](http://www.ebola-anthropology.net/key_messages/policy-briefing-on-community-based-ebola-care-centres)).

<sup>4</sup> WHO leadership statement on the Ebola response and WHO reforms, 16 April 2015 ([www.who.int/csr/disease/ebola/joint-statement-ebola/en](http://www.who.int/csr/disease/ebola/joint-statement-ebola/en)).

<sup>5</sup> For example, see T.W. Berngruber et al. (2013) 'Evolution of Virulence in Emerging Epidemics' PLOS Pathogens 9(3) ([www.ncbi.nlm.nih.gov/pmc/articles/PMC3597519](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3597519)).

<sup>6</sup> For example, see E. Cohen, (2014) 'Woman saves three relatives from Ebola' CNN, 26 September (<http://edition.cnn.com/2014/09/25/health/ebola-fatu-family>).

## Description of the programme reviewed

The CCCs were conceived at a time of great uncertainty. Around September to November 2014, predictive models were warning of potentially millions<sup>7</sup> of new Ebola cases and there were shortages of beds. Leading experts warned that delays would mean more deaths.<sup>8</sup> Health systems faced human resource shortages, and the capacity to deliver services and surveillance systems were weak.<sup>9</sup> Inequalities and poverty ran deep<sup>10</sup> and social trust and confidence in authorities was low.<sup>11</sup>

A core objective of the CCCs was to enable early isolation of EVD patients in places where there were no Ebola Treatment Centres (ETCs) or when they were full.<sup>12</sup> This was a response to widespread transmission of EVD in community settings across all districts in Sierra Leone; home care was considered as neither a safe nor a plausible option for reducing transmission.<sup>13</sup>

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A. Fassassi (2014) 'How anthropologists help medics fight Ebola in Guinea', 24 September ([www.scidev.net/global/cooperation/feature/anthropologists-medics-ebola-guinea.html](http://www.scidev.net/global/cooperation/feature/anthropologists-medics-ebola-guinea.html)).

P. Oosterhoff (2015) Ebola Crisis Appeal – Response Review. Disasters Emergency Committee ([www.ebola-anthropology.net/wp-content/uploads/2015/06/DEC-Ebola-Crisis-Appeal-Response-Review\\_18-June-15.pdf](http://www.ebola-anthropology.net/wp-content/uploads/2015/06/DEC-Ebola-Crisis-Appeal-Response-Review_18-June-15.pdf))

S.A. Abramowitz et al. (2015) Community-Centered Responses to Ebola in Urban Liberia: The View from Below ([www.ebola-anthropology.net/case\\_studies/community-centered-responses-to-ebola-in-urban-liberia-the-view-from-below](http://www.ebola-anthropology.net/case_studies/community-centered-responses-to-ebola-in-urban-liberia-the-view-from-below)).

The importance of community engagement in previous Ebola epidemics has also been documented in B.S. Hewlett and B.L. Hewlett (2006) *Ebola, Culture and Politics: The Anthropology of an Emerging Disease*. Wadsworth.

<sup>7</sup> When the numbers appeared to go down in October, WHO wrote that the reduced number of new cases was likely not to be genuine and instead might reflect the increasing problem of gathering accurate data. ([http://apps.who.int/iris/bitstream/10665/136020/1/roadmapsitrep\\_8Oct2014\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/136020/1/roadmapsitrep_8Oct2014_eng.pdf)).

<sup>8</sup> C.J.M Whitty et al. (2014) 'Infectious disease: Tough choices to reduce Ebola transmission', *Nature* (515)7526 ([www.nature.com/news/infectious-disease-tough-choices-to-reduce-ebola-transmission-1.16298](http://www.nature.com/news/infectious-disease-tough-choices-to-reduce-ebola-transmission-1.16298)).

<sup>9</sup> Statistics Sierra Leone, Ministry of Health and Sanitation, ICF International (2014) Sierra Leone Demographic and health survey 2014.

WHO (2014) Health systems situation in Guinea, Liberia and Sierra Leone. Ebola and Health Systems meeting Geneva, December 10-11 ([www.who.int/csr/disease/ebola/health-systems/health-systems-ppt1.pdf](http://www.who.int/csr/disease/ebola/health-systems/health-systems-ppt1.pdf)).

<sup>10</sup> See UNDP in Sierra Leone website ([www.sl.undp.org/content/sierraleone/en/home/countryinfo.html](http://www.sl.undp.org/content/sierraleone/en/home/countryinfo.html)).

<sup>11</sup> B. Rothstein and E.M. Uslaner (2005) 'All for all: Equality, corruption and social trust', *World Politics*, 58: 41-72.

M.C. Ferme (2001) *The underneath of things: violence, history, and the everyday in Sierra Leone*, London: University of California Press.

<sup>12</sup> A.J. Kucharski et al. (2015) Evaluation of the Benefits and Risks of Introducing Ebola Community Care Centers, Sierra Leone. Centers for Disease Prevention and Control ([wwwnc.cdc.gov/eid/article/21/3/pdfs/14-1892.pdf](http://wwwnc.cdc.gov/eid/article/21/3/pdfs/14-1892.pdf)).

<sup>13</sup> C.J.M Whitty et al. (2014) Op. cit.

Active case finding was proving impossible due to the ratio of contact tracers to cases so it was hoped that CCCs would support a strategy of passive case finding where suspect cases would voluntarily present to decentralised facilities.<sup>14</sup>

According to the DFID CCC tracker, DFID has funded 54 CCCs in Sierra Leone. Bed capacity ranges from 8 to 25 with a total of 504 beds. The first opened in Port Loko on 3 November 2014. UNICEF received £14,422,375 to oversee the setting up of CCCs. Between November and December UNICEF worked with the Ministry of Health and Sanitation (MoHS), building contractors and international NGOs (INGOs – who provided clinical support) to build 46 CCCs across five districts.<sup>15</sup> Other key partners involved in setting up the CCCs were Oxfam, Plan, and the International Rescue Committee (IRC). Clinical and operational support was provided by Concern, World Hope, Marie Stopes, Partners in Health, Médecins du Monde and also IRC.

Thankfully the worst-case scenario did not materialise and the general curve of the epidemic turned. Although the epidemic has not been stopped completely, in June 2015 most parts of Sierra Leone are seeing very little active Ebola transmission.<sup>16</sup>

Not all of the planned centres were opened. At the time of fieldwork, February 2015, most of the CCCs were empty. Though they triaged walk-ins there were limited admissions.<sup>17</sup> Most cases meeting the Ebola case definition and having reached the stage of ‘wet symptoms’ were transferred directly to ETCs rather than being admitted to CCCs. By February 2015 most districts had treatment centres, the number of ambulances had increased and national bed capacity outstripped the number of new cases.

The excess beds had become a matter of debate in policy circles at that point, with attention focusing on CCCs, especially those which had been set up in schools (which the President had announced were to re-open by the end of March). At the time of fieldwork the National Ebola Response Committee (NERC) had asked districts to report which CCCs could be closed. There was, and is, intense debate about the merits of keeping everything in place ‘on standby’ until zero cases is reached versus the merits of closing facilities in order to redirect resources to rebuilding work.

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<sup>14</sup> C.J.M Whitty et al. (2014) Op. cit.

<sup>15</sup> UNICEF (2015) Progress Report – Ebola Community Care Centres in Sierra Leone. Submitted to DFID

<sup>16</sup> WHO Ebola Situation Report – 17 June 2015 (<http://apps.who.int/ebola/current-situation/ebola-situation-report-17-june-2015>).

<sup>17</sup> UNICEF (2015) Op. cit.

This report presents an analysis of the impact that the CCCs have had on communities. At the time this evaluation was conducted several other evaluations were going on or had just been completed, and we have coordinated the work as much as possible to avoid overlap.<sup>18</sup>

Key questions the research explored are divided into two categories: (1) Community engagement with the development and management of CCCs, and (2) Post-Ebola use of CCCs.

We examine the perceptions on community engagement, local ownership and the role and function of the CCCs, taking a bottom-up approach where we focus on understanding the CCC and the health system from the perspective of communities. The research included discussions with policy makers and implementing partner to triangulate and better understand some of the differences between implementers, policy makers and communities. Each group operates and lives within specific epidemiological, demographic and political contexts in the different districts, and these are important if we are to understand their shared and divergent views and interests.

## **Methodology**

We reviewed the anthropological literature on the social-political determinants of health in Sierra Leone and examined data and documents of the CCC programme provided by DFID and its implementing partners to identify information and documentation gaps and inform the primary data collection strategies and evaluation design.

A Sierra Leonean research team with a mix of local language skills visited 14 villages in seven chiefdoms in Port Loko, Kambia, Tonkolili and Kono. Two villages were selected in each chiefdom: the village hosting the CCC (or closest to it) and a satellite village of the same chiefdom. We also conducted interviews with residents in one urban area close to an isolation centre in Maforkie chiefdom in Port Loko. Sites in each chiefdom were selected in consultation with the District Ebola Response Centre (DERC) and paramount chiefs.

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<sup>18</sup> ICAP at Columbia University for example conducted an Assessment of Ebola Community Care Centers in Sierra Leone (<http://icap.columbia.edu/news-events/detail/icap-conducts-an-assessment-of-ebola-community-care-centers-in-sierra-leone>). They looked at the quality of care, staffing and other elements of the CCC in the CCC themselves. This evaluation complements that work by focusing on the community outside the CCC. The team leader of this evaluation was also team leader for the Ebola Crisis Appeal – Response Review of the Disasters Emergency Committee (see Oosterhoff 2015, Op. cit).

Date	District	Chiefdom	CCC	Satellite village
7/2/15	Port Loko	BKM	Kabanthama	Mabureh
8/2/15	Port Loko	Maforki	Port Loko	Port Loko
9/2/15	Port Loko	Koya	Mateh	Mahoma
10/2/15	Kambia	Magbema	Rokuprr	FunkunyaIn
12/2/15	Tonkolili	Tane	Marrah	Mapake
13/2/15	Tonkolili	Kunike	Mawoli	Maseka
15/2/15	Kono	Fiama	Sawei	Waima
16-17/2/15	Kono	Nimiyama	Condama	Banbakonaya

At each site teams held group discussions with elders, men, women and youths focusing on community engagement and perspectives on the CCCs.

Focus group organisation and facilitation in the gerontocratic Sierra Leonean context require particular attention to allow different voices to be heard. People older than 45 have been particularly affected by Ebola, with a high cumulative number of confirmed and probable cases.<sup>19</sup> Sierra Leone also has a well-documented history of intergenerational conflicts with a particularly rich body of research on youth combatants.<sup>20</sup> In Sierra Leone 'youth' is a social rather than age-based category and indicates lack of social standing. A migrant stranger, for example, may be considered a youth even in relative middle age.

To hear different perspectives we conducted simultaneous focus groups with different interest groups in the community four groups. Conducting parallel sessions avoided the results of discussions in one group influencing the answers in others. In villages it is difficult to find a closed space where bystanders cannot see or overhear the groups. In the context of Ebola, anything perceived like an anonymous meeting with outsiders can become a source of rumours and have unintended and possibly harmful consequences.

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<sup>19</sup> For epidemiological data, see <http://ow.ly/MaTRR> or <http://apps.who.int/ebola/en/current-situation/ebola-situation-report-10-june-2015>. For the specific reasons: [www.ebola-anthropology.net/wp-content/uploads/2014/12/Older-people-and-Ebola-Ebola-Response-Anthropology-Platform.pdf](http://www.ebola-anthropology.net/wp-content/uploads/2014/12/Older-people-and-Ebola-Ebola-Response-Anthropology-Platform.pdf).

<sup>20</sup> J. Boersch-Supan (2012) 'The generational contract in flux: intergenerational tensions in post-conflict Sierra Leone', *The Journal of Modern African Studies*.

K. Peters and P. Richards (1998) 'Why We Fight': Voices of Youth Combatants in Sierra Africa', *Journal of the International African Institute*.

C. Bolten (2102) 'We Have Been Sensitized': Ex-Combatants, Marginalization, and Youth in Postwar Sierra Leone', *American Anthropologist* 114(3): 496–508

P. Richards (2005) 'To fight or to farm? Agrarian dimensions of the Mano River conflicts (Liberia and Sierra Leone)' *African Affairs*.

R. Shaw (2014) The TRC, the NGO and the child: young people and post-conflict futures in Sierra Leone. *Social Anthropology*.

We used a card system to document and examine the individual group dynamics, to avoid inflating the total numbers and to protect individual privacy. Active participants received a card with a number on it used to record the data. Research assistants also took notes on the mood and body language of the speaker, as these are key in understanding the meaning.

A total of 1,031 participants joined the discussions, of whom 688 participated actively. An international researcher conducted 78 semi-structured interviews with health authorities, District Medical Officers (DMOs), DERC representatives, implementing partners, CCC staff and Peripheral Health Unit (PHU) staff in Freetown, Port Loko, Kambia, Tonkolili and Kono.

### **Limitations of the evaluation**

A number of limiting factors should be born in mind in interpreting results of this rapid consultation.

- *Time and budget restraints.* The work was rescheduled for administrative reasons and had to be done within a two-week period. There were few experienced research assistants willing and able to undertake fieldwork in the middle of an Ebola outbreak and only a small budget for them.
- *People's availability.* While the team was generally welcomed the outbreak caused massive disruptions in daily life which affected the availability of respondents in the field. Planned inception and debriefing meetings with a broad group of stakeholders were cancelled by DFID due to scheduling constraints. High staff turnover also posed problems in terms of the availability and continuity of experts.
- *Fragmented documentation.* A large number of international and national actors were involved in the CCCs. Challenges in the coordination and sharing of documentation between these actors and DFID affected the evaluation team's access to data.
- *Inaccessibility and road conditions.* Not all outlying villages are located on a road, but time limitations meant we had to pick villages that were accessible by road. This may have biased responses about accessibility and use. The work was also limited by lodging constraints. Before the Ebola crisis villagers were often willing to house visiting research teams, but this is now against the law because of the fear that strangers might bring infection.
- *Language barriers.* Several communities were made up of groups speaking different languages. Krio serves as a lingua franca for the country as a whole, but not everyone can communicate easily in it. The team included speakers of the main relevant local languages – Temne, Kono, Mandingo, Fula and Limba – but it was not easy to hold group meetings with speakers of different languages. There was insufficient time to ensure that different language speakers always had the option to make their points in their mother tongue.



- *Electricity, lack of coverage and technical failures.* Lack of cell phone coverage and electricity supply to charge devices in some areas hindered communication between teams. This is also likely to also have affected awareness of villagers concerning CCCs and other Ebola response facilities, notably the 117 helpline. Cameras broke down and could not be fixed during fieldwork.
- *Gender inequities.* Although the evaluation was undertaken by a mixed gender team, responses may have been restricted by the fact that many villagers (women especially) are at times afraid to speak up in meetings, and some may have been restrained in what they said due to fear of stigmatisation.
- *Educational and other identity markers.* All team members – Sierra Leonean and international – were highly educated outsiders. All had considerable experience working with villagers and the use of participatory methods to engage meaningfully with communities, but their high level of education, mobility and other factors are likely to have influenced people's perceptions of the team.
- *Team illnesses.* Team members fell ill during and after the work with non-Ebola related diseases and had difficulties finding treatment, which caused considerable delays.
- *Lack of definitions of terms.* 'Community', 'community-based' and 'community-owned' were not clearly defined as geographic, cultural or political entities or a combination of these. This makes it more difficult to measure if and how communities have been engaged and to what extent that has been successful.

## **FINDINGS**

### ***Question 1: Community engagement with the development and management of the CCC in all sites***

#### *Policy and implementing partner perspectives*

The location of CCCs in the community meant that public buy-in had to be a priority.<sup>21</sup> Ebola facilities and teams both in Sierra Leone and in neighbouring countries had been feared and attacked. The selection of the site for the CCC went through the traditional paramount chief rather than the state district

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<sup>21</sup> C.J.M Whitty et al. (2014) Op. cit.

governance system.<sup>22</sup> Paramount chiefs have formally recognised governing powers, including the right to allocate land and settle disputes.<sup>23</sup>

*The moment you get the paramount chiefs, the section chiefs, then you've got the whole thing. If you get them to a meeting then the world goes round. The words of these chiefs are laws in some communities. If you do things without the chiefs then that thing doesn't succeed.* (International NGO worker, Kambia, male)

There are several chiefdoms in a district and the concentration of paramount chiefs differs.<sup>24</sup> The selection of the CCC usually follows a traditional political decision-making process and includes a well-established set of stakeholders (paramount chiefs, section chiefs, town chiefs, youth leaders and women's leaders).

These stakeholders are part of a system with multiple interlinked layers of governance from the paramount chiefs to the village level. Paramount chiefs are thus an entry point rather than an end point for reaching a diverse group of local residents through a system featuring many different local interest groups.

'Community-based' and 'community-owned' were leitmotifs in the policy and among all implementing partners. But while implementing partners used the same words, they were unclear whether this meant geographic, cultural or political entities or a combination of these. Without clear operational definitions community ownership is problematic as it is not clear where the resources and competencies come from.

Employing local residents as CCC staff was intended to foster integration and acceptance by people in the surrounding areas. A CCC employs medical staff and non-medical staff such as cooks, cleaners and watchmen. Trained medical staff and other resources for health are scarce in Sierra Leone.<sup>25</sup> When staff requirement policies include formal medical training it means there will in practice be a shortage of local residential staff willing and able to work in a CCC.

The establishment of the CCC has affected the PHUs. Staff at the PHU reported not having been paid their salary for months and said that normally they had to

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<sup>22</sup> There are 11 district chiefs in Sierra Leone and 149 chieftaincies.

<sup>23</sup> The British colonial administration introduced the chieftaincy system and the concept of 'ruling families' when it organised the Protectorate of Sierra Leone in 1896. They now play important roles in civil society building, economic development and democratic governance.

<sup>24</sup> D. Acemoglu, T., Reed and J.A. Robinson (2013) 'Chiefs: Economic Development and Elite Control of Civil Society in Sierra Leone', *Scholar*, Harvard University (<http://scholar.harvard.edu/files/jrobinson/files/history.pdf>).

<sup>25</sup> J. MacKinnon and B. MacLaren (2012) Human Resources for Health Challenges in Fragile States: Evidence from Sierra Leone, South Sudan and Zimbabwe. The North-South Institute. Also see Africa Health Observatory Sierra Leone Country Profile ([www.who.int/profiles\\_information/index.php/Sierra\\_Leone:Analytical\\_summary\\_-\\_Health\\_workforce](http://www.who.int/profiles_information/index.php/Sierra_Leone:Analytical_summary_-_Health_workforce)).

live off what patients gave them in return for treatment.<sup>26</sup> PHU staff did get hazard pay but the impact of the CCC was immediately felt when nurses at the PHU left for the CCC because of the more attractive salaries and other incentives such as meals.

*Many of the clinical leads and mentors working as supervisors in the CCCs have been taken from the PHUs and hospitals. It is not fair to have staff taken away from their posts, especially now things are getting quiet. We need to respond to other illnesses, not just chasing Ebola. (Senior government health worker, Tonkolili, male)*

*We think now people will be confused. There are parallel health systems which may cause problems in the future. They should transfer the funds from the CCCs to recover the PHUs to manage probable and suspect cases in the future and not to create parallel systems. (INGO health worker, male)*

*Does faith get restored by building parallel systems or by more investments in PHUs? (INGO health worker, female)*

Lack of clarity about staff requirements – for example whether a traditional birth attendant should be able to work in a CCC as health staff – has important implications about the expectations of communities about employment in the CCC. Opinions about the success and usefulness of the involvement of local residents as health staff varied. Respondents expressed the need for continuous training and supervision of all staff to avoid complacency.

CCCs were imagined as temporary structures within a specific vertical disease programme. However, this approach did not respond to the urgent need for affordable health care on the ground and conflicted with the professional sense of duty of medical staff.

For UNICEF the CCCs were about more than ‘more beds’, but were supposed to be focal points for community-based disease control, including case finding and social mobilisation.<sup>27</sup> UNICEF implementing partners described how the CCCs aimed to complement the other community based health facilities, the PHUs. Some PHUs were being used as Ebola holding centres: many were seeing reduced attendance while others had been abandoned. It was hoped the CCCs would absorb the Ebola cases, drawing them away from the PHUs and leaving them as trusted Ebola-free zones.

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<sup>26</sup> This suggests they lived off so called “user fees” which are part of internationally endorsed Result-Based Financing approaches to health. Sierra Leone is one of the three countries where the World Bank supports nationwide Results-Based Financing (RBF) (<http://siteresources.worldbank.org/INTAFRICA/Resources/AHF-results-based-financing.pdf>).

<sup>27</sup> UNICEF (2015) Op. cit.

*An objective was to re-establish the PHUs by taking the Ebola patients away from them. (Senior UN worker, Freetown)*

Partners in Health and Mary Stopes offered residents free health care and support. The roles of the CCC shifted as more treatment facilities were built and the epidemic reduced. Some CCCs moved to performing triage and referral functions as opposed to inpatient Ebola care. Others broadened the CCC concept to take on a wider and more significant public health role. They started providing villagers with free health care for diseases other than Ebola.

This could be seen as a form of mission creep that raised false hopes and expectations in the post-Ebola health system, but it is in line with medical professional ethics and duties to provide care.

### *Community perspectives*

A key finding is that use of the traditional hierarchical political structures was at once appreciated and resented at the village level. People felt that the paramount chief had to be involved in decisions regarding the establishment of public facilities, but they did not feel that the use of the traditional governance system rather than the district-level state governance system was inappropriate.

Some chiefs exercised their political influence in ways that caused resentment. There were complaints that landowners were not consulted about the use of their land and in some sites there were suggestions that the CCC was used to settle old scores. Focus group responses on land issues were often more guarded in satellite villages than in CCC villages, perhaps because they did not see it as their place to talk about such matters.

Staffing was an area where the power of chiefs and authorities attracted suspicion in some cases. The establishment of the CCCs created expectations of paid work which were not met. The allocation of paid employment was seen as unfair, particularly after local people contributed labour. In all districts we heard hints and accusations that employment was based on bribes or favouritism of the paramount chief.

*Before the establishment of the CCC, the officials told us that they would employ workers from our village. But when the preparatory work was finished only the councillor and the Mamie Queen did the selections. The councillor even said that our children are drunkards. (Nimiya Chiefdom, women's focus group discussion)*

In all four districts we found villagers who felt excluded from paid work.

*All workers at the CCC were engaged by the authorities from Matotoka and Freetown. That is because they are their relatives and some are their children, wives or girlfriends. They used their authority and power to employ their brothers and sisters and there is no one among them who came from our village. (Tane Chiefdom, youth focus group discussion)*

*Our children were all involved in the brushing, clearing and even building of the centre, but we were all ignored when it came to employment.*  
(Kunike Chiefdom, elders group, male)

Respondents were aware that local employment opportunities in the CCC were limited and that medical staff were not always locally available. But we heard many accusations against chiefs and local politicians of favouritism in allocating jobs.

People in satellite villages were well informed about the purpose and functioning of CCCs and just as critical of the recruitment process as CCC villagers. In most focus groups people were aware of the (high) salaries paid to CCC workers. They expressed gratitude for the dangerous work undertaken and good care offered by these staff, but recognised that they would face problems in reintegrating back into normal employment: it is possible this was a veiled expression of resentment at the closed, uncompetitive nature of the recruitment process.

These complaints have implications for how community-owned the CCCs are, and points to limitations in the rigid 'stakeholder'-driven cascaded model of engagement. This model in which information, skills and benefits are assumed to trickle down effortlessly and change whole systems has been widely critiqued.<sup>28</sup> It was notable that people taking part in the focus groups in the 'catchment area' village (which did not host the CCC) had a limited understanding of the CCC purpose. There were also some lingering doubts about the real purpose of the CCCs. In response to a question about whether they would recommend other communities to have a CCC one woman answered:

*I will not make any recommendations because as we have understood the game that is being played – the more CCCs are established, the more Ebola will stay.* (Kunike Chiefdom, women's group)

Cascaded information and benefit transfer models may have enabled CCCs to be established rapidly in an unfolding health emergency – a huge achievement given the circumstances – but it should not be equated with meaningful involvement and sustainable agreement of citizens. From our data we cannot verify staff selection processes, but the level of complaints suggests imbalance or that rationales were not explained well. The influx of resources to deprived regions can stir tensions and reinforce deeper suspicions. Explaining processes

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<sup>28</sup> Trickle down approaches are part of a neoliberal philosophy on economics that has been widely criticised as ineffective and increasing inequities. See for example: J.K. Galbraith (1982) *Recession Economics*. ([www.nybooks.com/articles/archives/1982/feb/04/recession-economics](http://www.nybooks.com/articles/archives/1982/feb/04/recession-economics)) or H. Stewart (2012) 'Wealth doesn't trickle down – it just floods offshore, research reveals' *The Guardian*, 21 July ([www.theguardian.com/business/2012/jul/21/offshore-wealth-global-economy-tax-havens](http://www.theguardian.com/business/2012/jul/21/offshore-wealth-global-economy-tax-havens)). Cascading approaches similarly assume that a process – such as a training of trainers on health – once started, at a high level are replicated to lower levels to reach a seemingly inevitable conclusion such as improved health system performance. Cascading is challenged for comparable reasons. See for example: David Hayes (2000) Cascade training and teachers' professional development. *ELT Journal* 54(2): 35-145 (<http://eltj.oxfordjournals.org/content/54/2/135.short>).

clearly to intended beneficiaries is vital in an emergency response, although it may not alleviate the structural reasons of suspicion. It should also be noted that the management of natural resources has also upset some people in some areas.

*Initially we were using the well that was dug by the school and young people. When the CCC came, they started to use the water and prevented us from using it. (Nimiya Chiefdom, women's focus group)*

In spite of concerns over the appointment of CCC staff, their skills and attitudes are widely appreciated.

*The CCC encourages all patients; staff tell them not to worry so much because they will be cured. The CCC is useful because it gives easy and quick response to our patients. (Nimiya Chiefdom, women's focus group discussion)*

*If [CCCs] had been established when Ebola first struck Sierra Leone then the death rate would not have increased. They built confidence. [Before people were going by ambulance to Kenema and Kailahun] and that is why people died. When they provided facilities within the community Ebola has now become very easy. People have confidence in the environment and your children take care of you. (CCC staff member, employed from the community, Tonkolili, male)*

The perception of CCCs may have become more positive over time. Respondents mentioned that previously they were afraid of the CCC, and some had been advised to avoid them. Implementing partners in Kambia reported ongoing problems with rumours relating to the taking of blood samples. However in focus groups participants indicated that they have confidence in the CCC because they had seen people return cured of Ebola and from other sicknesses.

*The CCC is very useful. Since the establishment of the CCC there are no untimely deaths caused by nurses who knew nothing about Ebola. (Tane Chiefdom, Youth focus group discussion)*

Rather than a place to avoid, the CCC is seen as a place to go for free consultation on Ebola and other diseases:

*We can now freely go to the CCC without fear or hesitation. Any other sickness as well as Ebola can be treated at the CCC. (Nimiyama Chiefdom, women's focus group discussion)*

*Patients are kept at this centre until their status is known. (Kunike Chiefdom, elder's group)*

Citizens are aware of Ebola symptoms, suggesting that health messages have diffused, but the practical arrangements for managing suspect cases varied. People spoke of taking people with Ebola symptoms to the chief or members of the task force or of calling for an ambulance to go directly to a treatment centre rather than to a CCC. The team observed suspect patients presenting to both the PHUs and to CCCs.

Memories from earlier times when patients were taken to distant treatment centres in Kenema or Kailahun – with many of them never returning – are still fresh. The establishment of CCCs and treatment centres within each district was therefore welcomed. There was understanding and acceptance of the dangers posed by bodily contact with patients, and reluctant acceptance that family contact had to be limited. Where CCCs had taken steps to communicate news (of death or recovery) to families by telephone, or to allow families to see and talk to patients from a distance, this was commended.

At first CCC workers had been shunned, but most groups reported that this was no longer the case due to frequent sensitisation about the true nature of Ebola infection risks. The workers were accepted locally and fears about transmission risks were calmed.

By providing a good level of free care, food and post-Ebola rehabilitation packages for survivors, care at the CCC differs from that in the PHU, where people said staff charge for treatment and leave care and food to patients' families. PHUs are also strongly associated with maternal and child health (*mami en pekin welbodi*), an association made stronger by the Free Health Care Initiative for pregnant and nursing women and children under five. The CCCs provide health care for people who are not covered by this and would usually pay out-of-pocket and cost-recovery fees. Overall CCCs are viewed as providing access to disease-specific care pathways (triage, tests and referral), prompt treatment, encouragement and free medicine.

CCCs are perceived to help treatment to start more quickly, enhancing survival chances. In official discourse, only a few 'stubborn' families now keep their cases unreported to the authorities until it is too late to start effective treatment. CCCs have contributed to better local understanding of Ebola risks. We found no reports of the wilder fears and allegations about Ebola as 'germ warfare' or a pretext to snatch body parts, as sometimes voiced when the only treatment centres were distant and ineffective. Some focus groups mentioned that they had learnt from CCCs how to care more safely for patients at home while waiting for the ambulance by improvising protection from plastic bags and offering the patient oral rehydration therapy or coconut milk for rehydration.

There was grudging acceptance that risks of Ebola infection, which were widely understood, demanded the suspension of normal burial procedures in favour of safe burial by trained burial teams. Nobody mentioned the hiding of dead bodies and secret burials. Respondents reported that restrictions on families attending funerals had relaxed, and that burial teams worked hard. Even so, villagers commonly complained that the work of the teams was disrespectful to the dead. This complaint appeared to be based on two common concerns: first, that burial teams comprised mainly young men (even teenagers) and that such young people hardly, as yet, knew the meaning of death and burial; and second, that relatives were excluded from the burial process (it was widely felt that more could have been done to give family's a role in the actual burial process). This

information corresponds to responses recorded in other studies and reports in Sierra Leone and the region.<sup>29</sup>

Despite land and recruitment concerns, the CCC represented a welcome new trend in health care provision in rural Sierra Leone. The acceptance of CCCs suggests that, for many people, there was nothing so deep seated about people's fears of existing health facilities that could not be overcome with the provision of effective triage and prompt care by kindly and well-trained staff. The lack of trust was more a rejection of inadequate facilities. However the fact that the CCCs were being warmly received may also be because the numbers of Ebola cases was greatly reduced by the time they were up and running so they were not strongly implicated in transmission or 'bringing Ebola' to communities.

The dynamics in each district are described in more detail below.

## **Port Loko**

### *Staff of implementing partners and authorities*

Port Loko was the first district to build CCCs. The CCCs were understood to have arrived at a time when they were needed: isolating people at a time of urgent need and doing so in a way which kept them close:

*Before, people had to be taken to Bo, Kenema or Kailahun and relatives couldn't visit. Now the centre makes it possible for patients to be seen by their families. There was a lot of Ebola around and it was taking 24 hours for ambulances. ... When Ebola started people were scared of the PHU. They thought you would die there. People have stopped having these fears now there is a centre. (Chief, Port Loko district, male)*

There was a sense of urgency due to a rapid increase in the number of cases that could not be accommodated in the PHU. This contributed to the acceptance of the CCC by residents:

*It was urgent. People were dying, they were crying. They had built a holding centre in the PHU and this meant there was no primary health care. The WHO came to give advice and the local people implemented it. (Sprayer, Port Loko district)*

CCCs were perceived by partners as having played an important role in reducing the burden of the epidemic in Port Loko. They also had political buy-in at the district level, with the DERC, the District Council (DC), District Medical Officer

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<sup>29</sup> P. Richards et al. (2015) Village Responses to Ebola Virus Disease in Rural Eastern Sierra Leone Second interim report to the SMAC program, DFID Freetown. Njala University. Also S. Abramowitz and P. Omidian (2014) Attitudes towards Ebola related funerary practices and memorialization in urban Liberia ([www.ebola-anthropology.net/key\\_messages/attitudes-towards-ebola-related-funerary-practices-and-memorialization-in-urban-liberia](http://www.ebola-anthropology.net/key_messages/attitudes-towards-ebola-related-funerary-practices-and-memorialization-in-urban-liberia)) and other sources on the same website ([www.ebola-anthropology.net/tag/burial](http://www.ebola-anthropology.net/tag/burial)).



(DMO) along with 'son of the soil' Alpha Kanu, the Minister of Presidential and Public Affairs,<sup>30</sup> all playing active roles in pursuing the CCCs.

Port Loko was the first district in the country to roll out CCCs. One of the DERC staff members identified CCCs as a turning point for bringing in partners and resources:

*That was the beginning of the revolution in making us the district with most bed capacity because of our foresight in thinking we needed the facilities.*  
(DERC staff member, Port Loko)

CCCs operated by Partners in Health reported offering non-Ebola services. The free health care principle which CCCs were based on was seen by implementing staff as more accessible than PHUs, which charge patients fees:

*Theoretically the PHUs are part of the community but unless you have the money then you can't use them. In contrast, people do attend the CCCs, where you don't pay.* (Health INGO worker, Port Loko, male)

Port Loko continues to have the highest rate of new infections in Sierra Leone attributed by authorities to unsafe burials and infections within quarantined homes.<sup>31</sup> A large-scale operation is planned in Port Loko and neighbouring Kambia aimed at ending the secret movement of cases, contacts, and dead bodies that has propagated transmission over the past two months. Measures proposed include the use of extended criteria for identifying and tracing contacts and improved incentives to comply with quarantine measures, all of which requires community trust and engagement.

### *Community perspectives*

There was a sense among the residents around the CCC in Mateh that the paramount chief had notified rather than consulted the landowning families about the allocation of land:

*The family were not happy about the land allocations. The paramount chief decided everything about it.* (Mateh, elders group, male, 45, village advisor, farmer, angry)

Residents in the nearby village had heard these rumours. They were, however, careful in making judgments:

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<sup>30</sup> He is also the official spokesman of the All People's Congress (APC) political party.

<sup>31</sup> A NERC press release of 5 March 2015 said: 'In recent weeks the trend of decline in new EVD cases in our country has stalled. Most new cases have been fuelled by unsafe burial practices'. Also see WHO Ebola Situation Report 10 June 2015 (<http://apps.who.int/ebola/en/current-situation/ebola-situation-report-10-june-2015>).

*We cannot tell much about the selection of the site. The only thing we know is that it is located at the Catholic primary school at Mateh (Mahoma, women's group, female, age 64, housewife, farmer, confused)*

In Mateh there were also concerns water and waste management as well as anger about the choice of putting the CCC in a school site:

*The CCC has engaged their school compound. It is now difficult to access their classroom for study. (Mateh, youth group, male, 17, student)*

The work of the medical staff was highly appreciated but there were allegations of nepotism and bribery in appointments to well-paid jobs:

*The PC and councillor only employed those who are in their favour. In fact 90 per cent are from other places. (Mahoma, elders' group, female, community leader, farmer)*

While there were concerns about the way communities had been engaged in the development of the CCC there was also acknowledgement that the CCCs met an urgent need. Rural and urban communities in Port Loko recognised and accepted that the situation had been dire and this had required quick political decisions:

*The site was selected because of the massive infection and death that occurred in this village due to Ebola. (Kagbantama, men's group, male, age 52, farmer)*

Different age groups in all communities showed appreciation for the risks that CCC staff had taken by working in an environment with a disease for which there is no cure, the stigma they faced and the possible consequences Ebola work posed for finding employment in the future.

*Since the virus has no drugs to cure patients, staff were stigmatised. (Mahoma, youth group, male, age 23, student)*

Locally recruited staff would – after initial rejection – be accepted back, which then helped families learn about living safely in an Ebola epidemic. People understood the value of learning these life-skills.

The establishment of the CCC was appreciated because it provided jobs and reduced the long distance travelling with sick patients to Kenema, Kailahun, etc:

*The CCC has provided employment for our brothers and sisters. It has long distance transportation of patients to Makeni. (Kagbantama, youth group, female, age 20, housewife)*

Most communities said that they would have liked to see more contact between the CCC staff and families and the sick. They also accepted that due to the severity of the disease, families needed to send sick members to the CCCs for specialised care. We heard several reports of how staff had encouraged families to provide safe and appropriate care for suspected Ebola victims while waiting for transfer to the CCC. Communities appreciated how survivors were provided with packages after leaving the care facility. Some people wondered why these

packages were given only to the survivor and not the whole family. Some families lost the belongings of many members when one was infected.

Case management of the dead was more problematic. Informing a family about the death of a patient by phone was felt as impersonal, but people acknowledged staff might need to do this for practical reasons.

But people disliked the medical undertaking and burial processes. There was a widely felt desire to be more involved in the undertaking – washing, dressing and praying – not just attending the burials from a distance:

*Let the workers inform the family about the death of their patients. Allow family to be involved in burial activities (wash, dress and pray on the corpse). (Mabureh, women's group, female, farmer)*

What upset and saddened people – including young people – was that youths were employed in burial teams. Youths are not seen as having sufficient respect for the dead:

*We want the government and local authorities to employ adults who are competent, have respect for the dead, and believe that they will one day die, [rather than] just to employ 17-18 year [old youths] who have no regard for the corpse and fail to realise that they will die one day. (Mahoma, youth group, female, age 19, student).*

*Families are not happy about the employment of small boys in the burial team. They have no respect for the corpse. (Port Loko, men's group, male, age 53, trader)*

## **Kambia**

### *Perspectives of implementing staff and authorities*

Kambia had 12 CCCs in total. Like Port Loko, Kambia is still seeing EVD transmission.<sup>32</sup> Implementing staff and authorities perceived CCCs as generally useful because of hard-to-reach populations (physically and culturally) and because there is no ETU in Kambia (the nearest is in neighbouring Port Loko). For these reasons the CCCs have been welcomed by the DERC.

However, authorities reported that communities pushed back on a couple of proposed sites and the sites appeared to have been chosen according to political opportunities – including community collaboration – rather than epidemiological data. The relationship between DERC and implementing partner Marie Stopes has also been challenging. One reason is that the CCCs are promoted to

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<sup>32</sup> WHO Ebola Situation Report 17 June 2015 (<http://apps.who.int/ebola/current-situation/ebola-situation-report-17-june-2015>).

communities as free health care, departing from the vertical and temporary emergency approach to the Ebola outbreak.

*The concept and role of the CCCs has not been fully understood. I think the fear that it was going to be difficult led people say that the CCC was for all health care, not just for Ebola. (DERC staff member, Kambia, female)*

*They are Community Care Centres. They are not just for Ebola. It doesn't need to be Ebola related – people should just come for check-ups. We are encouraging them to come. (Manager, INGO, Kambia, male)*

### *Community perspectives*

The communities we selected for a CCC placement felt the paramount chief and elders had selected a well-placed and easily accessible location close to the PHU.

Jobs were assigned by the paramount chief. CCC staff mostly came from the local Ebola task force:

*Cleaners, nurses, sprayers, contact tracers, cooks, sensitisers, doctors etc, were employed by the government and the paramount chief who employs unskilled labourers. (Rokupr, women's group, female, age 30, trader)*

There were rumours of high payment but it was felt that CCC employees were qualified, made sacrifices, and might face long-term difficulties in finding further employment.

*The government and stakeholders in the community recruit workers of high calibre. (Funkunyia, elder's group, male, community leader, farmer)*

Staff initially faced discrimination in the community but this has diminished over time. Respondents credited information and awareness campaigns for this change. Groups reported, however, that within their homes CCC staff were sexually rejected by their partners. This suggests confusion about the contradictory messages by the World Health Organisation (WHO) and the Centers for Disease Control and Prevention (CDC) on the transmission of Ebola through sexual contact, also found in other reviews of the response.<sup>33</sup>

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<sup>33</sup> P. Oosterhoff (2015) Op. cit. According to WHO, 'Men who have recovered from the illness can still spread the virus to their partner through their semen for up to seven weeks after recovery' ([www.who.int/csr/disease/ebola/faq-ebola/en](http://www.who.int/csr/disease/ebola/faq-ebola/en)). CDC agrees that 'multiple studies have shown the Ebola virus can persist in semen for longer than in blood or other body fluids'. Yet CDC's view is that sexual transmission of Ebola has not been definitively established. See CDC (2014) Review of Human-to-Human Transmission of Ebola Virus ([www.cdc.gov/vhf/ebola/transmission/human-transmission.html](http://www.cdc.gov/vhf/ebola/transmission/human-transmission.html)).

*Wives/husbands of CCC workers initially failed to share the same beds at night.* (Kambia district, elder's group, male, chief, farmer)

Informants had a clear picture of the formal processes for admission, separation of patients, care and after-care in a CCC. They also mentioned (disapprovingly) that some families, after years of self-reliance in health, had been reluctant to send their members to a CCC in an early stage of Ebola. Patients in the later stages of Ebola are the most infectious, in part because symptoms such as vomiting and diarrhoea that produce body liquids are worse.<sup>34</sup>

*They hide patients and administer medicines to them. They only sound the alarm when the situation is at its worst. At that time they will call 117 for help, when it is too late.* (Rokupr, men's group, male, age 38, farmer)

CCCs were appreciated by people of all age groups. They have provided free and accessible care (including food) for patients and are believed to have helped to drastically reduce Ebola death rates:

*The CCC has helped to reduce the Ebola death rate in our chiefdom. It has also stopped our patients travelling far away to Bo, Kenema or Kailahun for treatment.* (Rokupr, youth group, female, age 22, farmer)

Like in Port Loko, people did not like all the processes involved – taking blood samples, isolating suspected cases, quarantining families with confirmed Ebola cases and conducting medical burials – however, in all groups and communities they clearly understood and respected the need for them. They also did not complain about the deployment of military personnel for the surveillance of quarantined families, but they resented the way dead bodies were managed and were keen to be more involved in the undertaking:

*The burial team puts the corpse into a plastic bag and buries it the way they feel.* (Funkunya, women's group, female, age 36, housewife)

*It would be nice if the government involves the family in the burial process to pray on the corpse and see where it will be laid to rest.* (Kambia district, elder's group, male chief, farmer)

## **Tonkolili**

### *Perspectives of implementing staff and authorities*

Tonkolili has had relatively limited Ebola transmission, with sporadic cases continuing at the time of fieldwork and with multiple ETU options close by. DERC and ETU staff were strongly against the CCCs, perceiving them to be unnecessary, unsafe and drawing nursing staff away from the PHUs:

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<sup>34</sup> D.G. Bausch et al. (2007) 'Assessment of the Risk of Ebola Virus Transmission from Bodily Fluids and Fomites.' *The Journal of Infectious Diseases* 196 (Suppl. 2).

*Consider in this district: 13 CCCs; about 105 medical staff and the same hygiene/support staff; 25 Concern staff working full time to support them; and most days there are between zero and two patients in all of these CCCs, who would have been better to call the alert line as they are supposed to and be transported immediately to the MSF or Lion Heart facilities where they have the best chance of survival if they test Ebola positive. These are amateur medical facilities which are working counter to the fight against Ebola. (DERC staff member, Tonkolili)*

*I'd go further and say the CCCs are positively dangerous in how they are 'marketing' themselves to local communities. They are doing this social mobilisation, telling people to come to them, trying to get business. But they are not well trained and they are encouraging people to be transported when they may have Ebola. During the height of Ebola they might have been useful. (DERC staff member, Tonkolili)*

Other government authorities at the district level complained about a lack of coordination, flexibility and cooperation between key partners. Government authorities' complaints centred on the importance of the paramount chief in deciding where the CCC would be placed, bypassing the normal decision-making channels:

*It was not an issue of us going to negotiate. They are here to implement a plan. (DERC staff member, Tonkolili, male)*

*The approach the partners took to implementing the CCCs was wrong. They should have approached the health partners first but they engaged the paramount chiefs and the community first. By the time they got to us they already had a plan. They had sites, and criteria for qualification. We wouldn't have had so many. We would have built them in strategic areas, like those which are hard to reach, or where alerts take a while. (Senior health worker, Tonkolili, male)*

Some suggested that local authorities and citizens could not say no to the paramount chiefs or to the international partners implementing the CCC policy. Some authorities suspected these chiefs had been misled:

*The paramount chief thought it was a hospital coming, so they were pleased. (DERC staff member, Tonkolili)*

Paramount chiefs did describe feeling powerless to stop the bureaucratic process once it started:

*The CCCs created more bureaucracy, together with the command and the alerts. But we are poor, we can't say anything. ... They said they would bring nurses. We thought they would bring nurses and doctors, like the ones from Cuba. (Chief, Tonkolili)*

INGO staff also felt that the concept of the CCCs couldn't be turned back once it had started:

*It seemed like it was a rolling train which no one wanted to stop. It was also a train which started moving late. (Health INGO, female)*

The CCCs were indeed allocated using traditional political structures. They were never intended to be treatment centres and CCC staff were supposed to encourage people to be transported if they might have Ebola. That there are just a few persons staying overnight might seem like CCCs are not needed, but low numbers might also mean that the triage and transport work well, indicating that people with symptoms get transferred before nightfall and do not need to be registered as patients.

The district-level authorities had negative perceptions about the expertise and skill of the staff in the CCC. They did not trust the staff to be able to deal with Ebola:

*The personnel are not trained. Over 80-90% are not trained. That doesn't make you feel secure – even trained people in Kenema and Kailahun died. (DERC staff member, Tonkolili)*

*They are going by protocols and are not qualified to consult sick people. (Senior health worker, Tonkolili, male)*

CCC implementing partners are more positive about their role, pointing to the high rate of triage and to changed perceptions in the community:

*It's in the name, 'community'. They are like a filter, to take Ebola patients out of the PHU. They were never designed to be ETCs. They've been able to refer many suspect cases. I think they've done their job. (INGO, Tonkolili, female)*

*We want to avoid people keeping the sick at home, whether it is Ebola or not Ebola. The CCC then decides which referral to make. We encourage people to come with Ebola-related symptoms, like headache, fever, pain. We do have lots of examples of people coming with fractures or other things. They don't always know what the CCCs are for. (INGO, Tonkolili, male)*

### *Community perspectives*

People in communities around the CCC in Marrah, Tane Chiefdom, and the nearby Makpakie village and those around the CCC in Mawolie, Kunike chiefdom, and Kunike Sanda near to Masiaka agreed with some of the planning and coordination issues. They raised some further concerns about how top-down planning in some instances reproduced and reinforced existing inequities in villages.

Communities confirmed that the decisions came from Freetown and went directly to the paramount chief who met with the landowning family (the Gbla lineage) to discuss the selection of the site for the CCC. In Marrah, local volunteers excavated local materials but these were never used or paid for. The landowning

family did not receive rent and none of their family members was selected to work:

*Nurse, doctors, etc., were employed by the DMO and other health authorities. But the other staff (like cleaners, sprayers, security people, cooks, etc.) were employed by the paramount chief through favouritism and nepotism. (Marrah, elder's group, male, age 40, farmer, brave)*

People knew the district medical authorities and the paramount chief had appointed staff and they had heard about rates of pay over the radio. Some were angry because none of their own people had been selected:

*We can make no statement about how people treat members of our families working in CCCs because no staff were employed from this village. (Makpakie, elders' group, male, age 47, religious leader, farmer, angry)*

*There was no local employment. All the staff were selected from far away, like Makeni, Magburaka, etc, through who knows you and not by qualification. (Marwolie, youth, female, age 20, farmer)*

The anger in villages was about political nepotism and was not directed at the medical staff or the medical professionals who had been brought in from outside.

Villagers both near and far the CCC expressed the view that the CCC had been useful in many ways and appreciated the medical advice and free care. They knew about Ebola symptoms, quarantine and how to call for help and an ambulance, case admission and rules for care, and knew of rehabilitation packages for survivors:

*The family consults the chief and he in turn will tell the contact tracers and call 117 to collect the sick. (Elders' group, male, age 55, community health worker, Tonkolili)*

*The nurses and the other workers give care to the sick at the CCC. Families can visit patients but are not allowed to enter the isolation areas. They stand at a distance to exchange words of greetings. (Mawolie, men's group, male, age 24, mason)*

*Survivors, as we are hearing, should get foam mattresses, food, oil, clothing to wear and other household materials. (Makpakie, youth group, female, age 12, student)*

Contrary to the authorities, villagers were very positive about the CCC management and quality of care. They contrasted the free care at the CCC with the user fees at the PHU. The provision of food for patients was appreciated:

*Patients are treated and fed for free whilst PHU patients are charged for such services. (Masiaka, youth group, male, age 16, student)*

*The CCC is very useful because patients can no longer travel far distances to get medical assistance. Staff at the centre treat patients with*



*great care.* (Mawolie, women's group, female, age 71, housewife, farmer, happy)

*Patients get free treatment, free feeding while as those at the PHU pay for the services rendered to them.* (Mawolie, men's group, age 60, youth leader, farmer)

*The CCC has greatly help to minimise the virus in the Tonkolili District.* (Masiaka, women's group, female, age 60, house wife, farmer, happy)

The rules for quarantine, safe transport, isolation and safe burial were widely known and accepted. However, the undertaking process upset people's sense of dignity and care of loved ones:

*The corpse should be washed, dressed in white cloth, prayers offered [over it], and gently buried in the hometown [of the deceased].* (Makpakie, elders' group, female, age 45, chief, farmer)

In sum, residents and authorities agree that they have been bypassed in the implementation of the CCC, but disagree about the overall relevance and use of the services provided. Residents value the CCC, the staff and the services while the authorities doubt the relevance and quality of the services.

## **Kono**

### *Perspectives of implementing staff and authorities*

The CCCs came relatively late in Kono.<sup>35</sup> It got five CCCs in total that were planned more strategically (i.e. based on a combination of epi data and location) than in the other districts. There were few complaints about the engagement process. However, as an ETU was also opening the purpose of the CCC was not entirely clear and some felt they were redundant:

*I get the sense that the purpose of the CCCs is not been well planned. Are they for overflow? Or space for isolations?* (DERC staff member, Kono district, male)

*The CCCs came too late, after the peak. There were lots of cases in November and December, but Kono was the last one to get any CCCs.* (senior health worker, Kono, female)

Partners in Kono reported treating non-Ebola related diseases in a context with limited health care outside of the CCCs. The CCCs were seen by some as a Trojan horse for wider health system reform.

*The people have seen the impact of the CCC and everyone is seeing that if the CCC continues then the problem of sick people will be addressed.* (Community health worker supervisor, Health INGO, Kono District, male)

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<sup>35</sup> Security incidents spiked also in neighbouring Guinea: Ebola situation report, 28 January 2015 (<http://apps.who.int/ebola/en/ebola-situation-report/situation-reports/ebola-situation-report-28-january-2015>).

The CCCs were also used to impose byelaws, such as checking that visitors were not sick, reflecting the distrust and security problems in the district.

*Everybody is a suspect – there is no trust.* (CCC worker, Kono, male)

### *Community perspectives*

The selection of CCC sites took place after consultation with paramount chiefs and district elders. Access from various chiefdoms to a CCC was important.

Water supply to the CCC can be a source of conflict. It was known and appreciated that UNICEF fixed a pump to supply water to the CCC. But in Condoma respondents reported that the placement of the CCC stopped local people from using their local water supply:

*[There was] a problem between the town community and the CCC on water supply. The CCC prevented the community from using the water well earlier used.* (Condama, women's group, female, age 43, farmer, happy)

As in the other sites the paramount chiefs took a lead in the recruitment of staff. Some youth volunteers in Condoma who had cleared the land thought they would get permanent jobs in the CCC and were disappointed when staff from elsewhere were employed. High payment for high-risk jobs was seen as fair. The employment selection procedures were seen as reasonable but not perfect.

*The councillor asked the chief to submit ten names from the village. The chief selected each person from the various tribes through their tribal heads. Only one person went through the interview process.* (Bambakunaya, elder's group, male, age 92, community leader, farmer, sad)

CCC staff were accepted by the community, with some reservations:

*Due to frequent sensitisation, the villagers treat the workers very nicely.* (Kono district, elder's group, male, age 45, chief, farmer)

*The treatment of staff by families will not be as cordial as before. This is due to the fear about the hazards of the virus through touching etc.* (Waima, men's group, male, age 35, farmer, curious)

Case management, including contact tracing and isolation of suspected cases, was supported by the paramount chief. Contact tracers moved from house to house in search of sick people and politely instructed them to go to the CCC. Their attention to detail – such as providing water bags for rehydration while people waited – was widely appreciated. The inclusion of families in the care at the CCC improved over time, allowing families to visit their sick relatives from a distance.

*The nurses, doctors and other staff take great care of patients at the centre.* (Bambakunaya, men's group, male, farmer)

*Ebola patients or Ebola suspected cases are all free of cost. Food is also free. There is more encouragement for patients than ever existed at the PHU. (Kono district, elder's group, male, age 51, religious leader, farmer)*

*Government and non-governmental organisations greatly assist the survivors. (Sawie, women's group, female, age 30, farmer)*

The work of burial teams and the relaxation of some rules was appreciated. People described how they were initially asked not to visit the burial site, but that rules have since been changed and 'distant' visiting of the burial is allowed. People knew and accepted that they would be informed of a death by phone, that quarantine was imposed on families with Ebola patients and were well aware of the case management procedures. But some people wanted to be more involved in the undertaking while others missed being able to pray and conduct burials for the dead in their home town (sometimes far away).

*We prefer burial team to wash and dress corpse, and allow family members to stay afar and offer prayers before taken to the cemetery in the presence of some family members for burial. (Bambakunaya, youth group, male, age 17, student)*

### **Question 2: Post-Ebola uses of CCC physical structure, equipment and staff**

Answers about post-Ebola uses of the CCC site, staff and equipment were revealing. CCCs vary in their construction and location: some are located in permanent buildings such as schools but others are in tents; they can be at varying distances to PHUs and schools, within villages or set away from them, on main roads or more out of the way.

Respondents suggested that items which are possibly infectious or somehow harmful should be destroyed, and the rest should be re-used in the village or PHU. Exceptions were made for items of high value such as generators:

*Burn the bed, foam [mattresses], close off the toilet and waste disposal, destroy all used equipment except the tents and electrical appliances. (Kunike Chiefdom, youth focus group)*

*Some items, like the rubber buckets, hand gloves and any other materials that were used in treating Ebola patients, should be destroyed and the other items should be repurposed in the PHU. (Magbema chiefdom, youth group, female)*

There was a great desire to send children back to school, for which thorough site decontamination will be important. Decontamination processes will also need to address the anxiety related to aspects of waste management:

*They gathered all the waste from the CCC along my sister's farm road, set fire to it and ran away. The suffocating smoke has made my sister to change her way to her farm. (Nimiyama Chiefdom, women's focus group)*

In focus groups and in interviews with staff at the CCC a strong desire for new hospitals (and in some cases schools) was expressed. Expectations have been raised and it is clear to all that pre-Ebola conditions were not adequate:

*We need change, we can't go back to the old system. We need well-fortified health centres.* (CCC worker, Port Loko district, male)

*The PHU is small, the CCC structure is bigger – if it could be built on, replicated and improved after Ebola it would be good for the chiefdom and the surroundings. The health system was deplorable before – no equipment, no lab, the PHU has no light or water. We have safety workers here but the PHU lacks that. They don't have people specialised in cleaning.* (CCC worker, Kono, male)

*There is no latrine, it is not hygienic – no hand washing, no water, no ward for admission. I have to sleep in the observation room. I would like to take hygienists to the PHU. Giving treatment in these conditions is difficult: with no light I can't put IVs in easily and there is nowhere to keep drugs but on the floor.* (Health worker, Kono district, male)

Significantly, views on the decommissioning, disinfection, and post-Ebola (re)construction included a prominent role for government. Several villages would like the government to disinfect the sites for re-use. Data showed mixed views on the management of the desired new physical structures. Some wanted these to be managed by local committees headed by the chief and suggested maintenance could be financed locally. Others saw management and maintenance as the responsibility of the government and did not mention the INGO that had supported the CCC, perhaps because the roles and contributions of the government and INGO were not clear.

This has implications for rebuilding trust in health systems and the state post-Ebola: it suggests that MoHS and government legitimacy has not been completely lost and that there are specific opportunities for strengthening it in the short term. The treatment of staff post-Ebola is one such area. Citizens widely support compensation for CCC staff and recognition of the efforts they made and the risks they took.

*Government should provide and facilitate jobs for them. Let the president find jobs for them.* (Kunike chiefdom, youth group)

*Government should pay them off.* (Kunike chiefdom, youth group)

People recognise the value of the new knowledge on hygiene and Ebola which staff at the CCCs and communities have gained. The integration of this knowledge into the health system is another dimension of the post-Ebola recovery. Nurses employed in the CCCs speak of the potential for improvements in the post-Ebola health system:

*I will go back to the PHUs. We are trained to work in the PHUs. I've learned a lot here – how to take precautions – I will implement them in the PHU. I'll go back and improve it. I've learned about how to handle a*

*patient without contact, about Ebola transmission, about IPC – we had IPC before but now we have more knowledge. We will implement it – if we have the equipment. (CCC health worker, Kambia District)*

People fear that the process will not be managed well, with a return to business as usual. The point was most vividly expressed in the expectation that there will be more corruption because the staff in the CCC will have got used to ‘fabulous’ money and will become thieves or ‘peppeh doctors’.

A number of respondents drew parallels between the decommissioning of the CCCs and the Ebola ‘fighters’ who worked in them with the disarmament and rehabilitation process after the civil war:

*During the war, materials like armoured cars and guns were brought to this country and were burnt after the war. Therefore any material which has a connection with the Ebola should be destroyed after. (Kunike chiefdom, elders group)*

*After the war, DFID and the donors gave things to children and ex-combatants like scholarships and recreational facilities. We think it will also happen to the Ebola fighters. (CCC worker, male, Port Loko District)*

Calls for jobs, scholarships and compensation for ex-CCC staff were also justified in relation to post-war precedents around help for amputees and ex-combatants.

## **REFLECTIONS**

This section answers the ‘so what?’ question at different levels – donors, programme implementation partners, national stakeholders, CCCs, community beneficiaries and other stakeholders. While the CCCs were an innovative part of the Ebola response strategy, the criticisms that they were part of a parallel health system, that they aggravated or created coordination problems and that they suffered from mission creep are familiar from other health emergencies. This raises questions about the justification of ‘Ebola exceptionalism’ and points to the need to think carefully about re-organising health systems and engaging communities living in an Ebola-affected context.

People’s acceptance of the CCCs demonstrates that it is not hard to win them over if good and affordable services are provided. Even with unhappiness over staff and site selection, the benefits of the CCCs were recognised.

Fear and mistrust of health systems may have been overstated and assumed to be more ingrained than it was. Reduced attendance at PHUs and hospitals could have had multiple causes: fear of catching Ebola through lack of triage, fear of being misdiagnosed, unhappiness about poor quality or undignified care, or suspicions about the intentions of health care workers. The construction of CCCs dealt with some of these fears but the same results might have been achieved if resources had been put into the PHUs to provide similar free coverage.

Health-seeking pathways are still quite varied, with multiple options for people with suspected Ebola. The CCCs' role is now unclear: potentially confusing for Ebola suspects, and a stumbling block for the recovery of the health system. Aside from expectations about new hospitals, people want and need better quality health care, including transport. The CCCs demonstrate this is not something which needs to be community 'owned', but it must meet community needs. Communities understand and value biomedical expertise, and they appreciate this when combined with attentive staff and arrangements which mean quality health care is available to all and not restricted to particular illnesses or categories of people.

Lack of trust has been much discussed as a driver of the Ebola epidemic, with people's fragile trust in authorities being pushed to breaking point.<sup>36</sup> There is also evidence on the importance of trust in authorities in community engagement from other Ebola epidemics.<sup>37</sup> This evaluation found widespread complaints in the community about political nepotism during the process of setting up the CCC, especially with regards to employment. There was a sense in many communities that a few people are in charge of every decision made, and have the power to be rid of whomever they choose. This contrasts with the findings of another CCC evaluation which focused on the quality of care in centres.<sup>38</sup> This suggests a difference in the perspectives of insiders and outsiders in relation to the CCC. Those in the community who do not directly benefit watch those inside the CCC who do with a mix of envy and distrust distinct from their desire to have free access to health services. In a context with such inequality this is not surprising. However, it points to the need for beneficiary feedback in evaluation<sup>39</sup> and for transparency in the process of transition and CCC decommissioning to avoid deepening these inequalities and distrust.

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<sup>36</sup> P. Richards P, et al. (2015) 'Social Pathways for Ebola Virus Disease in Rural Sierra Leone, and Some Implications for Containment' *PLoS Negl Trop Dis* 9(4); A. Wilkinson and M. Leach (2014). Briefing: Ebola—myths, realities, and structural violence. *African Affairs* (<http://afraf.oxfordjournals.org/content/early/2014/12/04/afraf.adu080.full.pdf>).

<sup>37</sup> Hewlett and Hewlett (2006) Op. cit.

<sup>38</sup> They found that 'Staff from the Ministry of Health and Sanitation, implementing partners, staff at community care centres, and community members noted that the model was acceptable and feasible'. See S. Michaels-Strasser (2015) 'Innovation to confront Ebola in Sierra Leone: the community-care-centre model.' *The Lancet Global Health* 3(7) ([www.thelancet.com/journals/langlo/article/PIIS2214-109X%2815%2900045-5/fulltext](http://www.thelancet.com/journals/langlo/article/PIIS2214-109X%2815%2900045-5/fulltext)).

<sup>39</sup> L. Groves (2015) Beneficiary Feedback in Evaluation. DFID ([http://r4d.dfid.gov.uk/pdf/outputs/Evaluation/Beneficiary\\_Feedback\\_in\\_Evaluation.pdf](http://r4d.dfid.gov.uk/pdf/outputs/Evaluation/Beneficiary_Feedback_in_Evaluation.pdf)).

## ANNEX 1

### TERMS OF REFERENCE

#### Community-based Ebola Care Centres

#### DFID

### 1. Introduction

#### *Background*

Current Ebola epidemic control policy in Sierra Leone focuses on (a) triage and isolation in decentralised Community Care Centres (CCCs) or Holding Units, leading to (b) transfer to Ebola treatment units (ETUs) for those diagnosed as positive.

This formative evaluation examines the CCC with DFID plus implementing partners (UNICEF, PLAN, Partners in Health) in the western area, Port Loko, Tonkolili, and Kono.

### 2. Objectives of the evaluation

The main objective of the evaluation is to review progress of the project to date to engage communities in decentralised Community Care Centres (CCCs) or Holding Units. The evaluation will pay particular attention for community engagement, learning and innovation, community relevance and also discusses the policy interpretation and implementation process at different levels. It should provide pragmatic recommendations for the remaining project period. Key lessons from this response will be identified. Although a full cost-efficiency analysis of the program is outside of the scope of this evaluation, the sustainability and unintended side effects – positive and negative – of the current approach will be analysed.

The evaluation will pay specific attention to the ways an ‘outbreak/medical model’ of response has affected how the community viewed this response and the intended and unintended consequences. Was this done *with* them or *to* them? The evaluation will take heed of the many different interests based on class, gender, political affiliation, lineage that exist within a community. The evaluation will help to:

- a. Look back: what methods of community engagement have been used, did they work and how did this affect attendance and (if possible)
- b. Look forward: What are communities views on how to use the CCCs in the future if/when the epidemic wanes and we enter our ‘lumpy tail’ stage. What do they think should happen to all the money, people and things which have gone into Ebola vis a vis rebuilding the health system? Do they want them for

social mobilisation, do they want them taken down, do they want them kept open if hotspots/outbreaks return?

### 3. Methods

This evaluation will complement the formal evaluation both in methods and in approach. This evaluation will use rapid ethnographic and participatory methods rooted in epidemiological and programmatic realities.

We propose to use the following steps and methods:

#### I. Finalise the evaluation plan

In order to rapidly operationalise the specific evaluation questions and design an effective, feasible and mutually agreed evaluation plan, our evaluation would start with a desk review of the internal program documents and reports and a focused literature review of key documents on the context.

We will also interview and exchange information with key persons by skype or phone. This would not require more than can be done in a few days and some of it could, if necessary, be conducted concurrently with initial fieldwork.

This phase would have the following objectives:

2. Determining the availability and suitability of data on which to base the evaluation
3. Discuss initial findings from the desk review, clarify key evaluation questions, seek input for specific interview topics, further develop methods and reporting formats, decide on the field visit sites and select the case studies
4. Identify key informants for interviews, focus group discussions, site visits, and other meetings.
5. Build rapport and achieve stakeholder buy in.

#### II. Data collection in the field

**Key informant interviews** with a broad range of stakeholder groups, including international partners and community leaders. These include but are not limited to caretakers, community leaders, non-formal health providers, ebola survivors, their families and children (esp age 10-14 - old enough to know what is going on, young enough to be potentially more open at talking to anyone who wants to hear their opinion).

**Rapid ethnographic study approaches** are more likely to give valid and useful information about changes in perception and practice, including *why* this has occurred. Methods used during the rapid ethnographic study will be tested in the field and include some or all of the following:



- group discussions on community engagement on Ebola care and the centres within a wider health system context
  - One group with elders
  - One group with men
  - One with women
  - One with youth
- Political decision and system mapping.
  - Map out voting and holding office in traditional and constitutional political institutions and the links between these systems. Did the decision making process with regards to CCC site, building and staffing differ from the way decisions normally are or should be made?
- Observe daily life especially livelihood/education/social life
  - Livelihood
  - Accessibility
  - Living conditions
  - Visibility of Ebola messages and prevention activities/initiatives

### III. Feedback meetings

Prior to departure the team will present some preliminary findings, discussion and clarification points with key stakeholders to validate and adjust findings.

## 4. Timing and resources

The field mission will take place in early January with a view to providing a draft report by the end of January/mid-February.

A debriefing meeting with DFID and other key stakeholders will be held in Sierra Leone immediately on completion of fieldwork to discuss preliminary headline results

DFID will assign one focal point for the evaluation who is responsible for all interactions with the team.

We expect the field mission to be a maximum of 14 days in Sierra Leone, including the feedback meeting.

A further 12 days after the fieldwork is allowed for report writing and an additional two days for a workshop in Sierra Leone after the first draft of the report has been prepared in order to take account of feedback.

## 5. Field coordination

The DFID focal point of this evaluation will be responsible for helping to coordinate the field mission in Sierra Leone in mutual agreement with the team to allow to respond to a changing context including:

- Provide the team leader with a security briefing and support the team with other essential security measures in line with the security situation in Sierra Leone.
- Arranging two meetings with its counterparts. One meeting at the beginning of the evaluation to share information and reach agreement on tasks and facilitate expectation management. A second meeting takes place at the end of the visit, to share and triangulate finding and discuss dissemination and other post-evaluation steps.
- Collect key internal documents such as program proposals, progress and financial reports which the team is expected to read
- Compile contact information at the sites and of key partners
- Prepare the permits and passes for the team to be able to travel by road.
- Coordinate consolidated feedback to the draft report.
- Discuss any issues that emerge during the evaluation with the team in a constructive and amicable fashion to reach agreement on solutions

## **6. Coverage**

The evaluation is expected to cover Western Area, Port Loko, Tonkolili and Kono. However, a final decision on the sites will be made during the inception phase.

## **7. Sensitivity to vulnerable populations and ethical issues**

The evaluation team has in-depth and hands-on expertise working with vulnerable populations and longstanding research experience in Sierra Leone. We are aware that Ebola related stigma, fear and discrimination has to be understood within a broader context of structural political and economic inequities. We also know that collecting data for a review on health emergency programs like these is particularly challenging due to time and logistical constraints.

We will work discretely and in close collaboration with the program staff and the local leaders such as the paramount chiefs and district authorities. Participation will be voluntary, anonymous, and confidential. Informants and respondents will be briefed on the purpose of the project and the way data will be used, and can leave at any moment of the discussion. Informed verbal witnessed consent is required for every participant. Written consent is not meaningful and inappropriate for an illiterate population. People may feel pressured or scared to sign which can then result in rumours and fear especially in this current context. Rather than writing down people's names we will use cards with numbers during focus group discussions and we note personal details (sex, age, village for example) that have been mutually agreed upon before starting the discussion.

Men and women will be interviewed separately to reduce the risk of gender based silencing of women. We are aware that there are other power differences within a communities which give some people a bigger voice than others. By

working with a very experienced and well-trained team of research assistants that has already worked on Ebola we increase our cultural sensitivity to these power dynamics and this specific context.

A small gift may be provided to communities as a sign of appreciation for their time and efforts. This will be done in discussion with local researchers and leaders to avoid setting possible negative or disruptive precedents.

The data will be entered onto password protected computers. Notes and questionnaires will be locked during data entry in Sierra Leone and they will be taken out of the country afterwards.

## **8. Other coordination**

The consultant/s will arrange own visa and insurance and flights to Freetown. DFID will arrange suitable transport for the field team during their fieldwork.

## **9. Report**

The team will be responsible for delivery of a draft report and Executive summary written in English and submitted within 21 days of finalising the fieldwork. The report must be confined to the specific objectives of the mission and should not be more than 25 pages, excluding Annexes. Recommendations have to be prioritised using SMART approaches to programming and be limited to 8. In addition the team is expected to use its expertise to identify wider contextual issues that can affect long-term program results but may not be within the responsibility or authority of the current program.

Recommendations will be grounded in literature and reflect expertise of the team prior to this mission. However recommendations will mostly be based on empirical evidence gathered during the course of the mission. The response review findings are those of the author. Any communication on the findings will make it clear that the report reflects the opinions of the authors alone and not those of DFID. The report will be made publicly available by DFID within a month after the final report.

## **Team Profile**

A small team, preferably with Sierra Leonean nationals, with multidisciplinary backgrounds in monitoring and evaluation, health and anthropology, and community engagement. The team will also be able to mobilise and recruit experienced local assistants with diverse language skills to facilitate direct engagement with communities, especially those with limited formal schooling.

Key skills and abilities for the team:

- Previous experience in formative evaluations of complex multi-stakeholder health programmes

- Methodological expertise with participatory and result oriented evaluation methodologies
- A sound understanding of the context and social and psychological responses to the Ebola outbreak
- In-depth knowledge of the Sierra Leonean context
- Previous experience in the design and management of health emergency programmes, with focus on medical, community health and behaviour change response.
- Demonstrated ability to Knowledge of human rights in humanitarian and health settings and familiarity with humanitarian codes of conduct
- Excellent verbal and written communication skills in English

## ANNEX 2

### Community-based Ebola Care Centres Evaluation (ERAP) FGD theme list

The review explores two broad areas: (1) Community engagement in the development and usage of CCC during the Ebola outbreak (2) Community preference on post-Ebola usage of the CCC.

#### Community engagement

How have communities been engaged in the development of CCC during the Ebola outbreak with regard to:

- *Site selection*  
How has this site been selected and why? Why was this place chosen? How have the water supply and waste disposal been discussed? Were there alternatives? Who were involved in the decision making at what moment? What are the advantages and disadvantages of this site? Who owns the land? Has there been payment? How should a CCC site be selected? How were differences in ideas and interests dealt with?
- *Staffing*  
Who works in the centres? How have they been selected and why? Who made the decisions? How does their family treat them? What do you think of the payment? How should staff be selected, paid and evaluated? How were differences in ideas and interests dealt with?
- *Case management and the family*  
Who decides who should come to a CCC and how? What is the role of family in the care giving of patients at the CCC? Who gives care? How do patients get to a CCC? Can families visit? How should families be involved in the care of Ebola patients –at home and in a centre? What support do survivors and their families get? What do they need? How were differences in ideas and interests dealt with?
- *Body management*  
How do you know that somebody died of Ebola? What happens when somebody dies in the centre? How would you like to be informed? How would you like the CCC to be involved in the management of bodies? How were differences in ideas and interests dealt with?

#### Post-Ebola usage of the CCC

How should the CCC be used in the future if/when the epidemic wanes? What should be done with:

- 1) *The building.*  
Destroy or Repurpose? What would be a good use of this plot of land and this building? What contributions could communities make –if any? Who should manage the building? Who pays for maintenance? How about disinfection? Looting?
- 2) *The staff.*

What do you think will happen with the staff at the CCC? How would they be remunerated for their services? Will they face problems when they stop working in the CCC? What can staff do with the skills they have gained?

3) *The equipment.*

What equipment is there? Destroy or Repurpose? Who should manage the equipment?

**Relevance**

Has the CCC been useful? Tell us what you use the CCC for? What is the difference between a CCC and a PHC? What do you like about CCC and about PHC? Would you recommend other communities in Sierra Leone to have a CCC? What would you tell them to do? What should they not do?

## **ANNEX 3**

### **Community-based Ebola Care Centres Evaluation (ERAP)**

#### **Individual stakeholder interview semi-structured themed question list**

The review explores two broad areas: (1) Community engagement in the development and usage of CCC during the Ebola outbreak (2) Community preference on post-Ebola usage of the CCC.

#### **Community engagement**

How have communities been engaged in the development of CCC during the Ebola outbreak with regard to:

- **Site selection**  
How has this site been selected and why? Why was this place chosen? How have the water supply and waste disposal been discussed? Were there alternatives? Who were involved in the decision making at what moment? What are the advantages and disadvantages of this site? Who owns the land? Has there been payment? How should a CCC site be selected? How were differences in ideas and interests dealt with?
- **Staffing**  
Who works in the centres? How have they been selected and why? Who made the decisions? What do you think of this work/job? How does their family treat them? What do you think of the payment? How should staff be selected, paid and evaluated? How were differences in ideas and interests dealt with?
- **Case management and the family**  
Who decides who should come to a CCC? What have been bottlenecks in transport of patients? What is the role of family in the care giving of patients at the CCC? Who gives care? How do patients in more remote villages get to a CCC? How should families be involved in the care of Ebola patients –at home and in a centre? What support do survivors and their families get? What do they need? How were differences in ideas and interests dealt with?
- **Body management**  
How do you know that somebody died of Ebola? What happens when somebody dies in the center? How would you like to be informed? How would you like the CCC to be involved in the management of bodies? How were differences in ideas and interests dealt with?

#### **Post-Ebola usage of the CCC**

How should the CCC be used in the future if/when the epidemic wanes? What should be done with:

- 4) **The building.**  
Destroy or Repurpose? What would be a good use of this plot of land and this building? What contributions could communities make –if any? Who

should manage the building? Who pays for maintenance? How about disinfection? Looting?

5) *The staff.*

What do you think will happen with the staff at the CCC? How would they be remunerated for their services? Will they face problems when they stop working in the CCC? What can staff do with the skills they have gained?

6) *The equipment.* What equipment is there? Destroy or Repurpose? Who should manage the equipment?

Can you draw a map for me of the CCC in the health system?