POLICY BRIEFING ON
Community-based Ebola Care Centres
AUTHORS: Pauline Oosterhoff, Annie Wilkinson, Esther Yei-Mokuwa
Ebola Response Anthropology Platform
February 2015

A 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 positive. The epidemic is currently waning, there are sufficient beds in the ETU, yet new micro-epidemics emerge, raising questions about the future role and relevance of the CCC.

This briefing summarizes the preliminary findings of a formative evaluation conducted by the UK based Ebola Response Anthropology Platform in February 2015 on views of community leaders and residents towards 1) their engagement with the development and management of the CCC and 2) future usages of the CCCs physical structure, equipment and staff. A full data analysis is ongoing. We hope that the views presented here provide various options for the use of the CCCs during the bumpy road to zero.

Methods: A Sierra Leonean research team with an appropriate mix of local language skills visited 14 villages in 7 chiefdoms in Port Loko, Kambia, Tonkolili and Kono. Two villages were selected in each chiefdom: one which was hosting the CCC (or closest to it) and one which was in the same chiefdom, so plausibly part of the CCC catchment area. 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 Committee (DERC) and Paramount chiefs. At each site teams held group discussions with elders, men, women, and youth focusing on community engagement and perspectives on the CCCs. A total of 1,031 participants joined the discussions, amongst whom 688 participated actively. An international researcher conducted 78 semi-structured interviews with health authorities, district medical officers (DMO), DERC representatives, implementing partners, CCC staff and primary health unit (PHU) staff in Freetown, Port Loko, Kambia, Tonkolili and Kono. The findings reported below are based on a preliminary data analysis of the anonymized data.

Partner perspectives and policy debates concerning the CCCs

The CCCs were conceptualised at a time of great uncertainty. Models predicted cases into the millions and there were shortages of beds. Interviews found divergent opinions on their role and function, differing across districts and reflecting patterns of EVD transmission and the availability of EVD facilities and services such as ambulances and treatment units. UNICEF officials explained they were conceived of as a form of 'risk management', a place to isolate people which was safer than home or holding centers. In addition to admitting patients, they were to be focal points for community based disease control including safe beds, case finding, and social mobilization.

"*An objective was to re-establish the PHUs by taking the Ebola patients away from them"* (CCC Technical Lead, UNICEF, Freetown).

In Port Loko CCCs opened when there was high transmission and limited treatment options so they performed much of their original function

> *"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 had the perception you would die there. People have stopped having these fears now there is a centre (Paramount chief, Koya chiefdom, Port Loko, male)*

In areas like Kono and Tonkolili they arrived later when treatment centres and ambulances were more organised. This meant in some areas they were "redundant from day one" (DEST/DERC staff, Kono district) or that they shifted to performing triage and referral functions as opposed to inpatient care. There was

agreement from DERC officials and implementing partners that the CCCs needed to be scaled down. Some advocated the need to keep a few open until the epidemic was over, especially those in more remote areas where the transport time to treatment centres was longer. Some interviewees saw them not just as redundant but to making matters worse:

> *"Consider in this District: 13 CCC's; 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 2 patients in all of these CCC's, 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" (Humanitarian advisor, Tonkolili DERC)*

Observations at CCCs and interviews with CCC staff and implementing partners revealed a broadening of the CCC concept with the CCCs now fulfilling a wider and more significant role than originally anticipated by providing free health care to villagers for diseases other than Ebola:

> *"They are Community Care Centers. They are not just for Ebola, it doesn't need to be Ebola related, but people should just come for check-ups. We are encouraging them to come. That is how we have been able to dig out the isolated cases. That is the idea of the CCC. Everybody should feel free to access these facilities, it is not just for Ebola. They are primarily for the community to access health facilities."(CCC clinical manager, Marie Stopes, Kambia, male).*

Partners in Kono and Port Loko also reported treating non-Ebola sicknesses. In part this may be a strategy to dig out Ebola which has non-specific symptoms, but it also relates to the lack of healthcare outside of the CCCs, perspectives on medical ethics, obligations and capacity to treat people who are sick.

Exploring community perspectives in light of stated policy objectives and implementation processes raises issues about the coordination and coherence of Ebola response services, the allocation of resources during crises and the implications of the decision to set up parallel health services.

Question 1: Community engagement with the development and management of the CCC

The site selection of the CCC though the paramount chiefs followed the traditional political decision making process, and usually included a well established set of 'stakeholders' (paramount chiefs, section chiefs, town chiefs, youth leader and women's leader). A key finding is that usage of these hierarchical political structures was simultaneously appreciated and resented at the village level. People feel that the paramount chief had to be involved in decisions regarding the establishment of public facilities. However, some chiefs exercised their influence in ways deemed to be unsatisfactory and which was felt to result in disadvantage for some. There were complaints that landowners were not consulted about the use of their land, with suggestions in some sites that scores were being settled.

Staffing was an area where power – of chiefs and authorities – was suspected to have been abused. The establishment of the CCCs created expectations of financially compensated work which were not met. The allocation of paid employment was seen as unfair, particularly after local people contributed labor. Some hinted that employment was based on bribes or favoritism of the paramount chief.

> *"Before the establishment of the CCC, the officials told us that they'll employ workers from our village. But when the preparatory work was finished, and the CCC would be opened only the councilor and the Mamie Queen did the selections. The councilor 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 employed by the authorities from Matotoka and Freetown. That is because they are relatives to them and some are their children wives or girlfriends. They used their authorities and powers 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 during the employment stage" (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. However these complaints have implications for how community 'owned' the CCCs are, and points to limitations in the ridged 'stakeholder' cascaded model of engagement. It was notable that people taking part in the focus groups conducted 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 playing – the more CCCs are is established, the more Ebola will stay" (Kunike Chiefdom, women's group)*

Cascaded information and benefit transfer models may have enabled rapid CCC establishment 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 staffing 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 clearly to intended beneficiaries is vital in an emergency response although it may not alleviate structural reasons of suspicion. It should also be noted that the management of natural resources has also been upset 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 talks to them to not 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)*

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 have seen people return cured both from 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 now seen as a place to go for (free) consultation for diseases, including Ebola but not necessarily limited to it. The CCCs may not be seen as specific for Ebola but they are understood as places where one gets access to specific treatment pathways, one of which is Ebola.

"We can now freely go to the CCC without no fear or hesitation" Any other sickness (in addition to Ebola) can be treated at the CCC". (Nimiya Chiefdom, women's focus group discussion)

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

Memories from earlier times when patients were taken to distant treatment centres in Kenema or Kailahun, many without coming back, are still fresh. The establishment of CCCs and treatment centers within each district is therefore welcomed. Care at the CCC differs from that in the PHU because it is free to all. PHUs are strongly associated with maternal and child health, 'mammi-pikin wellbodi', an association made stronger by the Free Health Care Initiative for pregnant and nursing women and children under 5. The CCCs provide healthcare for people who are not covered by this and would usually pay out of pocket fees. Overall CCCs are viewed as providing access to disease specific care pathways (triage, tests and referral); prompt treatment; encouragement and free medicine.

It is not clear to what extent there were lingering fears of visiting Primary Health Units (PHU) and if and how CCCs have influenced that. It is clear that people's appreciation of their local CCC is not only (or even primarily) on account of their safe management of Ebola. This finding suggests that trust building in the PHUs and hospitals will be a longer process that might require considerable health system wide investments. However, people do respond quickly to first-hand experience and observation to overcome initial fear and renitence. The acceptance of CCCs suggests that there was nothing so deep seated about people's fears of existing health facilities that could not be overcome with the provision of free triage and prompt care by kindly and well trained staff. This may be coloured by the fact that Ebola transmission has slowed in most places. Therefore, fears that CCCs may bring Ebola to communities have not been confirmed and neither have CCCs been implicated in the vast numbers of deaths (e.g. people dying after being admitted and or transferred through a CCC).

There is considerable community level action around Ebola though its integration with the CCCs is not always clear. People are aware of key Ebola symptoms suggesting that health messages have diffused but arrangements for managing suspect cases in communities varied. People spoke of taking people with Ebola symptoms to the chief, or to members of the task force or calling for an ambulance to be taken directly to a treatment centre rather than to a CCC. The team observed suspect patients presenting to both the PHUs and to CCCs. Staff at DERCs indicated that direct transfer to treatment centres was now the preferred pathway as, with the existence of empty beds in treatment centres, admission to the CCC caused unnecessary delays.

Question 2 Post-Ebola usage of the CCCs physical structure, equipment and staff.

Questions about post-Ebola usage of the CCC site, staff and equipment were revealing. CCCs range in their construction. Some are located in permanent buildings such as schools but others are in tents. They can be close to PHUs and schools, within villages or set away from them, on main roads or more hidden. Location has implications for post-Ebola usage.

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. Distinctions were made especially 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 like the rubber buckets, hand gloves and any other materials that were used in treating Ebola patients should be destroyed and the other 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 anxiety produced by the full range of CCC activity, for example the management of waste.

> *"They gathered all the wastes from the CCC along my sister's farm road and set fire on them and ran away. The suffocation has made my sister to chance her way to her farm". Nimiya 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 may have been raised, but it is also 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" (cleaner in CCC, Koya chiefdom, male)

Significantly, views on the decommissioning, disinfection, and post-Ebola (re)construction included a prominent role for government. Several villages would like disinfection to be done by "government" for re-use. Data showed mixed feelings and 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 who 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 and it suggests 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 and recognition of the efforts that all staff at the CCC made and for risking their lives.

> *"Government should provide and facilitate jobs for them". Let the president find jobs for them (Kunike Chiefdom, Youth Group)*
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> *"Government should pay them off" (Kunike Chiefdom, Youth Group)*

There is recognition of the value of the new knowledge on hygiene and Ebola which staff at the CCCs and communities have gained. The integration of this 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 do the precautions, I will implement them in the PHU. I'll go back and improve it. I've learned 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" (nurse, Rokupr CCC, Kambia)*

There are some signs that people fear that the process will not be managed well, with a return to business as usual, specifically in the field of health a the lack of regulation and oversight. The need for proper monitoring was often mentioned but the point was most vividly expressed in the apparently widespread expectation that there will be more crime post-Ebola because the staff in the CCC will have got used to 'fabulous' money and will become thieves or 'peppeh doctors' in order to retain the lifestyle they've become accustomed to.

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

> *During the war, materials like armour 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)*

Calls for jobs, scholarships and compensation for ex-CCC staff were also justified by a post-war precedent for investments in amputees and ex-combatants.

Implications and reflections:

- Acceptance of the CCCs demonstrates that it is not hard to win people over if good 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 over simplified and assumed to be more ingrained than it was. Reduced attendance at PHUs and hospitals could have had multiple causes e.g. fear of catching Ebola through lack of triage, fear of being misdiagnosed, unhappiness about poor quality or undignified care, suspicions about bad intent from healthcare 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
- Health seeking pathways are still quite varied, with multiple options for Ebola suspects - the CCCs role is now unclear, and potentially a confusion for Ebola suspects and a stumbling block for the recovery of the health system
- Aside from expectations about new hospitals, people need and desire improved quality healthcare including transport. Surprisingly, 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 healthcare is available to all and is not restricted to particular illnesses or categories of people.

Recommendations:

- Replace top-down cascade models of the transfer of material and immaterial goods with multi- level approaches.
- Verify land and water usage rights and ownership of the plots where CCC - or any future community based facilities - are located. Decommissioning could include establishing whether there have been abuses and negotiate compensation for this
- Organize joint M&E and stock taking with local committees of trusted people to map out the contributions that have been made to improve transparency and accessibility. Committees inform results in public
- Link with and coordinate with INGO, UN and state livelihood and employment programs to facilitate transition. Work with local committee to inform residents and staff on available future packages- including compensation for CCC land use.
- The CCCs symbolize that the Ebola epidemic is ongoing. Decommissioning and decontamination needs a clear and comprehensive information and engagement strategy to explain what their destruction means and to manage expectations. Use "show us don't tell us" approaches and focus on process not only outcomes.
- Engagement and reconstruction strategies should recognize and build on local villager's ability to respond to a health emergency, change behaviors and initiate practical and strategic actions.
- PHUs associated with 'mammi-pikin wellbodi' and CCCs with general health for all. Consider strategies moving towards universal health care at PHUs > expand 'mammi-pikin wellbodi'.
- Invest in triage and outbreak capacity in PHUs to build/transfer confidence gained in the CCCs