

Comprehensive Program for Ebola Survivors

Endline Report

September 2018









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JSI RESEARCH & TRAINING INSTITUTE, INC.

1616 Fort Myer Drive, 16th Floor

Arlington, VA 22209 USA

Phone: 703-528-7474 Fax: 703-528-7480

Email: info@advancingpartners.org

Web: advancingpartners.org

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BACKGROUND

Project Overview

Distribution of EVD Survivors

PROJECT OVERVIEW

In late 2015, the government-mandated Comprehensive Program for Ebola Survivors (CPES) was established as part of the key interventions within the Post-Ebola Recovery Strategy. The CPES program, co-led by the Ministry of Health and Sanitation (MOHS) and Ministry of Social Welfare, Gender and Children's Affairs (MOSWGCA), was to improve the well-being of Ebola virus disease (EVD) survivors by providing basic and specialized health care and support to recover their livelihoods. Survivors were also included in the existing Free Health Care Initiative (FHCI) program, already offered to children under five, and pregnant and lactating women. This decision aimed at allowing survivors to access public-sector health services without cost.

With the CPES program, the MOHS embraced the responsibility of ensuring that the health system in Sierra Leone is equipped and able to respond to the specific needs of EVD survivors in a comprehensive manner.

The program is also supported by the Sierra Leone Association of Ebola Survivors (SLAES), which has helped operationalize the activities and facilitate access to improved clinical and social services.

Starting October 2018, key program advancements, human resources, and health care services are expected to be integrated within the MOHS service delivery and public health management structures.

The CPES program is an integrated partnership approach between Government, development, and implementing partners, which strengthens service delivery to EVD survivors, contributing to improvements in the survivors' overall well-being.

The CPES program:

April 2016-September 2017 Supported through a combination of the UK Department for International Development-funded Ebola Survivor Care Consortium (ESCC), led by GOAL; and the USAIDfunded Ebola Transmission Prevention and Survivor Services (ETP&SS) program, implemented by JSI Research & Training Institute, Inc. (JSI) in partnership with Save the Children (SC), Partners in Health (PIH), King's Sierra Leone Partnership (KSLP), and GOAL. Phase 1 The ESCC project support to CPES, which concluded in September 2017, was implemented nationwide (except in Bonthe district) by consortium implementing partners (IPs): GOAL, PIH, Medicos Del Mundo (MdM), International Medical Corps (IMC), SC, World Hope International (WHI), Welbodi Partnership, and KSLP. All partners worked with the MOHS, MSWGCA, and the World Health Organization (WHO)1. October 2017-September 2018 Transitioned from an implementing partner-led program Phase 2 to a Government-led one, supported by the USAIDfunded Advancing Partners & Communities project (Advancing Partners), with national coverage.

¹ Bonthe district was excluded because there were no EVD survivors recorded in the district. Furthermore, until May 1, 2017 Western Area Rural and Western Area Urban districts have been considered a composite district (Western Area) instead of two district districts.

PROJECT OVERVIEW

As the program developed, the MOHS recognized that many of the health issues facing EVD survivors, such as mental health, eye complications, etc., were also common for the general population, as well as other FHCI vulnerable population groups.

Phase 1

CPES activities were led and coordinated by a district coordinator and implemented by survivor advocates (SAs) and their survivor advocates supervisors (SASs), providing psychosocial support to survivors at the community level and facilitating their access to health services; clinical training officers (CTOs) in charge of providing clinical mentorship at the primary care level; and referral coordinators (RCs) at secondary and tertiary hospitals facilitating referrals through the continuum of care. All the positions were managed by the IPs, with oversight from the CPES Program Implementation Unit (PIU) and technical support from Advancing Partners.

EVD survivors were supported in:

- Accessing free medications at private pharmacies across the country
- Accessing higher level of care through financial support for transport and accommodation
- Accessing services not covered under the Free Health Care Initiative

These interventions sought to restore EVD survivors' confidence in the health system, ensuring that special health needs of EVD survivors were addressed.

However, feedback received by the MOHS and other stakeholders suggested that the program should have been more aligned with other MOHS priorities, including the FHCI and Community Health Worker (CHW) program; and be integrated within the broader MOHS health service delivery system and public health management structures.



PROJECT OVERVIEW

Changes were made to promote self-reliance and enable the integration of the CPES-supported health services and human resources within the MOHS system, and the EVD survivors within the FHCI.

Phase 2

The second phase implemented key changes to ensure better integration of EVD services within the MOHS service delivery and health management structures. With regards to human resources, the program embedded CTOs and RCs within the MOHS district-level structures, District Health Management Team (DHMT) and district hospitals respectively, ensuring that the line management of these positions is placed under key MOHS staff at the district level (e.g., District Health Sister and Hospital Superintendent). Further, the program contributed to transitioning the roles of SAs and SASs to CHWs to enable further integration of survivor care within the broader MOHS primary health care system.

Looking at the lessons learned and feedback from Phase 1, the program:

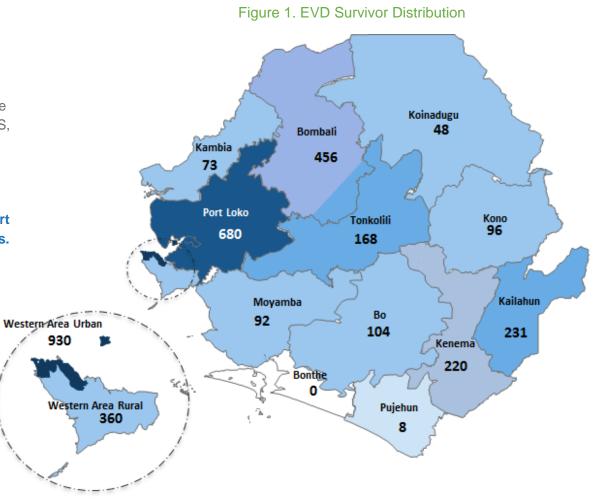
- Broadened the target group to include other FHCI populations
- Shifted the supply of medicines from open-ended private sector supply to the MOHS FHCI
- Interrupted the direct financial support provided to survivors (such as transport allowance) to access health services
- Transitioned community support to CHWs

While setting the stage for a sustainable exit-strategy, these changes were expected to have a negative impact on the perception EVD survivors have about the CPES program and the services received due to the challenges they have been facing since the transition, common to other FHCI populations, i.e., access to FHCI free drugs and services, transport support, etc.

DISTRIBUTION OF EVD SURVIVORS

A total of **3,466 EVD survivors** were registered by the National Ebola Response Centre (NERC) in Sierra Leone and recognized by MOHS, MSWGCAs, and WHO.

The distribution of these survivors varies across each district, with the highest number of survivors residing in Western Area (Rural and Urban), Port Loko, Bombali, Kailahun, and Kenema districts.



CPES GOALS & OBJECTIVES

CPES GOALS & OBJECTIVES

The program contributed to attaining the Resilient Zero objective of the Presidential 10–24 Month Recovery Plan and aimed to provide free health care for EVD survivors at MOHS facilities.

During Phase 2 of CPES, the program's objectives included a number of interventions aimed at progressing toward self-reliance, such as:

- The progressive integration of key human resources created by the program, such as CTOs and RCs, within the MOHS structures.
- Transition of the SA and SAS roles to CHWs and CHW peer supervisors.
- Institutionalization of the semen-testing program at the Sierra Leone Teaching Hospital Complex, Connaught Hospital.

CPES aims to improve the health and well-being of EVD survivors. Its long-term objective is to integrate survivor health care into mainstream clinical services, owned and managed by the MOHS.

Main Goals

- Improve access to care for all EVD survivors by reducing financial, logistical, and psychosocial barriers.
- Improve quality of care for EVD survivors by capacitating existing facilities and systems to provide better care across the health service delivery chain, from community to clinic to hospital.
- Address the risk of resurgence through sexual risk-reduction counselling and access to viral persistence testing.

Key Objectives

- Support EVD survivors in the recovery of functional capacity through effective delivery of health care and psychosocial services.
- Support the recovery of EVD survivors' livelihoods.
- Support EVD survivors' re-integration into their communities.
- Address the risk of resurgence associated with possible extended Ebola viral persistence in survivors.



RESEARCH QUESTIONS & METHODOLOGY

Quantitative Survey

Quantitative Sample

Survey Instrument

Data Collection & Management

Quantitative Analysis

RESEARCH QUESTIONS AND METHODOLOGY

Overall research activities seek to determine if the program achieves intended outcomes and impact by analyzing trends in disability experienced by EVD survivors, barriers to receiving health care, and satisfaction with service delivery. The evaluation of CPES uses a simple pre/post design by analyzing data from a baseline and endline survey to examine change in program implementation characteristics by the project's end in 2018.

Methodology

The baseline/endline assessments used a mixed-methods approach, including a quantitative and qualitative data collection that focused on understanding survivor experiences directly, as well as gathering perspectives and accounts from program implementing staff and stakeholders. Survey tools and interview guides developed were structured to reflect the CPES results framework and to answer the key research questions. Ethics review and approval for this research was obtained from JSI's institutional review board and the Sierra Leone Ethics and Scientific Review Committee of the MOHS.

Main research questions

What is survivors' knowledge of EVD? Are they aware of the link to sexual activity?

What barriers do EVD survivors face in their access to health services? Do they face any other stigma?

What percentage of male EVD survivors was tested for viral persistence? What percentage received counselling?

What services do EVD survivors currently receive through CPES? Are they satisfied with these services?

What is the extent of need for reproductive health services among women? Are they able to receive the services they need?

QUANTITATIVE SAMPLE

The study population for the survey was restricted to male and female EVD survivors 18 years of age and older in each of the initial project districts (excluding Bonthe district). The survey used lot quality assurance sampling (LQAS) methodology, which involves taking a small random sample in each set of groups within a given population.²

This methodology was used to develop the sample for data collection based on the total population of male and female EVD survivors provided by the Government of Sierra Leone. As such, the 18+ male and female sample was representative of the EVD survivor population at the national level by gender.

To identify sample units, the research team worked with the CPES PIU and SLAES in each district to generate a full list of eligible EVD survivors. From this list, a random number table was generated based on the EVD survivor sampling frame, and a two-step random sampling process was used by identifying chiefdoms within each district and male/female survivors in sampled chiefdoms. This sampling procedure was used to ensure:

- 1. A reasonable degree of certainty that the findings are representative of the target population.
- Ability to generalize findings across districts, but not representative within each district.

² More information on LQAS is available here – Lanata CF, Stroh G, Black RE. 1988. Lot quality assurance sampling in health monitoring. The Lancet 1988; 1: 122-123; Lanata CF, Black RE. 1991. Lot quality assurance sampling techniques in health surveys in developing countries: advantages and current constraints. World Health Stat Q.1991;44(3):133-9. http://apps.who.int/iris/bitstream/10665/47594/1/WHSQ_1991_44_3_p133-1 39_eng.pdf; JSI, 2006. Lot Quality Assurance Sampling, An Overview. Presentation at LQAS Conference, Sheraton Kampala Hotel 3rd July 2006. http://uphold.jsi.com/Docs/Resources/Conferences/presentation_overview-lqas_2006.pdf.

QUANTITATIVE SAMPLE

758 total EVD survivors

Surveyed in February 2017

372 males

386 females

751 total EVD survivors

Surveyed in May 2018

377 males

374 females

Pujehun district was dropped because of a very small population of survivors resulting in a sample size below the minimum required for LQAS. Survivors were oversampled in Port Loko, Western Area Rural, and Western Area Urban due to the high population of EVD survivors residing in these districts.

A total of 758 survivors (372 males and 386 females) were surveyed at baseline in February 2017 and a total of 751 survivors (377 males and 374 females) were surveyed at endline in May 2018 (Table 1).

Table 1. Breakdown of EVD Survivors Sampled for Quantitative Survey

	Baseline				Endline			
	Males	Female	Total	Males	Female	Total		
Во	19	19	38	21	19	40		
Bombali	19	19	38	21	19	40		
Kailahun	20	19	39	19	19	38		
Kambia	19	19	38	19	19	38		
Kenema	19	19	38	19	19	38		
Koinadugu	19	19	38	19	19	38		
Kono	19	19	38	19	19	38		
Moyamba	19	19	38	19	22	41		
Port Loko	100	115	215	100	100	200		
Tonkolili	19	19	38	20	19	39		
Western Area Rural	50	50	100	51	50	101		
Western Area Urban	50	50	100	50	50	100		
Totals	372	386	758	377	374	75 I		

QUANTITATIVE SURVEY INSTRUMENT

The quantitative data were collected by administering a structured questionnaire (Annex A)—reviewed by the CPES monitoring & evaluation working group, to the sampled male and female EVD survivors. The baseline/endline survey instrument covered:

- Basic demographic and socio-economic characteristics
- Knowledge and awareness of EVD
- Current and past services accessed
- Perceived quality of care
- Barriers to access to services
- Stigma faced
- Testing for EVD
- Psychosocial support received
- Disability

At endline, the program included two additional tools in the quantitative survey instruments to measure the level of depression and anxiety in EVD survivors.³

DATA COLLECTION & MANAGEMENT

The quantitative survey was administered to the sampled EVD survivors using the SurveyCTO mobile data collection platform. Enumerators were trained to administer the survey using tablets in the appropriate language for each district. All completed data forms were uploaded automatically to the mobile data collection server, where data collection checks were conducted daily.



³ These tools were added in the endline tools as part of a broader analysis that Advancing Partners is conducting about anxiety and depression in EVD survivors across the three Ebola-affected countries in West Africa: Guinea, Liberia, and Sierra Leone.

QUANTITATIVE ANALYSIS

The baseline and endline surveys were analyzed using Stata 14 software and included descriptive statistics on key indicators/outcomes relevant to CPES. Because of the oversampling in some districts, data were weighted for analysis. Results are presented by gender at the national level.

In addition to descriptive statistics, a series of factor analyses and/or scores were calculated for data related to quality of care, stigma, and disability. Factor analysis was used to determine which questions most influenced overall quality of care and stigma, prior to scores being calculated.

A factor analysis of the responses to all eight stigmarelated questions in the survey revealed that all questions posed were important in influencing the overall stigma experienced by EVD survivors at both baseline and endline.



CALCULATED SCORES

1

2

3

4

5 Strongly

Agree

Strongly Disagree

Quality of care

The quality of care (QOC) score was calculated as the mean response to a set of questions on EVD survivors' perceived quality of care received at the peripheral health unit (PHU) for their EVD-related health problems. All responses were on a scale of 1-5, where 1 was "Strongly Disagree" and 5 was "Strongly Agree." In the case of questions QOC4, QOC5, and QOC6 (see survey tool in Annex A) where 1 indicated a positive experience with quality of care and 5 a negative experience, the direction of the response was switched before any calculations were made.

Factor analysis revealed that the most important components related to overall quality of care were:

- 1. The perception that the health care being received was good
- 2. Ability to access care when needed
- 3. Survivors having access to specialists as needed
- 4. Health workers treated survivors in a friendly and courteous manner

A summary QOC score was calculated as the mean of the responses to these four identified factors giving equal weight to each response.

CALCULATED SCORES

1

2

3

4

5 Strongly

Agree

Strongly Disagree

Stigma

EVD survivors were asked to report if they had ever experienced stigma in a variety of scenarios. Factor analysis of these yes/no responses to all eight stigma questions revealed that all questions were important in influencing the overall stigma experienced by survivors. The proportion of EVD survivors who experienced any stigma was determined based on whether they responded "yes" to at least one of the stigma questions. The project further looked at the proportion of survivors who experienced stigma from a health worker based on whether the respondent indicated "yes" to at least one of the three statements related to their interactions with health workers.

Disability Assessment

The WHO Disability Assessment Schedule (DAS)⁴ (short) was used to measure the level of disability experienced by EVD survivors surveyed. Scores were calculated based on their responses to the 12 DAS questions indicating their level of difficulty completing daily tasks. Difficulty was scored with the following scale: none (0), mild (1), moderate (2), severe (3), extreme or cannot do (4). Scores from the 12 DAS questions ranged from 0 to 33, with a median of 9 and a mean of 9.68. Survivors were categorized as having a healthy life if they scored less than 25 percent on the DAS (composite score lower than 12).

⁴ Kostanjsek, T., Chatterji, N, and Rehm, J. 2010. Measuring Health and Disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0). World Health Organization. Accessed October 2016 at http://apps.who.int/iris/bitstream/10665/43974/1/9789241547598_eng.pdf?ua=1&ua=1.

CALCULATED SCORES

1

2

3

4

Strongly Agree

Strongly Disagree

Anxiety Score

The Generalized Anxiety Disorder-7 (GAD-7) tool⁵ was used to assess levels of anxiety experienced by survivors. Responses to each question were given a value (Not at all = 0, Several days = 1, More than half the days = 2, and Nearly every day = 3), and responses across the seven questions were summed to create a composite anxiety score for each respondent. Scores were then used to classify the level of anxiety experienced by the survivor as either No Anxiety (score of 4 or less), Mild Anxiety (score between 5 and 9), Moderate Anxiety (score between 10 and 14), and Severe Anxiety (score of 15 or higher).

Depression Score

The Patient Health Questionnaire-9 (PHQ-9) tool⁶ was used to assess levels of depression experienced by EVD survivors. Responses to each question were given a value (Not at all = 0, Several days = 1, More than half the days = 2, and Nearly every day = 3), and responses across the seven questions were summed to create a composite anxiety score for each respondent. Scores were then used to classify the level of depression experienced by the survivor as either No Depression (score of 4 or less), Mild Depression (score between 5 and 9), Moderate Depression (score between 10 and 14), Moderate to Severe Depression (score between 15 and 19), and Severe Depression (score of 20 or higher).

- 5 https://www.torbayandsouthdevon.nhs.uk/uploads/score-sheet-gad-7-anxiety-and-phg-9-depression.pdf
- 6 https://www.uspreventiveservicestaskforce.org/Home/GetFileByID/218



RESEARCH QUESTIONS & METHODOLOGY

Qualitative Data Collection

Qualitative Sample

Interview Guides

Data Collection and Management

Qualitative Analysis

QUALITATIVE DATA SAMPLE

Qualitative data comprised in-depth interviews using interview guides (Annex B) for each of the following groups of individuals:

- Survivor advocates (baseline only)
- PHU health staff (community health post [CHP] level)
- DHMT staff
- SLAES regional and district-level member staff
- EVD survivors (endline only)

A total of 21 interviews were conducted at baseline and 31 interviews at endline.

Data collection took place in selected project areas with combinations of high and low density of survivor populations: Western Area Urban, Bombali/Port Loko, and Kono/Moyamba. A breakdown of interviews conducted can be seen in Table 2.

Table 2. Qualitative Interviews Conducted at Baseline and Endline

	Western Area Urban		Bombali/	/Port Loko Kono/M		oyamba	National Level	
	BL	EL	BL	EL	BL	EL	BL	EL
Survivor advocates	3	-	3	-	1	-	-	-
PHU health workers	3	3	3	3	2	2	-	-
SLAES	1	2	1	2	1	2	-	1
DHMT	1	2	1	2	1	2	-	-
Survivors	-	4	-	4	-	2	-	-
Total	8	11	8	11	5	8	-	1

INTERVIEW GUIDES

Interview guides for each respondent type were created. Topics included:

- Barriers to accessing care
- Ability of health system to provide health services
- Referral systems in place
- EVD survivor needs
- Role of SLAES
- Sustainability

DATA COLLECTION AND MANAGEMENT

Interviewers completed qualitative data collection training at which interview guides were tested and translated into local languages. Respondents were selected based on input from the CPES PIU. All interviews were recorded and transcribed verbatim in English. An electronic record of each interview and discussion was created and transmitted to the research team. Transcripts were wiped of all identifying information and files stored in a folder that could only be accessed by the research team.

QUALITATIVE ANALYSIS

English transcripts were for thematic analysis using Nvivo 11 software. The research team developed and applied codes and used thematic analysis to synthesize the findings from the interviews. Qualitative data were interpreted alongside the survey data to better understand the perspectives of program implementers and survivor needs, and findings were summarized together.



RESULTS

Health Services

Referrals

Health Service Readiness

Quality of Care

Stigma

Mental Health & Psychosocial Support

Barriers to Accessing Care

Viral Persistence/ Sexual Behavior

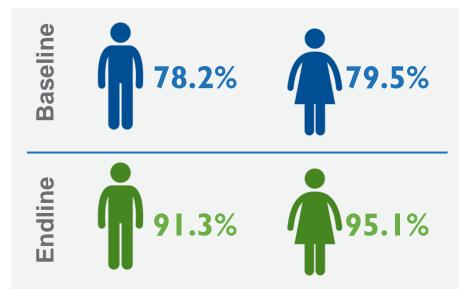
Disability Assessment

ACCESSING HEALTH SERVICES

Between baseline and endline, there was an increase in the proportion of EVD survivors that indicated accessing health services. Likewise, the endline showed an increase in the percentage of EVD survivors who experienced a health problem within the last year.

At baseline, 78 percent of survivors indicated experiencing a health problem within the three months prior to project implementation and at endline over 91 percent of survivors were found to have experienced some sort of health issue (Figure 3). Similar to baseline, more female survivors than male survivors experienced health problems over the course of project implementation.

Figure 3. Experienced Any Health Problems



The main health issues experienced by both male and female survivors include joint pain, headache, eye-related issues, pain, and fever (Figure 4), which are the same issues that were highlighted during the baseline assessment. These issues were further discussed as part of the qualitative interviews where survivors discussed joint pain, headaches, and eye-related problems as the major health issues survivors face following their EVD infection.

Figure 4. Types of Health Problems Experienced

	Base	line	Endline		
	(n=555)		(n=7	(02)	
	Female	Male	Female	Male	
	%	%	%	%	
Joint Problems	58.5	53.1	81.4	83.1	
Headache	59.2	49.4	65.2	76.7	
Eye Related Problems	26.1	21.4	39.6	36.5	
Pain	40.5	40.3	39.4	32.8	
Fever	53	55.7	22.6	30.8	
Abdominal Problems	38.1	27.4	24.5	25.4	
Other	10.2	17.1	12.3	17	
Neurologic Problems	24.5	17.2	3.8	12.1	
Sexual Health Problems	1.7	9.8	0	11	
Emotional Problems	11.3	11.3	11.6	7.5	
Hearing Related Problems	5.9	8.1	7.6	2.3	
Reproductive Health Problems	7.8	0.4	12.9	0.5	
Problems During Pregnancy	1.4	0	0.2	0	

ACCESSING HEALTH SERVICES

The results show that 96 percent of EVD survivors sought care at a health facility for their health issues at endline, compared to 89 percent at baseline (Figure 5). Only 2.7 percent of survivors did not seek care for their health issues though interestingly, males were less likely to seek care at baseline, and females were less likely to seek care at endline. Of those who did not seek care, lack of drugs at the PHU was the most common reason cited as well as not having resources (time and money) to travel to the facility.

Figure 5. Where Survivors Sought Care

Health facility
Outside health facility
Did not seek care

Baseline (n=555)				Endline (n=702)				
Male	Female	Total		Male	Female	То	Total	
%	%	%	n	%	%	%	n	
89.0	88.4	88.7	496	99.0	93.2	96.0	661	
6.9	10.4	8.7	43	0.9	1.7	1.3	21	
4.1	1.2	2.6	16	0.1	5.1	2.7	20	

At endline, only 1.3 percent of EVD survivors sought care outside of the facility, compared to 8.7 percent of survivors with health issues at baseline (Figure 5). Most of these survivors accessed treatment directly from a pharmacy with only a few indicating that they sought care from a traditional healer.

"...when I need any medicine I will just go to a pharmacy." -Survivor, Western Area Rural District

ACCESSING HEALTH SERVICES

Similar to baseline, survivors who sought care from a health facility were most likely to go to a PHU for care or a district hospital. Less than 1 percent of survivors reported going to a hospital in Freetown (tertiary level) for treatment (Figure 6).

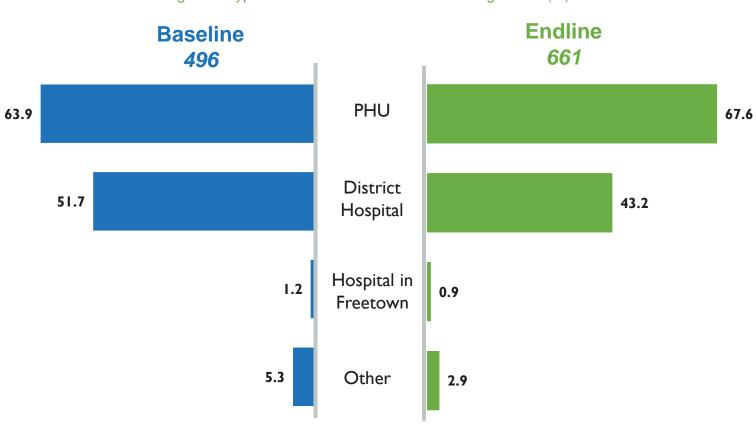
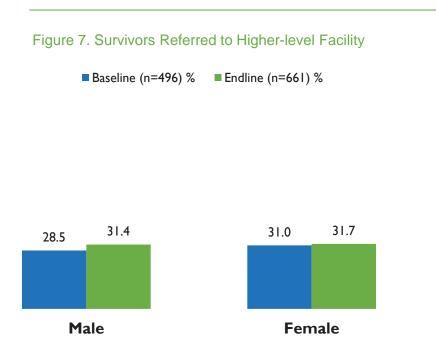


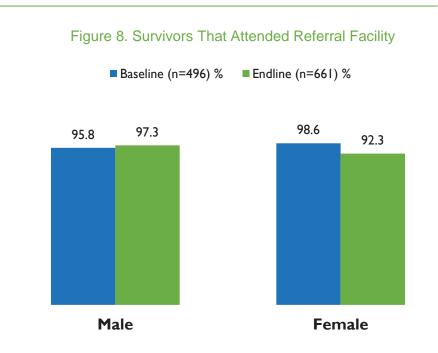
Figure 6. Types of Facilities Where Survivors Sought Care (%)

REFERRALS

Just under one third of EVD survivors interviewed at endline indicated that they were referred to a higher level facility to receive appropriate care, which is similar to the findings at baseline (Figure 7). In line with the baseline findings, almost all of the survivors that received referrals reported that they attended the referral facility (Figure 8).

Health workers discussed working with referral coordinators on multiple occasions. They view the RC role as the person who ensures clients make it to the referral facility and receive the necessary services. In some cases, referrals are made that allow survivors to access specialized care for services such as cataract removal. However, much of the discussion around referrals from respondents was linked to challenges with drug availability. In many cases, health facilities that did not have the necessary medications indicated that they refer clients to other facilities to access drugs.





REFERRALS

"At PHU level cases that we are not able to treat we will refer them. We will call the [Referral] Coordinator who will then call for ambulance if the case is serious. He will send the ambulance to come and collect them or if it is any other thing he will ask them to take transport. [The Referral] Coordinator was there he gave me all his numbers which we used to contact for referral."

- Health Worker, Bombali District

"Patients gets confused when they get to the hospital; but now we have clinical people [Referral Coordinator] waiting for the patients to be seen by doctors. And the approach now is holistic approach; we don't look only at survivors, all vulnerable groups, and the referral coordinator works for them."

– DHMT, Western Area Urban District

Survivors indicated they appreciated the role of referral coordinator to help them navigate the health system in order to access the necessary care, however in CPES Phase 2, referrals no longer came with a transportation benefit, which was cited by many survivors as a barrier to attending the referral facility.

Overall, facility staff indicated that they felt prepared (due to training and mentorship) to provide services to EVD survivors with the exception of more specialized care such as dealing with eye-related problems. Multiple respondents from the health facility, as well as DHMT, discussed the availability of general care provided free of charge to survivors as well as the availability of additional services at the PHU, such as mental health. In cases where the facility is not able to provide the necessary care, clients were referred to higher-level facilities.

All facility staff interviewed discussed the training they received and discussed how they felt it helped them know how to deal with the specific needs of their EVD clients. Furthermore, DHMT representatives discussed how these trainings have helped to fill the gap of mental health services since very few facilities could offer such services before the implementation of the program.

"...we give free general health service survivors needed. Services we cannot provide, we send for referral."

- Health Workers, Bombali District

"We are all trained and qualified staff here. Staffs talk and encourage survivors, because we are aware that Ebola was a horrific disease and that survivors suffers stigmatization."

- Health Worker, Moyamba District

"Well as a health worker, we were looking at Ebola to be a condition that is different from any other diseases that people are afraid of, and even the survivor's people were afraid to interact with them. But with the training, it able to helped us to put other patients and the survivors together and to interact with each other, and also me as a health worker I should be able to treat the survivors equally like any other patient whereas I should not take them as a special person or body. I should take them as equal to any other patient that's accessing the facility."

Health Worker, Port Loko District

DHMT respondents did indicate that while their existing staff have been trained and were capable of providing the necessary care, there are persistent human resource shortages and the general shortage of staff in the PHUs, which hinders service delivery.

"We are not able to provide all. If we have the medicines they required, we will treat them free. If we don't have drugs we will send them for referral."

- Health Worker, Bombali District

"...we are not getting that continuous counseling or advice and it's very rare presently..."

Survivor, Port Loko District

From the client perspective, many felt that the PHUs were not equipped to provide them care. Many indicated their frustration with the lack of drugs availability and being referred to higher-level facilities causing them to incur more costs associated with transportation. Furthermore, survivors specifically indicated that they felt there was a lack of counselling service availability with multiple respondents stating that they could not always access counseling services when needed.

During the implementation of CPES Phase 1, EVD survivors received continuous counselling mainly through the Survivor Advocates. As mentioned in the background SAs have been terminated with the transition between CPES Phase 1 and Phase 2.

As part of the CPES program, health staff in targeted facilities have received training on Psychological First Aid (PFA), which helps health workers recognize basic MH issues in patients and refer to higher level of care whenever needed. Further, focus was also given to improving the provision of MH services in district hospitals by training and providing continuing professional development to MH nurses in each of the district hospitals. At the community level, the transition from SAs to CHWs and the consequent training of CHWs on MH have occurred at a late stage of the CPES program.

The largest issue influencing survivors' perceptions of the quality of care received was the lack of drug availability, an issue that was discussed by almost every respondent interviewed. Many expressed their frustration with going to the facility only to find that the medication they need is not available. Many indicated that they were unhappy about having to pay for medication out of their pocket because their understanding is that healthcare for survivors should be free of charge.

As a whole, survivors agreed that facilities did have medical equipment but were lacking particular service provision, staff, and medications. Additionally, service availability seemed to vary greatly between facilities where tertiary hospitals were often perceived as being much more resourced than all other facilities.

"One of the main challenges is that, we are not having the adequate drugs at the health facility since [the partner] leave us.

At one time, I went to the hospital and they gave me some medicines so through the prescription list they gave I went to the closest pharmacy and purchased drugs [...]because I can afford that but what about the vulnerable people [...]

— Survivor, Port Loko District

"I need regular supply of drugs, as initially the treatment that was available at centers are no longer available for us. Since treatment is not delivered I decided to visit a native doctor."

— Survivor, Western Area Rural District

As described in the background, during the CPES Phase 1, EVD survivors had access to free drugs under the FHCI at all levels of care, as well as at selected private pharmacies across the country. The latter was a stop-gap measure implemented by the ESCC partners (supported by UKAid) to ensure that EVD survivors had free access to drugs, both those covered by the FHCI and specialty ones.

With the transition to a government-led program, and the phase out of the ESCC consortium, the stop-gap measure was concluded and therefore, since September 2017, EVD survivors have access to drugs provided under FHCI in the health facilities in the same way as the other FHCI population categories (pregnant and lactating women, and children under five), therefore facing challenges related to stock out, etc.

The abrupt transition between CPES Phase 1 and 2, and the associated changes, such as partners no longer directly funding the purchase of medications for survivors, often led to the misconceptions among survivors.

"For any Ebola survivors that go to Tombo they can give that particular survivor treatment that I can testify. But for other hospitals when you go there the only thing they can tell you is that CPES has ended and they have no treatment for Ebola survivors so we don't know where the problem is. This is one of the reasons why when the Ebola survivors get sick they don't go to those hospitals."

- SLAES, Western Area Rural District



With regards to specialty drugs for the most common health sequalae faced by EVD survivors, especially mental health, neurology, eye care, and joint pain, these were procured by USAID for the MOHS and distributed by the CPES PIU in 20 hospitals (secondary and tertiary) across the country for free access by EVD survivors and other FHCl populations. In consideration of their nature, these drugs were not distributed at the PHU level.

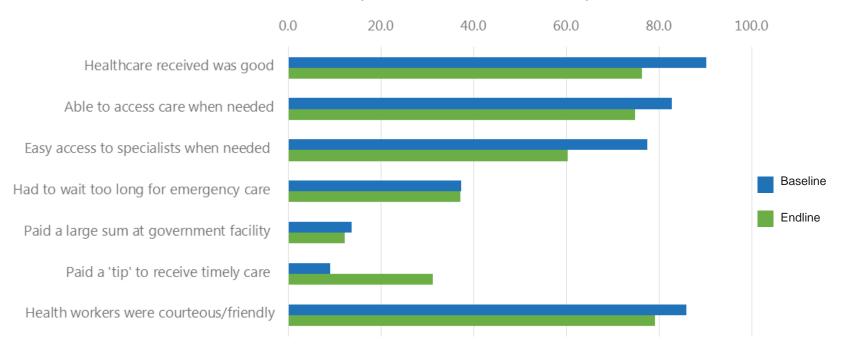
QUALITY OF CARE

Based on responses to questions related to quality of care, a composite quality of care score was created for each survivor's set of responses. There was no significant change in survivors' perceived quality of care between baseline and endline. The average quality of care score based on responses at endline (3.96 out of 5) was marginally lower than the average score found at baseline (4.08) (Figure 9).

Figure 9. Average of Quality of Care Score (on a scale of 1 to 5) at Baseline and Endline

Baseline			Endline			
Male	Female	All	Male	Female	All	
4.07	4.07	4.08	3.93	3.98	3.96	

Figure 10. Survivors That Agreed or Strongly Agreed with each of the Statements Regarding Quality of Care Received from the Facility



QUALITY OF CARE

Health workers and survivors spoke about quality of care in relation to drug availability and/or the experience of stigma. Specifically, multiple health workers raised the shortage of necessary drugs as a major barrier to their ability to provide adequate and high-quality care to Ebola survivors. Similarly, many survivors complained about being unable to get their drugs at PHUs. Some believed that drugs were available but being purposefully withheld by discriminatory health workers, especially after the removal of the survivor advocates who, in the past, promoted survivors' needs and followed up with providers.

As described in the background and under the Health Service Readiness section, the decline in the perceived quality of care as recorded during the endline can be explained by the changes in the services provided to EVD survivors as a result of the transition of the program from IP-led to government-led.

"When we go to the PHUs now, they ask if we are survivors and if we say yes, they will not give us [drugs]. They will say the drugs that are available are for children so I will not waste my time to go there. We are left with no option but to go to 34-hospital and it stressful for us to move from Willington here to Wilberforce. Before we had survivor advocates that visit us in our communities and talk to us to be visiting the CPES facilities but that has changed now. Since the SAs were out of the program, we never have access to health service at the PHU level. [...] It was far better for us then since the SAs helped us a lot. When they were around the doctors give us the required drugs since the SAs knew exactly what should be given to us because they are informed when we are supplied. Many things have changed."

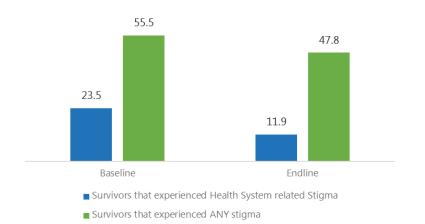
- Survivor, Western Area Urban District

STIGMA

Overall, **47.8** percent of EVD survivors experienced some instance of stigma, as indicated by a "yes" response to at least one of the stigma-related questions in the quantitative survey administered at endline (Figure 11).

This finding indicates a decrease when compared to the 55.5 percent of survivors that indicated experiencing some form a stigma at baseline. At baseline, slightly more men (61.5 percent) experienced stigma than did women (50.5 percent), but at endline, more women (49.7 percent) than men (45.8 percent) reported experiencing stigma.

Figure 11. Survivors That Indicated Experiencing Stigma (%)



Stigma experienced during survivor interactions with health workers decreased by 13 percent between the baseline and endline assessment with only 10.2 percent of survivors indicating that they felt stigmatized by health workers at endline. Similar to the general stigma reported at endline, slightly more women indicated experiencing stigma during health worker interactions than men interviewed for the endline assessment.

The majority of survivors interviewed expressed that stigma in health facilities had reduced significantly. Similarly, health workers felt that facility personnel were now better equipped to provide proper and equitable care to survivors; they spoke about receiving training and sensitization to this effect. Despite these marked improvements, some survivors complained about experiencing excessively long waiting periods before receiving care or being indefinitely ignored until they went home. Some explained that they were not given priority because they were no longer accompanied by survivor advocates; others complained that they were being ignored because they were poor and struggled to cover their health care expenses. Survivors perceived these experiences as discrimination, though they may not have been linked specifically to their status as Ebola survivors, or may be reflections of larger issues within the Sierra Leonean health care system.

"If they come to the center we would ensure that they were treated equally as to any other patient wherein we will not differentiate that since you are a survivor, sit down there or come at a specific time instead we will ensure they come at their own time they prefer."

—Health workers, Port Loko District

STIGMA

EVD survivors expressed discomfort about having to present their certificates at health facilities, which made them easily identifiable to other patients who subsequently discriminated against them. In some facilities, they were even made to sit in a specially designated area, which made their status public. One former survivor advocate spoke about working with DHMT to devise a system for the discreet identification of Ebola survivors, but this wasn't mentioned by other respondents.

"...when I go to the hospital, if I say am an Ebola survivor, it will not be easy for the nurses to attend to me; even when the announcement was made that when a person has survived, if you touch that person with your bare hands, the virus will not be transmitted, if a survivors go to the hospital, that is time you will see the nurses doubling the gloves on their hands to come to attend to you the survivor."

-Survivor, Western Area District

"Now survivors have to take their certificates to health facilities. Most survivors are not okay to be identified with a certificate. Most are ashamed. They feel stigmatized. The sitting arrangement at health centers also discriminates against them wherein survivors are seated separately from non survivors. This causes survivor patient to avoid visiting health centers. Sometimes the unique ways survivors are treated at health centers raises attention and most survivors dislike that. Survivors would like to be treated like any normal patients. These are some of the barriers: the sitting arrangement, certificates, and the attention. Survivors like when their cases are treated with all urgency. Survivors dislike when they have to present their certificates at health centers. The identification code of survivors is sufficed to identify them"

—Survivor, Port Loko District

STIGMA

While their discomfort is understandable, the necessity for EVD survivors to bring to the facility the discharge certificate is a result of two main factors: on one hand, the termination of the survivor advocates who used to accompany survivors to the facilities guaranteeing their survivor status; on the other hand, the verification and registration process of EVD survivors, which was supposed to conclude with the distribution of "identity" cards but was, unfortunately, never finalized by the government or partners.

In terms of stigma within the community, the majority of survivors reported a dramatic reduction, stating the efforts of survivor advocates and DHMT who worked with local authorities to sensitize communities. Given these efforts and the passing of time since the outbreak, many survivors felt that they had been welcomed back into their communities, though a few had to move away to escape their label. Survivors' perceptions seem to have changed as well—they expressed that looking and feeling healthy and being engaged in productive work has boosted their confidence and made them more difficult targets.

Nevertheless, some survivors reported continued stigmatization in the community, including name calling and discrimination in housing and transportation. One survivor reported that he and others like him continue to endure constant ridicule within the community due to their inability to sexually perform.

"Things have gotten better because of chiefs, law: first when I came it was like that people were not sitting by us, no one gets closer to us it was just my children and I, but when people start coming talking to the chiefs, talking with them they gave the law, saying if anyone did that (stigmatized) they will pay a fine so, so, so that when it cut-off."

-Survivor, Moyamba District

STIGMA

"[In the] community we have no problem, we are doing fine. Like me, except I tell you that I am a survivor else you not know by just looking at me. So we are all doing fine, we are living happily. They do invite us to attend weddings we do things in common so we thank God that stigma is dying out bit by bit within the community."

—Survivor, Kono District



MENTAL HEALTH & PSYCHOSOCIAL SUPPORT

Mental Health

As part of the endline survey, EVD survivors were screened for both anxiety and depression. Based on the survivors' answers to each of the screening tools, they were categorized by their level of anxiety and depression.

Over half (57.7 percent) of the EVD survivors interviewed during the endline did not show any signs of anxiety. About one third of them (31.6 percent) had signs of mild anxiety and just under 10 percent were classified as having moderate anxiety. Only 1.5 percent of all survivors screened presented with signs of severe anxiety. Additionally, women showed higher rates of anxiety compared to men (Figure 12).

About half (46.6 percent) of EVD survivors screened showed symptoms of mild to severe depression. 28.5 percent were categorized as having mild depression. 18.1 percent of survivors were found to have signs of moderate to severe depression. Furthermore, women showed more signs of depression than men (Figure 13).

These findings were consistent with information discussed during the qualitative interviews, where survivors described sometimes feeling sad or unable to stop worrying about being able to meet their health and livelihood needs. One survivor from Western Area Urban district described the need for mental health services stating that:

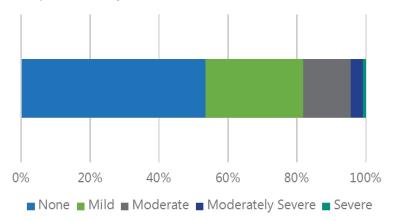
"...the mental issue is also related to the psycho-social problem because if you started thinking about the amount of people you have lost you would became sad sometimes you feel like talking to nobody."

Figure 12. Degree of Anxiety-related Symptoms
Experienced by Survivors within the Past Two Weeks

0% 20% 40% 60% 80% 100%

None Mild Moderate Severe

Figure 13. Degree of Depression-related Symptoms Experienced by Survivors within the Past Two Weeks



MENTAL HEALTH & PSYCHOSOCIAL SUPPORT

Psychosocial Support

The vast majority of survivors at both baseline (96.6 percent) and endline (90.5 percent) reported receiving some form of psychosocial support either at home or at a health facility (Figure 13). In looking at the number of times that survivors received individual counseling, most survivors (54.6 percent) received multiple instances of individual counselling within the past year and over a third receiving individual counseling three or more times over the previous year. At endline, the number of times survivors received individual counseling was more evenly distributed with about one third of survivors reporting 1-2 instances of individual counselling with the past year, about one third receiving three or more instances of counselling, and one third reporting that they received individual counselling many times within the past year (Figure 14).

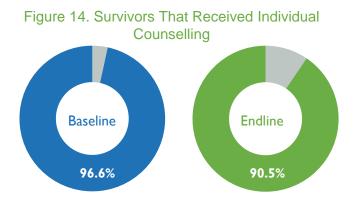
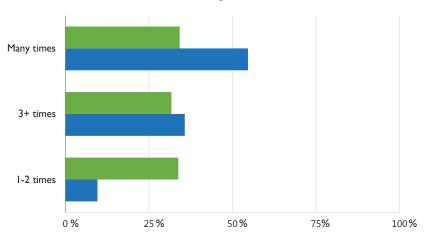


Figure 15. Number of Times Survivors Received Individual Counselling in the Past Year



Multiple survivors discussed the psychosocial support that occurred at the community level. Many of these instances of support were aimed to help sensitize the community on embracing survivors. The majority of survivors interviewed felt that that such support was very much needed to help mend their relationships within their communities.

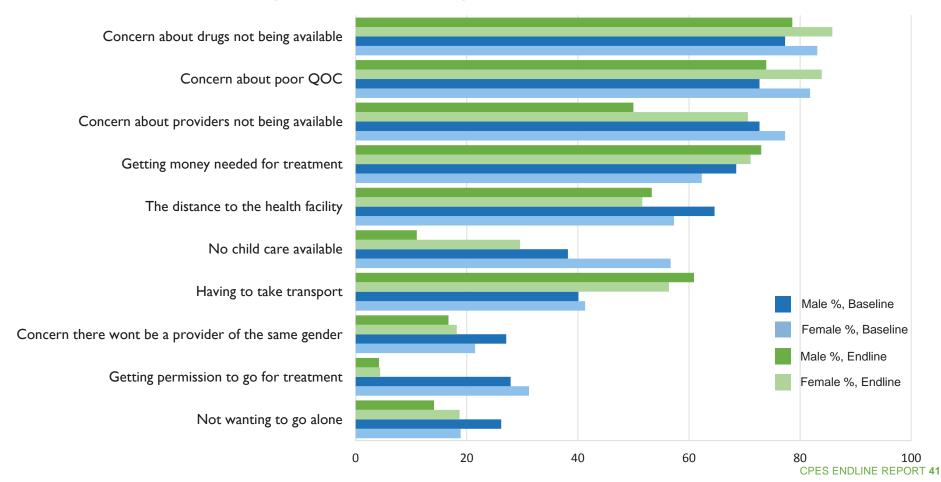
"...the psychosocial counseling that I need is the frequent visitation by NGOs and social workers. There is an NGO that sensitize and counsel people on how to interact and how your community should embrace survivors and we had such kind of workshops. If psychosocial counselors [continue to be] available they will be able to counsel us."

— Survivor, Bombali District

BARRIERS TO ACCESSING CARE

In exploring barriers faced by survivors when accessing care, similar results were observed at both baseline and endline. At the time of both assessments, the **biggest barriers to accessing care indicated by survivors was concern about drugs not being available at the facility**. Other major barriers at both baseline and endline included concern about poor quality of care for services received at the facility, concern about providers not being available, and issues around the money needed for treatment (Figure 16).

Figure 16. Barriers to Accessing Health Care Services Faced by Survivors



BARRIERS TO ACCESSING CARE

Similar to the quantitative findings, nearly all respondents interviewed mentioned transportation cost, long distances, and drug unavailability as major barriers to access to health services. With many survivors having to travel far to reach the nearest health facility, the initial CPES initiative to cover transportation cost had temporarily alleviated this barrier. With the conclusion of this support since September 2017 (as explained in the background section), many survivors explained that they simply didn't have the funds to pay for transportation or would have to forgo basic necessities such as food to cover the cost.

"We have some of our colleagues who live in interior villages and can't afford the transportation to come. The sickness will get serious on them. When SAs existed, we use to borrow money and come because they always refunded us. We all know that the cost of living is not easy. For those who are not working, it's not easy to come. Some prefer to use their 10,000 Leones to buy food for their children instead of paying transportation."

Health workers and DHMT members expressed the same concerns, stating that survivors were seeking care at health facilities less frequently due to their inability to cover the cost of transportation. Many survivors did not come to health facilities until or unless they experienced a significant deterioration in their health status. Several respondents explained that survivors were reluctant to invest their money and time to cover transportation because they're not guaranteed high quality service once they arrive at these facilities, especially with stock outs being a common occurrence. Another DHMT member explained the country's efforts to address this issue of inaccessibility, with the recent training and deployment of community health workers who will be providing care to survivors, among others.

"During Phase 1, when you were sick and come from Kenema to Makeni, they would refund you but it has come to a point that the government has taken charge of the project and that support has been cut off. Now for example, someone is sick and pays 20,000 Leones to reach the health facility and at the end of the day maybe the drugs will not be available and he has to return. He cannot have the good service he came for. I think that is a really big barrier that has made the attendance drop."

—DHMT, Bombali District

-Survivor, Kono District

BARRIERS TO ACCESSING CARE

The unavailability of drugs at PHUs was identified as barrier to access by survivors, health workers, and DHMT members interviewed. Survivors explained that they were rarely able to acquire the necessary drugs at PHUs; instead, they were given prescriptions and asked to visit a private pharmacy or hospital, or given drugs that did not meet their needs. Due to this common occurrence, many saw visits to PHUs as a waste of time, instead choosing to head directly to pharmacies or hospitals.

Health care workers and DHMT members recognized the country-wide inadequate supply of drugs as a major issue and expressed frustration with the situation. As a result, health facilities continued to be ill-equipped to meet the needs of EVD survivors as well as the other FHCI populations, who came expecting to receive full treatment and drugs free of charge.

"We don't receive any treatment from government hospital except for 34-hospital. When we go to the PHUs they will not treat us. We are told that there are no drugs. The ones that are available are for children so unless we are given a prescription to buy drugs. We have to beg for transport to go to 34-hospital because it is very far from here."

- Survivor, Western Area Urban District

"There are times when you go to the [health facility] and they will just give you Panadol, and that will not cure you of your sickness. If you want your health, you will just have to go look for the proper medication from a nearby pharmacy."

-Survivor, Western Area Rural District

"We do not have provisions. If a survivor sees that they are supposed to get six drugs and one is not at hand, we tell them to go buy it. And oh, it's a problem. [...] They say we should provide it, but we do not have the mandate to provide it.

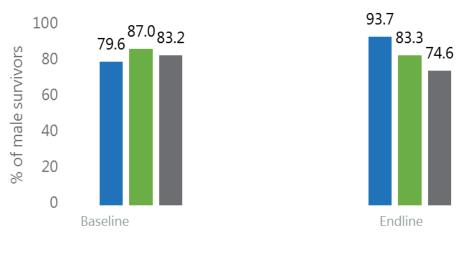
We do not have money, and [the government] does not supply it."

-Health worker, Western Area Rural District

VIRAL PERSISTENCE/ SEXUAL BEHAVIOR

An increase in the number of men participating in viral persistence testing was observed between baseline and endline with 79.6 percent of men reporting that they had ever participated in viral testing at baseline and 93.7 percent of men reporting that they had ever participated in semen testing at endline. However, fewer men reported receiving pre/post counselling on Ebola viral persistence and receiving the results of their most recent semen test at endline compared to baseline (Figure 17). This might be explained by the conclusion of the Public Health England (PHE) support to the Makeni Government Hospital for viral persistence testing, which occurred in November 2017.

Figure 17. Male Survivor Participation in Viral Persistence Testing

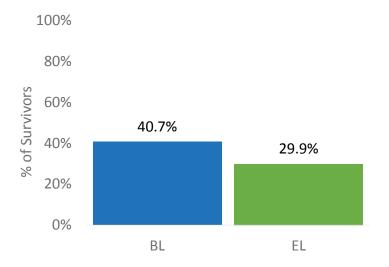


- Ever participated in semen testing for Ebola viral persistence
- Received any pre/post counselling on Ebola viral persistence
- Received results of last semen test for viral persistence

DISABILITY ASSESSMENT

Based on an analysis of the WHO Disability Assessment Schedule (DAS) (short), 40.7 percent of survivors experienced some level of disability at baseline. At endline the proportion of survivors experiencing some level of disability dropped by about 10 percent with only 29.9 percent reporting some form of disability (Figure 18). At both baseline and endline, women reported higher rates of disability.

Figure 18. Survivors That Experienced Some Level of Disability



Looking at the breakdown of specific tasks that EVD survivors found most difficult (defined as having 'severe' or 'extreme' difficulty) five tasks stood out at both baseline and endline (Figure 19):

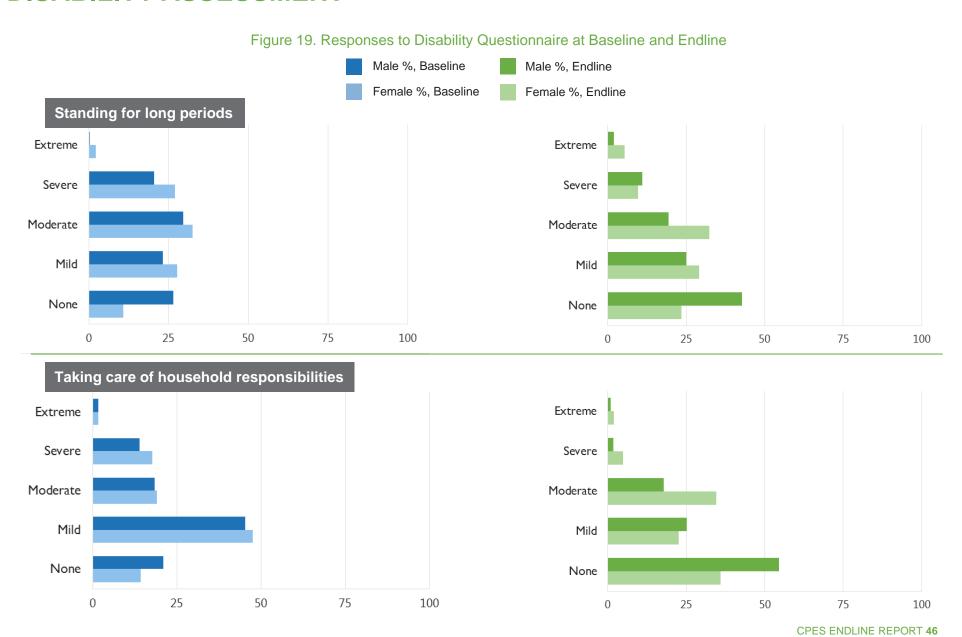
- · Standing for long periods.
- Taking care of household responsibilities.
- Affected emotionally by health problems.
- Concentrating for at least 10 minutes.
- · Walking a long distance.

One survivor described the change in his disability status as the following:

"We are not physically disabled by amputation but we are disable right. Some of us don't do hard work again at all no matter what we do, like me when I was coming up there was no work that was hard for me to do but now to spread my bed is hard for me and to do cleaning, cooking and the rest my body will be so much tired [...] for now I can't do those stuffs."

- Survivor, Kono District

DISABILITY ASSESSMENT



DISABILITY ASSESSMENT

Figure 19. Responses to Disability Questionnaire at Baseline and Endline

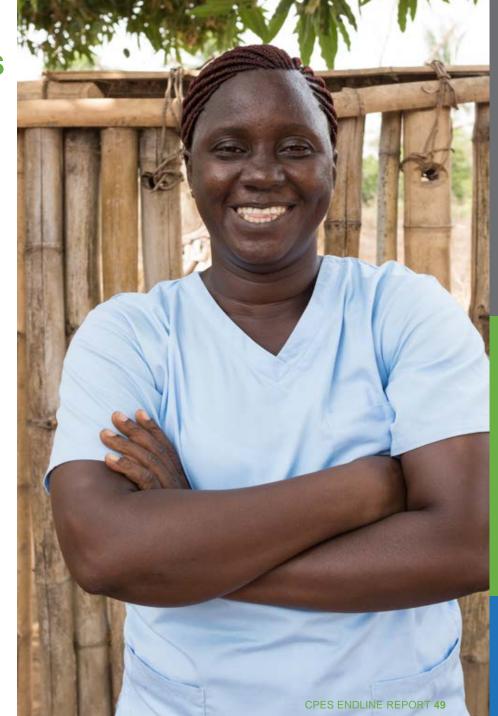


CONCLUSIONS & RECOMMENDATIONS FOR THE FUTURE

CONCLUSION & RECOMMENDATIONS FOR THE FUTURE

The CPES program has without any doubt responded to the needs to restore EVD survivors' confidence in a country health system heavily disrupted by the Ebola outbreak; and ensured that their special needs were addressed in a timely and efficient manner. Ten percent more survivors were able to lead a healthy functional life because of the project intervention. Moreover, there has been a 7.7 percent reduction in the proportion of survivors reporting some sort of stigma and a 10.2 percent drop in the proportion of those reporting stigma during their last interaction with a health care provider.

However, almost three years after the beginning the CPES program it is clear that the program, as initially designed, was not sustainable and that several considerations for an earlier and better planned transition from an IP to a government-led program should have been made, as clearly outlined from the endline results.



CONCLUSION & RECOMMENDATIONS FOR THE FUTURE

Access to services and drugs: The need to restore confidence in the health system and ensure access to services to improve survivors' health status in a context where a) the health system was disrupted, b) referral system was not strong and c) there was a consistent stock out of FHCI drugs across all facilities have brought the program to establish a completely parallel system. Although beneficial in the beginning, it has created unrealistic expectations by EVD survivors for what the government would have been able to sustain in the long term, particularly considering that EVD survivors are part of the FHCI categories and none of the other targeted populations receive this type of support.

Recommendation: For similar programming in the future, it would be advisable for the MOHS, development, and implementing partners to consider the long-term impact of short-term interventions, so as to minimize impacting further on perception of the quality of care received. Also, proper communication with the beneficiaries about transitions should be planned to limit the risk.

Community support: At the time CPES started, the MOHS was about to roll out the new CHW policy; therefore, the position of the survivor advocates was created to respond to the initial unavailability of CHWs to take up the role. As seen from the result of baseline and endline, the peer-to-peer approach implemented with the SAs has helped reducing stigma associated with EVD and supported the rebuilding of trust between survivors, the communities, and local health facilities. However, when SAs were terminated, the transition to CHWs hadn't happened yet and this has clearly impacted the perception that EVD survivors have on the overall support provided to them at the community level.



Recommendation: Two main recommendations for future similar programs are: 1) if a community-level mechanism is already in place, i.e., CHWs, it is recommended to implement the activity through the established mechanism rather than creating a new one with similar functions; 2) if the mechanism is not in place, it is advised to ensure that the transition between the short-term intervention and the long-term solution is planned on-time to limit gaps in the community and ensure there is complementarity and learning.

CONCLUSION & RECOMMENDATIONS FOR THE FUTURE

Communication of the transition and program transition: feedback received during the endline survey, particularly the qualitative interviews, show that the transition process lacked a clear communication strategy at the various levels, from communities to the higher level of the MOHS. Survivors, health workers and DHMT staff mentioned the "end" of CPES when the program was instead transitioning from an IP-supported program to a government-led one. This is most probably the result of a transition that happened fast following the "sudden" phase-out of the UKAid funds for the program and a lack of planning.



Recommendation: It is recommended, as the program plans for the transition to a fully government-led and supported program, to ensure that proper and on-time communication is provided at the various levels of the MOHS system and in the communities so as to limit the challenges faced during the transition to, and the implementation of, phase 2. For similar programming within MOHS in the future, it is recommended to plan with partners from the beginning how to ensure a smooth transition within MOHS structures and even more on how to utilize, from the beginning of the program, already existing resources within the MOHS to limit transition and communication challenges.



ACRONYMS

CPES Comprehensive Program for Ebola Survivors

MOHS Ministry of Health and Sanitation

MOSWGCA Ministry of Social Welfare, Gender and Children's Affairs

EVD Ebola virus disease

FHCI Free Health Care Initiative

SLAES Sierra Leone Association of Ebola Survivors

SC Save the Children Partners in Health

KSLP King's Sierra Leone Partnership ESCC Ebola Survivor Care Consortium

IP implementing partner MdM Medicos Del Mundo

IMC International Medical Corps WHO World Health Organization

SA survivor advocate

SAS survivor advocates supervisor

CTO clinical training officer RC referral coordinator

PIU Program Implementation Unit CHW Community Health Worker

DHMT District Health Management Team NERC National Ebola Response Centre

QOC quality of care

PHU peripheral health unit

DAS Disability Assessment Schedule

Annex A: CPES Endline Survey Questionnaire

Date (MM/DD/YYYY): Enumerator Name number:		Team Number:	
Survivor ID Number:	District*:	Chiefdom*:	Community:
Rural □ Urban: □			
Closest PHU:			
Distance from PHU:	(miles)	Time taken to get to PHU:	(minutes)
*Fields with drop-down options			
Was consent obtained from the EV	D Survivor to participate in the	e survey? Yes: □ No: □	
Is there an IPA Monitor present for	the survey? Yes: No:		

Background Characteristics

Respondent's age:
Sex: Male: □ Female: □
Literate: Yes: No: [if NO, skip to Head of Household]
Highest level of education attended:
Primary: Secondary: Tertiary: University None:
Head of the household: Yes: □ No: □
Marital Status: Single: □ Cohabiting: □ Currently Married: □ Divorced: □ Widowed: □ Separated: □
Have you ever had children? Yes: □ No: □
Number of children:
Main Source of livelihood: Agriculture: □ Business □ Skilled worker (tailor, carpenter etc.): □ Teacher: □ Health worker (Nurse, doctoretc): □ Other professional employment: □ No source of livelihood □
Other Sources of livelihood: [Select all that apply]
Agriculture: Business Skilled worker (tailor, carpenter etc.): Teacher: Health worker (Nurse, doctor etc): Other professional employment: No source of livelihood

No.	PART 1: Knowledge and Awareness on Ebola: Now, I would like to ask you some questions about what you know about some things related to your health		Resp	oonse
		Yes (1)	No (0)	Don't know (99)
K1	Have you ever heard of a disease called EBOLA? [If No or Don't know, skip to Part 2]	1	0	99
K2	Can one reduce their chances of getting Ebola from a survivor by not having sex with him/ her?	1	0	99
K3	Can one reduce their chance of getting Ebola from a survivor by using condoms when having sex with him/her?	1	0	99
K4	Can an Ebola survivor appear healthy?	1	0	99
K5	Can an Ebola survivor who is pregnant pass EBOLA to her unborn child?	1	0	99
K6	Have you received information about services that are available for ebola survivors?	1	0	

No.	PART 2 Health Services Received :		Response	
	Now, I would like to ask you some questions about health services that you may			
	have received in the past year (March 2017 – March 2018)			
		Yes (1)	No (0)	Don't know (99)
HS1	Have you had any health problems in the last year?	1	0	
	[If Yes, go to HS2 else skip to Part 4]			
HS2	What health problems have you experienced in the past year? [select all that			
	apply but do not read the list aloud to the respondent.]			
	□ Eye related problems			
	□ Hearing related problems			
	□ Abdominal problems			
	□ Numbness, dizziness, pins & needles			
	□ Head ache			
	□ Emotional problems (poil hat, frustrated, vexed)			
	□ Sexual health problems (such as impotence for men)			

	□ Reproductive health problems (Difficult in become pregnant, prolonged bleeding, increased pain in menses)		
	□ Problems during pregnancy (preterm birth, still birth, increased PIH)□ Fever		
	□ Pain		
	Other (specify)		
	□ Don't know		
HS3	Where did you seek care for this health issue?		
	□ Health facility [Set the skip pattern for HS5]		
	□ Somewhere outside the health facility, including pharmacy, traditional		
	healers, religious or community leaders, or others [Set the skip pattern for HS4]		
	□ I did not seek care [Set the skip pattern for HS3a]		
HS3a	If you did not seek care, please explain why not		
	- -		
	[Answer and move to Part 3]		
HS4	For the location outside the health facility, where did you go to get treatment for		
	your health problem? [Answer and move to Part 3]		
	1 Community Health Worker		
	2 Pharmacy		
	3 Country doctor/traditional healer		
	4 Pastor/Imam		
	5 Community leader		
	Other (specify)		
HS5	For any of the health problems in question HS2, what type of health facility did		
	you go to? [Select all that apply]		
	1 PHU (community health center (CHC), maternal and child health post		
	(MCHP), community health post (CHP))		
	2 District or Regional hospital		
	3 Hospital in Freetown		
	4 Other (Specify)		
	99 Don't know		

HS6	How many times did you go to treat the health problem(s)?			
	1 Once			
	2 Two times			
	3 More than two times			
	99 Don't know			
HS7	Were you referred to a higher level facility to get better treatment?	1	0	99
	[If No or Don't know, go to Part 3]			
HS8	Were you able to go to the referral facility to get the treatment?	1	0	99
	[If No or Don't know, go to HS9, else go to Part 3]			
HS9	Please explain why not [select all that apply?]			
	1. Getting permission (from relative, spouse etc.) to go for treatment			
	Getting money needed for treatment			
	3. The distance to the health facility			
	4. Having to take transport			
	5. Not wanting to go alone			
	6. No child care available			
	7. Concern that there may not be a female health provider [for women participants] or a male health provider (for male participants)			
	8. Concern that there may NOT be any health provider at the health facility			
	9. Concern that there may be no drugs available at the health facility			
	10. Concern with the quality of care available not good enough			
	96. Other (Specify)			

No.	PART 3 – Specifics about health issues experienced and care received :	Response				
	For each of the health issues specified by the respondent indicated in HS2, ask the following questions:					
		Yes (1)	No (0)	Don't know (99)		
S1	Did you seek health care for [insert specified health issue]?	1	0			
S2	Where did you seek care for [insert specified health issue]?	1	0			
	 Primary facility (PHU) Secondary facility (District or Regional Hospital) Tertiary facility (Hospital in Freetown)Somewhere other than a health facility [skip to S7] Other (specify) 					
S3	Do you feel that your access to care for [insert specified health issue] was adequate?	1	0			
S4	Was the quality of healthcare that you received for [insert specified health issue] satisfactory?	1	0			
S5	Were you referred to another facility for the treatment of [insert specified health issue]?	1	0			
S6	Do you feel that you should have been referred for [insert specified health issue]?	1	0			
S7	In the past two years (since the end of the ebola time), do you feel that care for [insert specified health issue] has: [Enumerator read options] 1. Got much better 2. Got a little better 3. Stayed the same 4. Got a little worse 5. Got much worse 99. Don't know					

We are interested in getting your feelings, good and bad, about the health care you have received. I will say some things people say about health care. Please listen carefully, thinking about the health care you are receiving now. If you have not received care recently, think about what you would expect if you needed care today.

No.	PART 4: Quality of Health Care: These questions relate to the care you received in the past 3 months (e.g. since January 2018)			Response)		
	How strongly do you agree or disagree with each of the following statements?						
		Strongly Disagree (1)	Disagree (2)	Uncertain (3)	Agree (4)	Strongly Agree (5)	Has it improved? Yes/No/ Don't know
QOC1	The health care you were receiving was good						
QOC1	Has there been any improvement in the last year?						
а							
QOC2	You were able to get health care when you needed it						
QOC2							
а	Has there been any improvement in the last year?						
QOC3	You had easy access to the health specialists when you needed them						
QOC3	Has there been any improvement in the last year?						
а							
QOC4	Where you went to get health care, people had to wait						
	too long for emergency treatment						
QOC4	Has there been any improvement in the last year?						
а							

QOC5	You paid a large amount when you visit			
	GOVERNMENT (not survivor specific) health facilities			
	which you were not reimbursed for			
QOC5	Has there been any improvement in the last year?			
а				
QOC6	You paid a small 'tip' to receive health care in a timely			
	fashion -			
QOC6				
а	Has there been any improvement in the last year?			
QOC7	Your health care workers treated you			
	in a friendly and courteous manner			
QOC7	Has there been any improvement in the last year?			
а				
QOC8	You were satisfied with the services you received			
QOC8	Has there been any improvement in the last year?			
а				
QOC9	You had a regular place to go for healthcare			
QOC9	Has there been any improvement in the last year?			
а				

No.	PART 5: Stigma Scale: The next questions are about your personal observations and experiences on the support you receive from the community as a survivor. I will read issues and you answer yes or no. Again, these refer your experience in the past year (since March 2017).		Resp	oonse
		Yes (1)	No (0)	Don't know (99)
STIG1	People talked badly about you because of your EBOLA survivor status			
STIG1				
а	Has there been any improvement in the past year?			
STIG2	Someone else disclosed your EBOLA survivor status without your permission			

STIG2			
а	Has there been any improvement in the past year?		
STIG3	You were verbally insulted, harassed and/or threatened because of your EBOLA		
	survivor status		
STIG3			
а	Has there been any improvement in the past year?		
STIG4	You were physically assaulted because of your EBOLA survivor status		
STIG4			
а	Has there been any improvement in the past year?		
STIG5	You felt that people did not want to sit next to you, for example on public transport, at church or		
	mosque, or in a health facility because of your EBOLA survivor status		
STIG5			
а	Has there been any improvement in the past year?		
STIG6	You were denied health services because of your EBOLA survivor status		
STIG6			
а	Has there been any improvement in the past year?		
STIG7	Healthcare workers talked badly about you because of your EBOLA survivor status		
STIG7			
а	Has there been any improvement in the past year?		
STIG8	A health worker disclosed your EBOLA survivor status without your		
	Permission		
STIG8			
а	Has there been any improvement in the past year?		
STIG9	Have you ever been treated badly by health staff because of your status as an Ebola Survivor		
	(for example, whether you have been refused service, or made to wait for longer than other		
	patients)?		

STIG1	Do you think that treatment of Ebola survivors by doctors and nurses has gotten better, gotten		
0	worse, or stayed the same since just after the ebola time? [Enumerator read: Since March		
	2016] [Enumerator read options]		
	Got much better		
	2. Got a little better		
	3. Stayed the same		
	4. Got a little worse		
	5. Got much worse		
	99. Don't know		

No.	PART 6: Psycho-social Support & Counselling		Resp	onse
	The next questions are about the counselling support you have received from your assigned Survivor Advocate or PHU in the past year (since March 2017).			
		Yes (1)	No (0)	Don't know (99)
CPES1	Thinking back to the time from when you were discharged to when this program started –	1	0	99
	when last rainy season started - have you received any psycho social support/counselling on			
	EBOLA?			
	[if No or Don't know, skip to CPES4]			
CPES2	Did you receive psychological first aid at the health facility or participate in and community	1	0	99
а	healing dialogues (CHDs)			
	(CHDs are group meetings where someone helps the community discuss EBOLA and			
	survivors)			
	[If No or Don't Know, skip to CPES3a]			
CPES2	How many times?			
b	1. None			
	2. 1-2			
	3. 3+			
	4. Many			
	99. Don't Know			

CPES3	Did you receive individual counselling – either at home or in the clinic with a professional	1	0	99
а	counsellor?			
	[If No or Don't Know, skip to C]			
CPES3	How many times?			
b	1. None			
	2. 1-2			
	3. 3+			
	4. Many 99. Don't Know			
	Next we would like to speak to you specifically about your interactions with your Survivor			
00504	Advocate.	4	0	
CPES4	Overall, were you happy with the assistance provided by your Survivor Advocate?	1	0	
CPES5	When Survivor Advocates were working, how often did you interact with your Survivor			
	Advocate? [if NONE, move on to Part 7]			
	1. None			
	2. 1-2			
	3. 3+			
	4. Many			
	99. Don't Know			
CPES6	What was the reason for interacting with the Survivor Advocate? [select all that apply]			
CFLSO	1. Assistance going to a health facility			
	Need additional care at higher level facility			
	3. Needed counselling			
	4. Help settling disputes (between survivor and community, family etc.)			
	96. Other assistance needed (please specify)			
	(P.0400 0P00.1)			
CPES7	Did you physically meet with the survivor advocate?	1	0	

No.	Part 7: Barriers to Access: Many different factors can prevent people from getting medical advice or treatment for themselves. The next questions are about your experiences in the past year. When you are sick and wanted to get medical advice or treatment, is each of the following a big problem or not?	Response		
		Big problem (1)	Not a big problem (2)	Don't know (99)
B1	Getting permission (from relative, spouse etc.) to go for treatment			
B2	Getting money needed for treatment			
B3	The distance to the health facility			
B4	Having to take transport			
B5	Not wanting to go alone			
B6	No child care available			
B7	Concern that there may not be a female health provider [for women participants] or			
	a male health provider (for male participants)			
B8	Concern that there may NOT be any health provider at the health facility			
B9	Concern that there may be no drugs available at the health facility			
B10	Concern with the quality of care available not good enough			

	PART 8: Sex and Sexual behaviour: The next questions ask about sexual behaviour. There is no right or wrong answer. Your response will not be linked to you in any way or shared with anyone, including your partner, family, or others.	Response			
No.		Yes (1)	No (0)	Don't Know (99)	
SB1	In the past 12 months, have you had sex?	Yes (1)	No (0)	Don't know (99)	

	[If No or Don't Know, skip to Part 9]				
SB2	The last time you had sex, did you use a condom?	Yes (1)	No (0)	Don't know (99)	
SB3		Often (1)	Sometimes	Never (3)	Don't know (99)
	How often was a condom used when you have had sex?		(2)		
SB4	Have you ever participated in semen testing for EBOLA viral	Yes (1)	No (0)	Don't Know (99)	
	persistence? [Applies to men only]				
	[If No or Don't Know, skip to Part 9]				
SB5	When was the last time you were tested for EBOLA viral	1 month/less	2 or more		Don't know (99)
	persistence? [Applies to men only]	ago (1)	months ago		
	[If Never or Don't Know, skip to Part 9]		(2)		
SB6	Did you receive the results of your last semen test for EBOLA viral	Yes (1)	No (0)	Don't know (99)	
	persistence? [Applies to men only]				
SB7	Did you receive any pre/post counselling on viral persistence?	Yes (1)	No (0)	Don't know (99)	
	[Applies to men only]				

PART 9: Disability Assessment

The interview is about difficulties people have because of health conditions.

By health condition I mean diseases or illnesses, or other health problems that may be short or long lasting; injuries; mental or emotional problems; and problems with alcohol or drugs.

Remember to keep all of your health problems in mind as you answer the questions. When I ask you about difficulties in doing an activity think about...

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity

When answering, I'd like you to think back over the past 30 days. I would also like you to answer these questions thinking about how much difficulty you have had, on average, over the past 30 days, while doing the activity as you usually do it.

Use this scale when responding: None, mild, moderate, severe, extreme or cannot do.

In the past 30 days, how much difficulty did you have in:

		None (1)	Mild (2)	Moderate (3)	Severe (4)	Extreme or cannot do (5)
D1	Standing for long periods such as 30 minutes?			, ,	, ,	
D2	Taking care of your household responsibilities?					
D3	Learning a new task, for example, learning how to get to a new place?					
D4	How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?					
D5	How much have you been emotionally affected by your health problems?					
In the	past 30 days, how much difficulty did you have in:					
D6	Concentrating on doing something for ten minutes?					
D7	Walking a long distance such as one mile [or equivalent]?					
D8	Washing your whole body?					
D9	Getting dressed?					
D10	Dealing with people you do not know?					
D11	Maintaining a friendship?					
D12	Your day-to-day work/school?					
H1	Overall, in the past 30 days, how many days were the present?	ese difficulties	6	Record num	nber of day	/s
H2	In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?		Record nun			

H3	In the past 30 days, not counting the days that you were totally unable, for	
	how many days did you cut back or reduce your usual activities or work	Record number of days
	because of any health condition?	<u>-</u>

No.	PART 10: Associations		Resp	oonse
	The next questions are about Survivor Associations in Sierra Leone			
		Yes (1)	No (0)	
SA1	Have you heard of a group called the Sierra Leone Association of Ebola Survivors (SLAES)?	1	0	
SA2	From your knowledge, what do they do?/ what is their role? 1. Represent or advocate for Ebola Survivors 2. Deliver health services to Ebola Survivors 3. Give information to Ebola Survivors 4. Give support or non-health services to Ebola Survivors 96. Other			
SA3	Are you a member of the Sierra Leone Association of Ebola survivors?	1	0	
SA4	How confident are you in the survivor network's ability to support/address your needs and represent you? 1 Very confident 2 Somewhat confident 3 Not at all confident			

This completes the questionnaire. Thank you.

Annex B: CPES Endline Assessment Qualitative Data Collection Guides

Instructions to facilitators: Before you begin, you must read the information sheet (Annex 2) out to the respondent.

The following questions are a guide. An in-depth interview should feel like a conversation (where the respondent does most of the talking). It is best to begin with easy, open ended questions so the respondent feels comfortable and it allows them to convey in their own words their experience. Focus on the respondent's experience and weave the topics and subtopics into the conversation (rather than worrying about asking each question as written). Try not to ask them to generalize or summarize their opinions on the CPES program until the very end. Try not to ask Yes/No questions or leading questions. Ask respondents to illustrate their opinions with examples or use their examples to draw out their feelings and perceptions. You should probe and ask follow up questions only where appropriate.

Interview Code:					
Name of Facilitator:					
Name of Note taker:					
Date:					
District:		_			
Location of Interview:			_		
Type of respondent (Please circle one)	SLAES		DHMT	PHU Staff	Survivor
IF DHMT, current role:					
Sex (Please circle one):		Man	Wo	oman	
Interview Start Time:					

Instructions: Please introduce yourself to the respondent and thank him or her. After they have introduced themselves, turn on the audio recorder.

PHU Health Staff (who have treated EVD survivors)

Let's begin by talking about your work, especially your interaction with EVD survivors.

- 1. What has been your experience treating EVD survivors in the past year?
 - a. For how long have you been treating EVD survivors at your PHU?
 - b. About how many EVD survivors came to your PHU in the last three months? (majority men/ women & children/adults). Have these numbers changed over the past year (seeing more survivors or fewer survivors at the clinic each month)
 - c. What were the health problems they faced?
 - d. Are the health problems faced by women or children different? Why or why not?
- 2. Are you able to provide the care and treatment the EVD survivors needed at your PHU?
 - a. How/why not?
 - What services did you provide?
 - Do you have any limitations such as drug availability? Please explain
 - Did it cover women and adolescents and children as well?
 - b. (IF no, what services are you unable to provide?
 - c. Have you received any training on how to provide care for or interact with EVD Survivors?
 - Describe the training you have received, what did you learn?
 - Do you feel that the training equipped you to deal the EVD Survivor health problems? Why/How?
- 3. What are the processes involved in referring EVD survivors to district hospitals?
 - a. How many of the EVD survivors were referred to a district hospital?
 - b. What services did they need that could not be offered at your PHU?
 - c. Do you think the district hospital was able to provide these services?
- 4. Tell us about how well your PHU is equipped to treat EVD survivors? (Probe for staff, medicines, supplies, and equipment)
- 5. What issues do you face regarding resources in treating EVD survivors (probe for staff, medicines, supplies, staff training, and equipment needed to treat survivors' needs)
- 6. What are some other challenges you have faced when treating EVD survivors? (Give specific examples)
- 7. In what ways do you interact with the Government CPES implementing programs for EVD survivors?
 - a. In what ways do you interact with the following groups in relation to the health services you provide? How often?
 - 1. Survivor advocates (when they were working)?
 - SLAES members?
 - Social workers and psycho-social counselors?
- 6. Overall, what changes have you seen (if any) that have improved the situation of EVD Survivors?
 - a. What changes do you think are still needed?
- 7. Is there anything else you want to discuss?

Thank the re	spondent for their ti	me and ask if they hav	e any questions for	you. Turn off the recorder.
End Time				

DHMT

Let's begin by talking about your work, especially with regard to CPES and provision of health services to EVD survivors in your district.

- 1. Please tell us about the DHMT's role in implementing CPES in this district.
 - a. How does the DHMT coordinate CPES activities in the district? Has this role changed at all over the past year?
 - b. How does the DHMT oversee the role of the district hospital and PHUs in the services they provide?
- 2. What is the DHMT's role in ensuring EVD survivors receive the health services related to post Ebola health issues?
 - (Probe for care for bones/joints problems, eye infections, adnominal pain, numbness, fever etc.)
- 3. What services are provided at:
 - PHUs
 - district hospitals
 - provincial/national hospitals
 - a. Has there been any change to types of services or accessibility of services available at any of these levels in the past year?
- 4. In what ways are mental health and psycho-social issues addressed?
 - a. Has this changed over the past year (i.e. have the provision of services become more or less accessible over the past year)? If so, how?
- 5. What about the health needs of women, adolescents and children? How are they addressed?
- 6. What is the process for patients who need more specialized care and how (if at all) has it changed since the beginning of the CPES Project?
- 7. What aspects of the care for Ebola survivors are:
 - Working well in your district? Give reasons
 - And what aspects are not working well? Give reasons
- 8. Tell me about the necessary resources that <u>the district hospitals and PHUs</u> have for survivors? [examples infrastructure, medicines, supplies, equipment, staff].
 - a. Are you able to provide health services to all survivors? (probe for men, women, adolescents and children)
 - b. Which services do you provide for:
 - Men
 - Women
 - adolescents
 - and children
 - c. If not, what are some of the issues faced?
 - d. what are some of the ways in which the DHMT has tried to resolve/deal with these challenges in the past year?

9. In your view, do all survivors have access to the health care they need? Why or why not?
10. Overall, what changes (if any) have you seen to improve the health situation of survivors? a. What issues still remain?
11. Is there anything else you want to discuss?
Thank the respondent for their time and ask if they have any questions for you. Turn off the recorder.
End Time

SLAES

Now we are going to talk about the situation of EVD survivors in this district.

- 1. What are some of the types of health problems they face?
 - a.
- 2. What is your view on whether the health system is able to meet the needs of EVD survivors in this district? Probe for all types of services at:
 - PHU
 - District hospitals
 - Regional/national hospitals
 - a. Has the health system's ability to achieve these needs changed over the past year?
- 3. What happens when a patient needs more specialized care? Has this process changed since the implementation of the CPES project? If so, how?
- 4. In what ways are mental health and psycho-social issues addressed?
 - Probe for support & advise they need to deal with their stress/stigma
 - Probe for differences for men, women and children
 - Probe for how addressing mental health and psycho-social support has changed (if at all) since the implementation of the project
- 5. What EVD survivor needs are currently being met?
 - a. What aspects of care for Ebola survivors are working well?
 - b. What aspects of care for Ebola survivors are not working well?
 - c. Has the health systems ability to meet survivor needs changed in the past year (if so, how?)
 - d. What are some of the reasons for why EVD survivors' needs are not being met?
- 6. Tell us more about the barriers EVD survivors face in accessing health services.
- 7. In your view, what are some of the things that can be done to take care of the challenges faced by EVD survivors?
- 8. How does SLAES work with EVD survivors to support their needs especially their health needs?
 - a. How is it engaged with the DHMT and health service provision by PHUs and district hospital?
 - b. Is SLAES work with survivors currently sustainable?
 - If so, how
 - If not, what would be needed to sustain them?
- 9. Overall, what changes (if any) would you like to see in the near future to improve the health situation of survivors? Why?
- 10. Is there anything else you want to discuss?

Thank the respondent f	or their time and ask if they have any questions for you.	Turn off the recorde	r.
End Time			

EVD Survivors

- 1. What are some of your needs as an EVD Survivor? Can you give me some examples?
 - a. What health services do you need in general?
 - How often do you need these services?
 - And where do you access health services?
 - b. What psycho-social support and counseling do you and/or other EVD Survivors need in general?
 - Probe for support & advise they need to deal with their stress/stigma
 - c. Of all the needs mentioned, what specific needs apply to women and children? (probe for any other needs apart from those listed)
 - d. In your view, how can some of the needs you just mentioned best be met?
- 2. What are some of the problems you and other survivors have faced when they access health or other social support services? (Please refer to all levels at the clinics & hospitals.)
 - Probe for issues such as (distance, stigma faced, time/transport issues, service readiness
 of facilities, type of care needed, any gender related biases)
 - a. Has this changed at all during the last year?
- 3. Tell us more about the barriers you and other EVD survivors face in accessing health services.
 - a. Have these changed in the past year?
- 4. Have you experienced stigma as an EVD survivor?
 - Probe on what kinds of stigma (at the health facility, at the community level, self-stigma)
 - a. Has your experience of stigma changed over the past year (has it gotten better or worse at the facility, at the community, etc.)

	anything else you espondent for thei	want to discuss? r time and ask if th	ey have any que	stions for you.	Turn off the	recorder.
End Time						

