



# Comprehensive Program for Ebola Survivors

## Impact Report

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### Mohammad Bailor Jalloh, MPH, MOR

Chief Executive Officer and Founder  
FOCUS1000  
15A, Main Motor Road, Brookfield,  
Freetown  
Sierra Leone  
232 79060692  
[mbjalloh@focus1000.org](mailto:mbjalloh@focus1000.org)

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## Acronyms

CI	Confidence Interval	N	Sample size
CDCP	Center for Disease Control and Prevention	NA	Not Applicable
CTO	Clinical Training Officer	NS	Not Statistically Significant
CPES	Comprehensive Program for Ebola Survivors	p	Probability value
DHMT	District Health Management Team	PHU	Peripheral Health Unit
ESCC	Ebola Survivors Care Consortium	PiH	Partners in Health
ETC	Ebola Treatment Center	PIS	Personal Interview Survey
ETP&SS	Ebola Transmission Prevention & Survivor Services	PP	Percentage Point(s)
EVD	Ebola Virus Disease	QoC	Quality of Care
EVP	Ebola Virus Persistence	RCT	Randomized Control Trial
IDI	In-Depth Interview	SA	Survivor Advocate
IMC	International Medical Corps	SE	Standard Error of the Mean
IP	Implementing Partners	SES	Socioeconomic Status
JSI	JSI Research & Training Institute, Inc.	StC	Save the Children
LQAS	Lot Quality Assurance Sampling	STI	Sexually Transmitted Infection
MdM	Medicos del Mundo	SLAES	Sierra Leone Association of Ebola Survivors
MoHS	Ministry of Health and Sanitation	USAID	United States Agency for International Development
MSWGCA	Ministry of Social Welfare, Gender and Children's Affairs	WHI	World Hope International
		WHO	World Health Organization

## Executive Summary

### Background and Research Design

In late 2015, the President of Sierra Leone, His Excellency Ernest Bai Koroma, instructed the Ministry of Health and Sanitation (MoHS) and the Ministry of Social Welfare, Gender, and Children's Affairs (MSWGCA) to

*"The survivors are our sisters, brothers and relatives. Therefore, government and stakeholders should look after their needs by incorporating their health care needs into the national health care system."*

**Male DHMT IDI respondent, Western Area-Urban**

lead a Comprehensive Program for Ebola Survivors (CPES) to improve the well-being of Ebola Virus Disease (EVD) survivors by providing both basic and specialized healthcare. CPES's long-term objective was to improve the wellbeing of approximately 3,500 EVD survivors that could be reached by CPES by integrating survivor health care into the national MoHS system. The 10 to 24-month recovery plan's goals were to provide free healthcare for EVD survivors at MoHS facilities by (1) reducing financial, logistical, and psychosocial barriers to treatment, (2) increasing the capacity of existing facilities and systems to provide better care across the health service delivery system, and (3) reduce the risk of EVD resurgence through sexual risk-reduction counselling and access to viral persistence testing. CPES was implemented in 13 districts by a complex consortium of implementation partners (IP) that included international funders, government agencies, non-governmental partners and EVD survivor support groups.

This report provides an analysis of the research that was conducted by Focus1000 that was implemented in a longitudinal (Baseline<sup>1</sup> vs. End-line) design and that used mixed methods (quantitative personal interview surveys (PIS) with EVD survivors and qualitative in-depth interviews (IDI) with key informants). There was no comparison or control group. Ten over-arching research questions were developed to guide the research and to help assess the achievement of CPES's goals and objectives. Each research question is in two parts: (a) What is the current level of each variable of interest? and (b) Has there been any change during the period from baseline to end-line in the level of the variable? Sub-group analyses were done by (1) gender, (2) age, and (3) region. The qualitative research

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<sup>1</sup> The term "baseline" is used throughout this report because this first survey provides the first point of evidence for the research, but in fact, CPES began implementation of the program activities in April 2016, approximately 10 months prior to the baseline survey.

was designed to add a deeper understanding from the perspective of the diverse group of implementers and beneficiaries to guide future program improvement.

For the PISs, Lot-Quality Assurance Sampling (LQAS) techniques were used to select respondents from sampling frames of registered EVD survivors using two steps to assure both geographic and gender representation in the sample. The baseline survey sample consisted of 386 women and 371 men and the end-line survey sample had 356 women and 338 men. The survey questionnaire contained 11 question modules with questions to address each of the 10 research questions and to provide demographic and socioeconomic status (SES) data on the respondents. Seven scale variables were created both to help summarize the findings and to increase the power of statistical tests. There were only 7 to 10 months between the baseline and end-line surveys, so there was relatively little time for the CPES program to have an impact.

Twenty-one IDIs were conducted at baseline and 24 at end-line partitioned among five key informant types (Survivor Advocates (SA), Peripheral Health Unit (PHU) staff, Sierra Leone Association of Ebola Survivors (SLAES), District Health Management Team (DHMT) staff, and MSWGCA staff).

### Summary of Results

Analysis of 12 independent variables indicate that the baseline and end-line survey samples are very similar to each other except for a fairly major difference (14 pp) in the rural/urban mix of the communities sampled, and minor differences in education/literacy and marital status. This similarity of samples is important because it means that comparisons of baseline to end-line dependent variables are fair comparisons and are not biased by demographic or socioeconomic differences between the samples.

Table A summarizes the key survey results by showing the means for the scale variables at baseline and end-line, and any statistically significant change between surveys. Key findings from the survey data are:

1. The EVD knowledge scale was fairly high (3.5 out of 5) at baseline and showed no change between baseline and end-line.
2. Unfortunately, the number respondents reporting health problems increased by 6 pp to 82% at end-line, and the number of health problems they report increased for both women and men by about 0.7 problems between baseline and end-line. Women consistently reported about 0.3 more problems than men, but they were also asked one more question than men which may explain that difference.
3. In contrast, the level of disability that respondents report has declined substantially between baseline and end-line (4.4 scale points or 45%). These results are supported by improvements in how many days these disabilities (1) made it impossible for the respondent to carry out their usual activities or work (decline by 1.2 days/month or 36% decline), and (2) the number of days they had to reduce their usual work (decline of 1.4 days/month, or 36% decline). One can reconcile the seeming contradictory results of respondents reporting more health problems, but also reporting less severe disabilities and fewer

days when the disabilities interferes with their work/routines, if the health problems people are having have become less severe, or the health care and counseling they are receiving is helping them to manage their health problems more effectively.

4. Nearly all respondents (89%) report going to a health facility to seek care, even at baseline, but there was an increase in the percentage of EVD survivors who report going to a health care facility to treat their health problems between baseline and end-line of 6 pp. Women were somewhat less likely to report going to a health facility at baseline (87% vs 92% for men), but were the same as men at end-line (95% for both genders). Women reported an increase between baseline and end-line for going to a PHU (12 pp) but decreases in going to a Hospital (-21 pp) and to a hospital in Freetown (-5 pp). Men, by contrast, reported no change in going to the PHU or to a District hospital, but a large decrease in going to a hospital in Freetown (-16 pp). So, there are gender differences in health treatment seeking behavior, and there have been changes in the location of healthcare treatment over time that might be related to changes in clinic capacity and/or referral policies. It is also likely that these changes in health-seeking behavior are related to declines in disability, so respondents could seek care at more local health facilities rather than being referred to Freetown.
5. Two scales were created to measure perceptions of healthcare received (1) a 7-Question scale based on seven Likert agree/disagree questions, and (2) a perception of healthcare improvement based on a yes/no question whether each of the healthcare perception questions was improving or not. The healthcare scale remained unchanged between baseline and end-line but the perception of improvement of healthcare actually increased by 0.5 scale points (10%). Women scored lower than men for both of these scales at baseline, but they had about equilibrated or surpassed men in their perceptions of healthcare improvement by end-line.
6. Fortunately, there has been a substantial decline in perceived barriers to healthcare by about 1.7 points (85%). This decline was greater for men (2.4 points) than for women (1.1 points).

<b>Table A. Summary of key quantitative results for scale variables</b>				
<b>Scale Variable</b>	<b>Respondents</b>	<b>Baseline (Mean)</b>	<b>End-line (Mean)</b>	<b>Difference (Scale Points)</b>
5-Question EVD knowledge scale-All (Maximum = 5)	All	3.5	3.4	NS
Count of the number of reported health problems (Max of 12 for women and 10 for men)	Women	2.3	3.0	0.7
	Men	2.0	2.7	0.7
12-Question Disability Scale (larger number indicates more disability)	All	9.7	5.3	-4.4
7-Question Healthcare Perception Scale (larger number indicates better perceived care)	All	7.6	7.8	NS
7-Question Healthcare Improvement Scale (larger number indicates better care)	All	4.8	5.3	0.5



10-Question Barrier Perception Scale (larger number indicates more perceived barriers)	All	-2.0	-3.7	-1.7
8-Question count of the number of types of stigma people report experiencing (Maximum = 8)	All	1.9	0.7	-1.2

7. The number of types of stigma that respondents reported declined by 1.2 types (63%) from baseline (1.9) to end-line (0.7). Women reported more stigma at baseline, but also declined more than men, so at end-line both genders reported experiencing roughly equal amounts of stigma. Even though all of the questions about experienced stigma declined from baseline to end-line, none of the questions on respondent perceptions of whether stigma is improving or not were statistically significant different between baseline and end-line. This is likely at least partly the result of the fact that these perception questions were only asked of those who reported experiencing the stigma, so the sample sizes are small and the respondents asked the question had experienced the stigma. It is also possible, respondents have just become more aware of and/or sensitive to any stigma they do experience; even though it appears to be declining, many EVD survivors are still experiencing it at fairly high levels.
8. Nearly all EVD survivors have met face to face with their SAs and have received psychosocial support from them and others in the CPES program multiple times. Respondents are universally happy with this support.
9. There has been a decline of 11 pp in the percent of respondents who reported being sexually active in the previous 6 months. The decline in sexual activity is only observed for women (-17 pp) as male survivors did not report a decline. Among the sexually-active respondents, condom use has declined both in use of a condom at last sex (-15 pp) and in the frequency of use (-28 pp for often or sometimes use). For men, semen testing for Ebola viral persistence is both high and increased to 96% at end-line. And while most men report having received the results of their test, it is not possible to know from our data if the decline in condom use is related to men who tested negative stopping use because they were no longer deemed to be a risk to spread EVD, or men just abandoning condom use regardless of their EVD status.

*"The survivor's health care service should be blended in the normal health care system so that there will be continuity of service provision for EVD survivors."*

**Male DHMT IDI, Moyamba**

### Discussion summary

The survey data is correlational, not experimental, so one cannot infer that CPES caused the changes that were measured. However, the intense effort put forth by CPES and corroborating evidence from IDIs, strongly suggest that CPES was positively related to the measured changes. The amount of change is encouraging given the short 7 to 10-month interval between PIS surveys and the improvement it signals in the quality of EVD survivors' lives. It is also important to remember that the baseline survey was implemented some months after the initiation of CPES program activities, so some of the program's impact may have occurred prior to the baseline survey.

*"... We need our health care to be completely taken care of... So, if the government can make sure that all the drugs that we need are always available at health facilities throughout the country and make sure that we stop going to the pharmacies to buy drugs that also will be great."*

**Male SLAES IDI, Moyamba**

Male and female survivors have experienced the disease differently in many respects (e.g., stigma experienced, barriers to healthcare perceived, number and types of health problems), but CPES has reduced some of these differences so that by end-line, male and female respondents reported more similar outcomes and experiences.

In conclusion, CPES made substantial progress on several of its goals and objectives. Access to healthcare for all EVD survivors has been improved by reducing financial, logistical, and psychosocial barriers. Further, the perception that the quality of care for EVD survivors has improved is increasing. This is likely caused by the increased capacity of existing facilities and systems to provide better care across the health service delivery chain, including a referral system to make sure survivors are treated at a facility that has appropriate treatments and drugs available. EVD survivors were supported in their recovery of functional capacity through effective delivery of healthcare and psychosocial services. Perhaps most notable was the success in using SAs to deliver individualized services and counselling. EVD survivors have been supported in the re-integration into their communities through a reduction in stigma. While additional progress on many of these goals/objectives is needed, important progress has been made.

There is less or conflicting evidence that CPES has made progress on two other goals/objectives. The goal to reduce the risk of EVD resurgence through sexual risk-reduction counselling and access to viral persistence testing shows mixed results with a high and increasing prevalence of semen testing and test result counselling being measured. However, there is a decline in the use of condoms and the understanding that condoms are an effective means of reducing EVD infection risk. The reduction in disability also reduced the number of days survivors are not able to perform their normal routines, including work, which should improve their livelihood status. However, many IDI respondents called for increased focus on survivor livelihoods, especially for women and people living in rural agricultural areas. That we measured more impacts on health goals rather than on livelihood goals is not surprising as the program was focussed more on health outcomes during the period of study.

## Recommendations

Fifteen recommendations emerge from this study, including:

### **Recommendations for improving health care access:**

1. There is a need for and value of continued free healthcare for a population whose livelihoods have been interrupted or destroyed by the disease and/or stigmatization that arose out of that experience.
2. The health care service for EVD survivors should be integrated into the normal health system.
3. A means for providing access to the specialized drugs and treatment needed by survivors is needed into the future even if CPES moves into a second phase.
4. The health community should continue to build trust in the health delivery system (hospitals, clinics, etc.), as that trust will facilitate treatment response should another Ebola, or similar disease, outbreak occur.
5. Even though perceived barriers to accessing healthcare have declined, they are still prevalent and so continued emphasis on eliminating barriers is required.
6. Transportation to access health facilities continues to be a major barrier and finding affordable means for survivors to travel to appropriate facilities should continue to be a priority. EVD survivors are a known “vulnerable group”, but there may be other similar groups who share similar barriers to health care access and working towards solving problems such as lack of transportation may improve access for more than just the one vulnerable group.
7. The EVD survivor community is worried about continuity of care following the conclusion of CPES Phase I, and communication efforts should be undertaken to assure and instruct survivors in how their future care will be handled.

### **Recommendations for the prevention of EVD spread by sexual contact:**

8. There should be continued emphasis on semen testing for men until the science is clear on when they are no longer infective. There is an ongoing Ebola Virus Persistence study in Sierra Leone to determine the length of time EV remains viable in survivor body fluids (including semen, breast milk and ocular fluids). So far, the study has found *“that Ebola can remain in the semen for up to at least 9 months. Previous studies had detected Ebola virus in semen for up to 6 months. CDC is conducting further tests to determine if the virus is live and potentially infectious this long after recovery. The study also shows that the virus in semen reduces over time. Because of the possible risk of sexual transmission, CDC advises male Ebola survivors to abstain or use condoms unless they know their semen is negative for Ebola”* (CDCP, 2018). WHO presented data that indicates that persistence can be up to 32 months. It should be noted that the last incidences of potential / suspected transmission were in early 2016.

9. There should be an increased emphasis on condom use to help prevent future transmissions. Condom use seems to be positively correlated with semen testing, so counselling on condom use when semen testing is done should be continued. This effort could be coordinated with other programs, such as those addressing HIV and STI prevention, and programs using community health workers to implement them.
10. In CPES Phase 2, ensure that counseling for discordant EVD status couples is included in services, and that it emphasizes the need for semen testing, abstinence and condom use as appropriate.

**Recommendations for other types of support:**

11. Survivors greatly benefited from the psychosocial support they received from various components of the CPES Program given the emotional as well as physical trauma many have suffered. They would benefit from continued psychosocial support.
12. Even though rates of stigma experienced have declined, it remains prevalent and so continued emphasis on eliminating stigma is required.
13. Given the key role that SAs played, they need to be acknowledged for their service and supported in ways that may allow them to continue to support survivors if CPES continues in a second phase. A majority of SAs called for the government not to forget about them now that the CPES programme has transitioned from the first phase. The reliance on volunteers, such as SAs, to provide access to health care services at the community level creates challenges in training, management of workload, and providing incentives that need to be addressed in future programming.
14. Government ministries and NGOs need to be made aware that school-aged children and orphans need educational and psychosocial support.
15. Survivors continue to need increased support for their livelihoods, and this may be most important in rural agricultural areas where skills training is minimal. Women also need financial support to undertake business to take care of their basic financial needs.

## Introduction

### Project Overview<sup>2</sup>

In late 2015, His Excellency Ernest Bai Koroma, the President of Sierra Leone, instructed the Ministry of Health and Sanitation (MoHS) and the Ministry of Social Welfare, Gender, and Children's Affairs (MSWGCA) to lead a government-mandated Comprehensive Program for Ebola Survivors (CPES) to improve the well-being of Ebola Virus Disease (EVD) survivors by providing both basic and specialized healthcare. The MoHS and the MSWGCA have assumed the responsibility of ensuring that the healthcare system in Sierra Leone is adequately equipped and able to respond to the specific needs of EVD survivors in a comprehensive manner. The CPES program began to be implemented in April, 2016 (Jeppesen, personal communication to Vaughan, March 19, 2018).

### CPES Goals and Objectives

CPES aims to improve the wellbeing of EVD survivors by integrating survivor health care into the national MoHS system. Its long-term objective is to integrate EVD survivor healthcare into mainstream clinical services, which were established and are managed by MoHS.

The CPES program contributes to attaining the “Resilient Zero” objectives of the Presidential 10 to 24-month recovery plan and aims to provide free healthcare for EVD survivors at MoHS facilities, including all clinic visits, in- and out-patient procedures, specialized care (e.g., ophthalmology, neurology, mental health, reproductive health for women), medications and diagnostic testing. There are three long-term objectives for CPES:

1. To improve access to healthcare for all EVD survivors by reducing financial, logistical, and psychosocial barriers.
2. To improve quality of care for EVD survivors by increasing the capacity of existing facilities and systems to provide better care across the health service delivery chain, from community to clinic to hospital.
3. To address the risk of EVD resurgence through sexual risk-reduction counselling and access to viral persistence testing.

To achieve these over-arching goals, CPES has set four short-term objectives:

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<sup>2</sup> This Project Overview is taken nearly verbatim from the Baseline quantitative (Davis and others, 2017) and qualitative (Focus 1000, 2018) research reports.

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

### CPES Implementing Partners

Since 2016, the CPES has been supported through a combination of the United Kingdom's Department for International Development-funded Ebola Survivor Care Consortium (ESCC) led by GOAL, and the USAID-funded Ebola Transmission Prevention and Survivor Services (ETP&SS) project, implemented by JSI Research and Training Institute Inc. (JSI).

The ESCC project support to CPES was implemented in 13 districts by a consortium of nine implementing partners (IPs; Table 1), all of which work with the MoHS, MSWGCA, and the World Health Organization (WHO).

CPES activities are led and coordinated by a district coordinator and implemented by a team of Survivor Advocates<sup>5</sup> (SA) and their supervisors at the community level; Clinical Training Officers (CTOs) at the primary care level; and referral coordinators at secondary and tertiary hospitals.

CPES's intended beneficiary population is EVD survivors in Sierra Leone who are collectively represented by a civil society organization named the Sierra Leone Association for EVD Survivors (SLAES).

**Table 1.** CPES Implementing Partners

District	Implementing Partners
Bo	GOAL
Bombali	World Hope International (WHI)
Kailahun	Save the Children (StC)
Kambia	GOAL & Partners in Health (PiH)
Kenema	GOAL
Koinadugu	Medicos del Mundo (MdM)
Kono	PiH
Moyamba	MdM
Port Loko	PiH
Pujehun	StC
Tonkolili	WHI
Western Area Rural <sup>3</sup>	International Medical Corps (IMC), King's Sierra Leone Partnership, and the Welbodi Partnership (tertiary care)
Western Area Urban <sup>4</sup>	IMC, King's Sierra Leone Partnership, and the Welbodi Partnership (tertiary care)

<sup>3</sup> As of May 1, 2017, IMC was replaced by StC and supported through the USAID ETP&SS JSI-managed project until September 30, 2017.

<sup>4</sup> As of May 1, 2017, IMC was replaced by GOAL and supported through the USAID ETP&SS JSI-managed project until September 30, 2017.

<sup>5</sup> All Survivor Advocates are also EVD survivors themselves.

works with established government networks and IPs to operationalize referral systems that facilitate improved service access for EVD survivors.

The CPES program seeks to address challenges faced by EVD survivors through an integrated partnership approach between Government and development partners that strengthens service delivery to EVD survivors, thereby contributing to improved overall survivors' well-being.

### Distribution of EVD Survivors

Figure 1 and Table 2 show that there is high geographic variability in the distribution of EVD survivors<sup>7</sup>, with the highest number in the west, but very low numbers in the southwest and north east districts. Table 2 also shows that there is a wide range in the rate of EVD survivorship (as a function of total population), and that the districts with the highest number of EVD survivors are not necessarily the districts with the highest rate of EVD survivors. For example, the district with the most EVD survivors is Western Area-Urban, but the rate there is only 0.12%, whereas the highest rate is found in the Western Area-Rural district (0.21%). Thus, geographic variation and distribution of EVD survivors were two of the challenges faced by the IPs in implementing their program equitably and efficiently across the country and were also challenges faced by the evaluation team in finding representative samples of respondents.

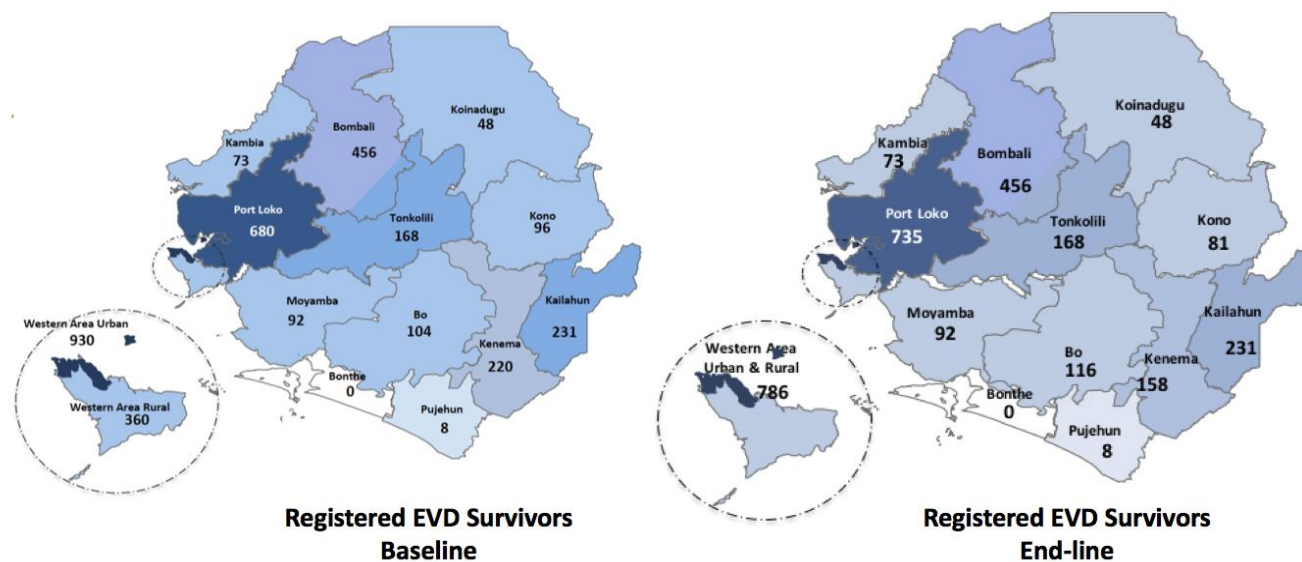
For the end-line PIS, Focus1000 compiled a revised sampling frame of EVD survivors based on the CPES PHU Registered Database used by the CPES IPs, and it differed slightly from the baseline sampling frame (see Figure 1 and Table 4) with a total number of registered survivors of 2,952, of which 2,001 were 18 years old or older.

**Table 2.** District-level population and rate of EVD survivors

District	2008 Household Population <sup>6</sup>	Number of Registered EVD Survivors (Baseline)	Rate of EVD Survivors
Bo	300,256	104	0.03%
Bombali	324,677	456	0.14%
Bonthe	129,878	0	0.00%
Kailahun	357,175	231	0.06%
Kambia	270,376	73	0.03%
Kenema	363,463	220	0.06%
Koinadugu	265,683	48	0.02%
Kono	254,285	96	0.04%
Moyamba	258,506	92	0.04%
Port Loko	453,019	680	0.15%
Pujehun	225,373	8	0.00%
Tonkolili	346,807	168	0.05%
Western Area-Rural	169,807	360	0.21%
Western Area-Urban	764,484	930	0.12%
<b>Total</b>	<b>4,483,438</b>	<b>3,466</b>	<b>0.08%</b>

<sup>6</sup> 2008 household population data are taken from SSL and ICF Macro, 2009.

<sup>7</sup> There were more than 3,466 EVD survivors who were discharged from Ebola treatment centers (ETC), but not all could be tracked or reached by CPES.



**Figure 1<sup>8</sup>.** Geographic distribution of EVD survivors used for baseline and end-line sampling frames.

<sup>8</sup> Figure 1 is taken from Davis and others (2017) for baseline and from Fraenzel and Alva (2017) for end-line.



## Impact Research Methods

A longitudinal research design was conducted by Focus1000 that was implemented in (1) a Pre-Post (Baseline vs. End-line) design that used (2) mixed methods that consisted of (a) quantitative personal interview surveys (PIS) of registered EVD survivors and (b) qualitative in-depth interviews (IDI) with key informants (Fraenzel and Alva, 2017; Focus1000, 2017a). Because the CPES program began implementation in April, 2016 (Jeppesen, personal communication to Vaughan, March 19, 2018), our baseline survey is not a true baseline in the sense of it measuring the state of affairs prior to program implementation, but it is our first point of measurement. Similarly, because CPES is continuing in a Phase 2, our end-line is not a true post program measure, but is the last point of measurement in the current study. The impact research design and protocol were reviewed and approved by the Sierra Leone Ethics and Scientific Review Committee (Fraenzel and Alva, 2017 and Fraenzel, 2017).

## Research Questions

Ten over-arching research questions were developed to help assess the achievement of the CPES project objectives. In most cases, the research questions are two-part: (a) What is the current level of the variable of interest? and (b) Has there been any change from baseline to end-line in the level of the variable? The research questions are:

1. Are the baseline and end-line samples comparable to each other in basic demographic and socio-economic characteristics so that comparisons of their data are fair?
2. What are respondents' levels of knowledge of EVD, including the linkage of the spread of EVD by sexual contact?
3. What health issues do the survivors face currently?
4. What is the current level of disability of EVD survivors?
5. What health services do EVD survivors currently receive through CPES?
6. Are EVD survivors satisfied with the services that they are receiving?
7. What barriers do EVD survivors face in accessing health services?
8. Do EVD survivors face any stigma related to their EVD status?
9. What psychosocial support are EVD survivors receiving from CPES?
10. What is the current sexual behavior of EVD survivors and what risk is there in a resurgence of the virus?

- a. What percentage of male EVCD survivors have been tested for viral persistence, and what percentage of them have received counseling?
- b. What is the extent of need for reproductive health services among women, and are they able to receive the services they need?

### Quantitative Personal Interview Surveys

Following the research protocol (Fraenzel and Alva, 2017), the study population for the surveys included male and female registered EVD survivors who were 18 years old or older in each of the districts of Sierra Leone except Bonthe and Pujehun, where there were almost no registered survivors (Table 4). Because EVD survivors occur at relatively low rates in the general population (0.02% to 0.21%), Lot Quality Assurance Sampling (LQAS) was used to find survivors to interview (Lanta and Black, 1991). IPs and SLAES in each district provided the research team with a sampling frame of registered EVD survivors. A two-step random sampling process was used to select respondents from two sub-groups (1) Chiefdoms to ensure broad geographic and cultural diversity coverage, and (2) male/female to assure adequate gender representation for sub-analyses. This sampling procedure was used to ensure:

**10 Research questions were addressed by a survey with 12 question modules**

1. A reasonable degree of certainty that the findings are representative of the target population.
2. The ability to generalize findings across districts, but the samples were not large enough to be representative within districts.

A survey questionnaire instrument was developed (Appendix A) in collaboration with the CPES monitoring and evaluation group. The baseline and end-line questionnaires were identical except that a number of questions were added to the end-line questionnaire to *“to capture more information that we feel would inform future programming and assist with external validity”* (Fraenzel, 2017). These additional questions assessed (a) access to healthcare during program implementation, (b) experience with the referral system during the program, (c) a module of 37 questions from the Washington Group on Disability Statistics (2018), and (d) a question about dental health issues. One module on the history of health issues that was included in the baseline was found to be redundant with another module, and after baseline analysis it was eliminated for the end-line survey. The baseline and end-line questionnaires assessed 12 areas of interest:

1. Basic demographic and socio-economic characteristics of respondents;
2. Knowledge and awareness of EVD;

3. Current disability and quality of life (all respondents were asked questions about disability in both the baseline and end-line surveys, and the end-line cohort also completed the full Washington Group extended question set on functioning<sup>9</sup> (Fraenzel and Alva, 2017);
4. Nature and extent of health problems;
5. Reproductive and sexual health problems;
6. Current and past health services the respondent had accessed;
7. Perceived quality of and satisfaction with healthcare received;
8. Barriers encountered (or perceived) to accessing the healthcare services;
9. Stigma the respondent had experienced;
10. Psychosocial support received by the respondent;
11. Sexual activity, condom use and testing for EVD in semen for men;
12. Roles played by SA and SLAES during program implementation.

**Fieldwork for the Baseline was conducted in February 2017 and the end-line fieldwork was done between September and December 2017, only 7 to 10 months apart.**

The questionnaire was administered to respondents 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 and data collection checks were conducted daily.

The baseline data was collected between February 2 and 14, 2017, and the end-line data was collected between September 21 and December 7, 2017, so there were only 7 to 10 months between surveys. There was relatively little time for the CPES program to have had an impact. Difficulties in coordinating with the IPs, finding respondents, and logistical and transportation issues delayed the end-line survey and the enumerators had to make two excursions into the field to complete the end-line survey. Baseline and end-line respondents are independent samples.

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<sup>9</sup> The research protocol (Fraenzel and Alva, 2017) called for asking six so-called “Short Set” questions of all respondents and the other 31 questions of a defined subsample of 188 respondents. However, by mistake, all end-line respondents were asked all of the Washington group disability questions.

Baseline and end-line data were sent to Vaughan in separate SPSS data files. Vaughan merged the data into a single file to conduct longitudinal analyses of change over time. Because the sampling frames of EVD survivors were slightly different from baseline to end-line (Figure 1 and Table 4), the data were not weighted to compensate for under and over sampling of districts because of concern that weighting might introduce a bias<sup>10</sup>. The same districts (and Chiefdoms) were sampled at the same rate in baseline and end-line, so the clearest measure of change over time is to not weight the data. The statistical tests that were used to detect differences between baseline and end-line (critical value of  $p < .05$ ) included:

- *Chi-Square* ( $X^2$ ) test for categorical variables with a *z-Test* to determine which response option, if more than two, was responsible for any statistically-significant change.
- *ANOVA* for continuous variables.

Seven scale variables were created from the data in order to summarize results and improve statistical power. The scales were created by assigning numbers to each response option and then simple summation for relevant question groups. These scales include:

1. 5-Question EVD Knowledge Scale, based on the five knowledge questions for which a respondent was given a +1 for each knowledge question that they answered correctly. Larger scores on this scale indicate more EVD knowledge, and possible scores ranged from 0 to 5.
2. 10 (men) to 12 (women)-Question Count of the number of reported health problems EVD survivors report. Larger scores on this scale indicate more health problems, and possible scores ranged from 0 to 10 for men and 0 to 12 for women.
3. 7-Question Treatment Scale, based on seven questions about respondents' perceptions of the quality of or their satisfaction with the treatment the EVD survivor had received (+2 for strongly positive, +1 for positive, 0 for uncertain, -1 for negative, and -2 for strongly negative). Larger scores on this scale indicate more positive perceptions of the health treatment received, and possible scores ranged from -14 to 14.

**7 scales created to summarize survey questions by topic and to increase statistical power to detect change**

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<sup>10</sup> The baseline report was weighted to adjust for over and under sampling of districts relative to the rate of registered EVD survivors in the sampling frame, so there are some differences in the frequencies for some variables reported here and in the baseline report (Davis and others, 2017) because these analyses are not weighted.

4. 7-Question Treatment Improvement Scale to assess the respondents' perceptions of whether the treatment was improving or not for the seven treatment questions (+1 for "Yes" is improving, -1 for "No" not improving). Larger scores on this scale indicate the more positive perception that the treatment is improving over time, and possible scores ranged from -7 to 7.
5. 8-Question count of the number of types of stigma people report experiencing (+1 for each type of stigma they report). Larger scores on this scale indicate more types of stigma encountered, and possible scores ranged from 0 to 8.
6. 10-Question Barrier to Treatment Scale to assess the respondent's perception of whether ten possible barriers were a problem or not (+1 for "Big Problem", -1 for "Not a Big Problem"). Larger scores on this scale indicate more "Big Problem" barriers, and possible scores ranged from -10 to 10.
7. 12-Question Disability Scale to assess the respondent's current level of disability for 12 activities (0 for None, 1 for Mild, 2 for Moderate, 3 for Severe, and 4 for Extreme or Cannot Do). Larger scores indicate increased disability, and possible scores ranged from 0 to 48.

#### Qualitative In-Depth Interviews with Key Informants

The In-Depth Interview (IDI) approach was chosen because it captures respondents' perceptions and thoughts on specific issues of interest related to the CPES program (Fraenzel and Alva, 2017). IDI research allows for detailed and penetrating discussions with individual respondents who have played a key role in implementing the program or who were served by the program. The end-line IDI were conducted by Focus1000 in October 2017, about one month after the first phase of the CPES program concluded. IDI interview guides (Appendix B) were developed to explore:

- Respondents' views on the ability of CPES to provide health services to EVD survivors;
- How constraints on the health staff in providing services to EVD survivors are being addressed;
- What referral systems are in place and how they are working;
- How survivors' needs, including those of women and children, have been addressed;
- Ideas on how improve the CPES program implementation;
- Lessons learned and any insights gained on the CPES program implementation.

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 IP working in each district. All interviews were recorded and transcribed verbatim into English. An electronic record of each interview was created and transmitted to the research team. Transcripts were wiped of all identifying information, and files were stored in a folder that could only be accessed by the research team.

The IDI transcripts were analyzed by Focus1000 using a thematic analysis framework in Nvivo 11 software (Nvivo, 2018). The research team developed a set of codes to summarize and synthesize the findings to obtain rich and useful insights from the data. Qualitative research results

are integrated into this report together with the quantitative data to triangulate results and to add depth of understanding to the quantitative findings. However, a complete report of the qualitative findings is given in Focus1000 (2018).

Table 3 shows the number of IDIs that were conducted at baseline and end-line for each of the key informant types (1) SAs<sup>11</sup>, (2) PHU health workers, (3) SLAES members, (4) DHMT staff, and (5) MSWGCA staff. Interviews were conducted in three geographic areas (1) Western Area-Urban, (2) Bombali/Port Loko, and (3) Kono/Moyamba

**Table 3.** Number of key informant in-depth interviews conducted

Key Informant	Baseline Number of IDI				End-line Number of IDI			
	Western Area-Urban	Bombali / Port Loko	Kono / Moyamba	Total	Western Area-Urban	Bombali / Port Loko	Kono / Moyamba	Total
Ebola SAs	3	3	1	7	3	3	1	7
PHU staff	3	3	2	8	3	3	2	8
SLAES	1	1	1	3	1	1	1	3
DHMT	1	1	1	3	1	1	1	3
MSWGCA	0	0	0	0	1	1	1	3
<b>Total</b>	<b>8</b>	<b>8</b>	<b>5</b>	<b>21</b>	<b>9</b>	<b>9</b>	<b>6</b>	<b>24</b>

## 4. Results

**Table 4.** Number of registered EVD survivors in sampling frames and sample sizes for PIS survey (Adults only, aged 18 and older)

District	Baseline				End-Line			
	Registered Survivors	Male (N)	Female (N)	Total (N)	Registered Survivors	Male (N)	Female (N)	Total (N)
Bombali	456	19	19	38	456	19	19	38

<sup>11</sup> All SAs are also EVD survivors.

### Baseline and End-Line Sample Sizes

Table 4 shows the sample sizes for adults (aged 18 and older) for the PIS surveys that were used in the baseline vs. end-line impact analyses. 757 adult EVD survivors were interviewed at baseline and 694 at end-line. Roughly equal numbers of men and women were interviewed in each survey. The sample sizes used give national-level analyses a margin of error of about 4 percentage points ( $\pm 4$  pp) with 95% confidence (WHO, 1996). Because the sample sizes per district were small in most cases, no district-level analyses are done, but geographic analyses are done

Kambia	73	19	19	38	73	10	16	26
Koinadugu	48	19	19	38	48	17	18	35
Port Loko	680	99	115	214	735	87	91	178
Tonkolili	168	19	19	38	168	19	17	36
<b>North Region</b>	<b>1,425</b>	<b>175</b>	<b>191</b>	<b>366</b>	<b>1,480</b>	<b>152</b>	<b>161</b>	<b>313</b>
Kailahun	231	20	19	39	231	19	19	38
Kenema	220	19	19	38	158	18	17	35
Kono	96	19	19	38	81	18	16	34
<b>East Region</b>	<b>547</b>	<b>58</b>	<b>57</b>	<b>115</b>	<b>470</b>	<b>55</b>	<b>52</b>	<b>107</b>
Bo	104	19	19	38	116	18	19	37
Moyamba	92	19	19	38	92	20	20	40
<b>South Region</b>	<b>196</b>	<b>38</b>	<b>38</b>	<b>76</b>	<b>208</b>	<b>38</b>	<b>39</b>	<b>77</b>
Western Area-Rural	360	50	50	100	786	43	51	94
Western Area-Urban	930	50	50	100		50	53	103
<b>West Region</b>	<b>1,290</b>	<b>100</b>	<b>100</b>	<b>200</b>	<b>786</b>	<b>93</b>	<b>104</b>	<b>197</b>
<b>Totals<sup>12</sup></b>	<b>3,458</b>	<b>371</b>	<b>386</b>	<b>757</b>	<b>2,944</b>	<b>338</b>	<b>356</b>	<b>694</b>

**22% to 23% of all Registered EVD Survivors in the sampling frames were interviewed in both the Baseline and End-line surveys.**

by the four regions (North, East, South and West) as defined by SSL and ICF Macro (2009). However, even in the regional aggregation, there were only about 77 respondents in the South region in each survey. Regional-level analyses are less precise than the national analyses due to the smaller samples, with a margin of error of about  $\pm 5$  pp for North region and  $\pm 10$  pp for South Region at the 95% confidence level (WHO, 1996).

<sup>12</sup> The total number of registered survivors differs from the maps shown in Figure 1 by 8 for both baseline and end-line because Table 4 does not include the 8 survivors in Pujehun, as no interviews were done there.

**Research Question #1:** Are the baseline and end-line samples comparable to each other in basic demographic and socio-economic (SES) characteristics so that comparisons of their data are fair?

Data in Table 5 indicate that baseline and end-line samples are very comparable to each other except for:

- Community type, with the end-line being 14 pp more urban. Urban communities are defined as those that have a population of 2,000 or more, while rural communities have fewer than 2,000. It is noteworthy that a few communities were rated as being urban at baseline but rural at end-line (and vice-versa), so there may be some subjectivity in this designation.
- Baseline respondents are slightly more literate even though the end-line respondents report having slightly more formal education.
- End-line respondents are slightly more likely to report to be cohabiting.

- 1. Bonthé and Pujehun Districts are not included in this study due to the low number of EVD survivors in those districts.**
- 2. There are roughly equal number of men and women in samples because of gender “quota” samples that were drawn.**
- 3. All respondents in the baseline vs. end-line comparison are aged 18 or older.**

**Table 5.** Comparability of baseline and end-line samples

Independent Variable	Response option	Baseline	End-line	Difference
Gender	Female (N = 386; 356)	51%	51%	NS
	Male (N = 371; 338)	49%	49%	NS
Age in years	Average (SE)	33.7 (0.42)	34.5 (0.44)	NS
Age groups (10-year groups)	18 to 29 (N = 335; 281)	44%	41%	NS
	30 to 39 (N = 224; 204)	30%	29%	NS
	40 to 49 (N = 109; 116)	14%	17%	NS
	50 and older (N = 89; 93)	12%	13%	NS
Literate (p = .036)	Yes	45%	41%	-4 pp
Highest grade attended (p = .001)	Primary	17%	8%	-9 pp
	Secondary	69%	76%	NS
	Tertiary	11%	10%	NS
	University	2%	6%	4 pp
Head of Household	Yes	72%	71%	NS



Marital Status (p = .037)	Single	23%	20%	NS
	Cohabiting	2%	5%	3 pp
	Currently married	46%	49%	NS
	Divorced	1%	<1%	NS
	Widowed	26%	24%	NS
	Separated	2%	2%	NS
Ever had a child	Yes	83%	86%	NS
Number of children if had child	Average (SE)	3.0 (.10)	3.3 (.10)	NS
Main source of livelihood	Agriculture	29%	30%	NS
	Business	38%	42%	NS
	Skilled worker	13%	10%	NS
	Teacher	1%	1%	NS
	Health worker	3%	3%	NS
	Other professional	3%	3%	NS
	No source of livelihood	13%	11%	NS
Community type (p = .000)	Rural	73%	59%	-14 pp
	Urban	27%	41%	14 pp
Distance to nearest PHU (miles) <sup>13</sup>	Mean (SE)	2.4 (.14)	2.7 (.14)	NS
<b>NS</b> indicates the difference between baseline and end-line is not statistically significant. <b>PP</b> means Percentage Points. <b>p</b> is the statistical probability				

**Research Question #2:** What are respondents' levels of knowledge of EVD, including the linkage of the spread of EVD by sexual contact?

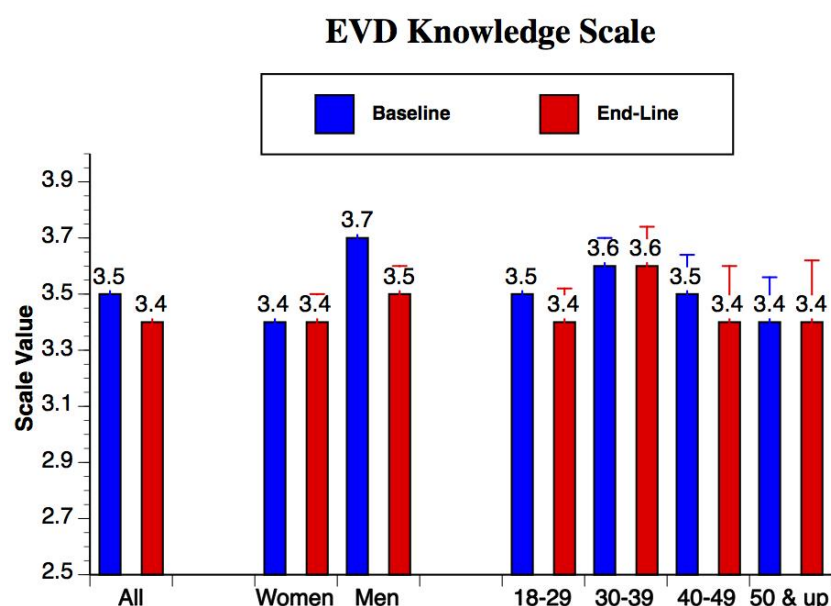
Data in Appendix C indicate that awareness knowledge of Ebola is universal (100%) even at baseline, which is expected in a sample that includes only Ebola survivors. There are statistically-significant declines in two knowledge variables and increases in two others between

**26% of respondents at baseline and 24% at end-line report being widowed. This is much higher than the 3% value reported by women in the 2008 DHS (SSL, 2009), likely a result of their EVD experience.**

<sup>13</sup> One independent variable (Time to PHU) is not presented because it was subjective based on enumerator judgement and was inconsistent with other data. For example, there was little correlation between distance and time to PHU and respondents in the same community often had very different times estimated by the enumerators.

baseline and end-line. However, the Knowledge scale variable (Figure 2) shows no change between baseline and end-line when all respondents are included, suggesting no overall change in knowledge at the population level. However, there was a slight decline for men of about 0.2 scale points. It is also important to note that women overall show slightly lower knowledge levels than men at baseline (0.3 points), but this difference is eliminated at end-line due to the previously mentioned decline for men.

There is very little variation in the Knowledge scale by region (Appendix I) at baseline as the regions range from 3.4 to 3.6, but at end-line the variation increases to a range of 3.0 to 3.7, which is caused by a 0.3-point increase in the Eastern region and a 0.4 decline in the Western region.



**Figure 2.** EVD Knowledge scale for all respondents and disaggregated by gender and age group. 95% CI error bars are included.

The understanding of some of these knowledge variables is complicated in part because some of the questions are ambiguous, or the science may still not be clear about what the correct responses are (WHO, 2018a). For example, whether or not a survivor is symptomatic can influence their infectivity. A second example is that pregnant women who are asymptomatic may not be able to transmit the virus to their unborn fetus (WHO, 2018b). The wording of the survey questions does not allow for this complexity/subtlety of the real-life scientific state of knowledge.

Perhaps the most noteworthy trend is the 8 pp decline in the percentage of respondents who know that condom use is a means of reducing the risk of transmission. This is consistent with data provided later that condom use has declined and is problematic for prevention of a future outbreak of EVD.

**Research Question #3:** What health issues do the survivors face currently and have they changed across time?

Data in Table 6 indicate that there have been substantial increases between baseline and end-line in both the percentage of respondents who report health problems (6 pp) and in the average number of health problems they report (an increase of 0.8 problems per survivor). The increases are the same for women and men (0.7 problems). Older survivors report a slightly higher increase in the number of health problems than younger survivors. The most common health problems people report at end-line are joint problems (75%), headaches (69%), pain (62%), Dental (62%), fever (58%), abdominal issues (28%), and eye-related (24%).

A complicating issue in this analysis is that all people, survivors and people who never contracted Ebola, suffer health issues that are unrelated to their Ebola status. Malaria, for example (mentioned in many IDI), is not known to be related to Ebola as it is spread independently by mosquitoes, and all people are subject to having headaches or joint problems at some point in their lives. The assumption underlying these analyses is that those health problems that are unrelated to EVD status are independent and equally likely to occur in both the baseline and end-line time periods, and so should not contribute to any observed trends in the quantitative data.

**Table 6. Health problems in past 3-months**

Variable	Response option	Baseline	End-line	Difference
Have you had any health problems in the last 3 months?	Yes	76%	82%	6 pp (p = .001)
Type of health problem they had (of those who had a health problem; N = 554 at baseline and 569 at end-line)	Joint	61%	75%	14 pp (p = .000)
	Headache	50%	69%	19 pp (p = .000)
	Pain	41%	62%	21 pp (p = .000)
	Dental	Not asked	62%	NA
	Fever	43%	58%	15 pp (p = .000)
	Abdominal	24%	28%	4 pp (p = .038)
	Eye-related	25%	24%	NS
	Emotional (Poil hat, frustrated, vexed)	9%	13%	4 pp (p = .015)
	Numbness, dizziness, pins & needles	23%	11%	-12 pp (p = .000)
	Reproductive (Difficulty becoming pregnant, prolonged bleeding, increased pain in menses. Women only (N = 289; 299)	8%	8%	NS
	Hearing-related	4%	4%	NS
	Sexual (such as impotence in men)	4%	2%	NS
	Problems during pregnancy (preterm birth, still birth, increased PIH) Women only (N = 289; 299)	2%	0%	-2 pp (p = .000)

Number of health problems (All respondents) <sup>14</sup>	Mean (SE)	2.1 (.07)	2.9 (.08)	0.8 (p = .000)
Number of health problems (Women)	Mean (SE)	2.3 (.11)	3.0 (.10)	0.7 (p = .000)
Number of health problems (Men)	Mean (SE)	2.0 (.09)	2.7 (.11)	0.7 (p = .000)
Number of health problems (Aged 18 to 29)	Mean (SE)	2.1 (.11)	2.8 (.12)	0.7 (p = .000)
Number of health problems (Aged 30 to 39)	Mean (SE)	2.1 (.13)	2.8 (.14)	0.7 (p = .000)
Number of health problems (Aged 40 to 49)	Mean (SE)	2.1 (.17)	2.9 (.17)	0.8 (p = .001)
Number of health problems (Aged 50 and older)	Mean (SE)	2.3 (.24)	3.2 (.19)	0.9 (p = .002)

The number of health problems is highly variable by region (Appendix I) at baseline, with the North region reporting the fewest (1.3) and the South region the most (3.4). This variation declines substantially by end-line so that all regions report survivors having between 2.7 and 3.4 problems, with the North region doubling to 2.7 problems and the West region increasing by 0.4 problems.

In-Depth Interviews<sup>15</sup> revealed a variety of health problems for survivors, since the time they were discharged from the Ebola Treatment Center (ETC), including widespread body pain, erection problem for men, menstrual problems for women and eye sight decline were the most common and most serious health issues affecting the survivors. A few SLAES IDI respondents mentioned problems like complete impotency for some men and barrenness for some women, loss of hearing and other serious complications as some of the permanent health problems faced by the survivors. Almost all of the PHU staff mentioned that the main health problems faced by EVD survivors are joint pain, eye sight issues, abdominal pain, and menstrual problems by women, and malaria by children. They however said, malaria drugs are always available and they have always treated children.

*“Well we had thirty-two health complications but to cut it short, the major ones that were recorded in all health facilities were generalized body pain, we had problems with our manhood for us the men, and the women had their menstrual problem which was a very serious problem or issue. And one of the biggest things was the eye problem that had already made some of our members gone almost blind before the biggest complaint recorded in almost all the different PHUs across the country.”*

**Male SLAES IDI respondent, Western Area Urban**

<sup>14</sup> A total of 12 health problems were asked about in both baseline and end-line, but two of these were gender-specific issues. So, women were asked about 12 health problems and men were asked about 10 health problems.

<sup>15</sup> All text in green boxes are direct quotes from key informant in-depth interviews.

*“For me the most important things that they need is the health care...Some of them complain about the eye sight, the eye sight still torments them, yes sir. We have some children who have lost his/her hearing, and he/she still have that problem. We have some women after the Ebola they developed pressure and up till now it torments them. Even the complications are still present, the joint pains, some will tell you that when I sleep and wake up my body is all over aching me...”*

**Male SA IDI respondent Western Area**

**Research Question #4:** What is the current level of disability of EVD survivors?

Twelve disability questions were asked in both surveys by having the respondent rank their level of ability/disability for each one from “None” to Extreme or cannot do” (Appendix D). The most severe disabilities at baseline were (1) walking a long distance (32% rated this as severe or extreme), (2) Standing (26%), (3) Emotional (21%), (4) Taking care of household responsibilities (17%), and (5) Concentrating for 10 minutes (12%). All 12 disability variables showed improvement over time, and this is best seen in the 12-Question disability scale (Figure 3), which decreased by 4.4 points (45%) between baseline and end-line. The decrease was larger for women than for men (4.7 points vs. 4.3 points), but women generally reported more disability than men overall by about 2 scale points. The decrease in disability was also larger for older respondents than for younger respondents (except for the oldest age group), but older respondents reported more disability than younger respondents overall.

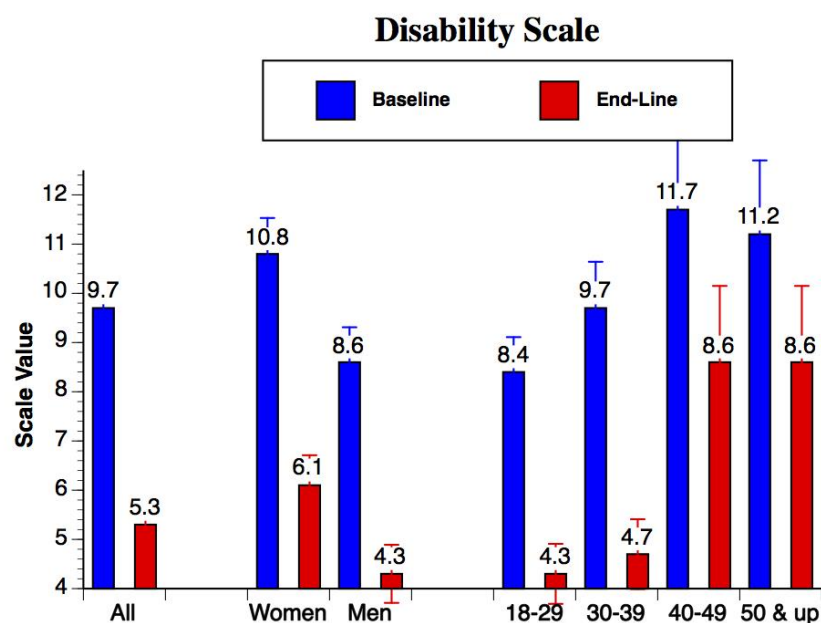
These results are supported by improvements in how many days these disabilities (1) made it impossible for the respondent to carry out their usual activities or work (decline by 1.2 days/month or 36% decline), and (2) the number of days they had to reduce their

usual work (decline of 1.4 days/month, or 36% decline) even though the average number of days/month respondents had these disabilities remained about the same (4.5 days/month).

It is difficult to reconcile the results of respondents' reports of having more health problems, but also reporting having less severe disabilities and fewer days when the disabilities interfere with their work/routines. However, this could possibly be explained if the health problems people are having have become less severe, and/or the health care they are receiving is helping them to manage them more effectively.

Scores on the disability scale varied from 7.9 in the North region to 12.5 in the West region at baseline (Appendix I). Disability scores decreased dramatically in the West by 8 points, and by about 4 points in both the North and East. There was no change in the South, and at end-line, the regions ranged in the disability scale from 4.1 in the North to 8.3 in the South.

There is a very inconsistent relationship between change in the disability scale and change in the number of days symptoms were present, or how many days the disability was limiting. For example, the disability scale decreased the most in the West region (8 points) and as might be expected, this was also reflected in substantial declines in the number of days the disability was present (-4.9 days), totally limiting (-3.5 days), and reduced usual activities (-4.8 days). However, in both the North and East, the disability scale declined by about 4 points, but in the North, this is associated with an increase in the number of days the disability was present (1.3 days) and totally limiting (0.7 days), and in the East there was no change in the number of days for any of the three disability presence/impact measures. Finally, in the South, there was no change in the disability scale, but substantial declines in the number of days the disability totally limited them (-5.2 days) and limited their usual activities (-5.4 days).



**Figure 3.** Disability scale for all respondents and disaggregated by gender and age group. 95% CI error bars are included.

The Washington Group Disability questions that are reported out in Appendix E were only asked at end-line, so no analysis of change over time is possible. The data suggest a variety of physical ailments, the most common relating to (1) vision, (2) mobility, (3) memory, (4) physical strength, and (5) emotional issues. For some questions that used a filter, the sample sizes are extremely small (e.g.,  $N < 10$ ).

#### Research Question #5: What health services do EVD survivors currently receive through CPES?

Nearly all respondents report going to a health facility to seek care even at baseline (Table 7), but there was an increase in the percentage of EVD survivors who report going to a health care facility to treat their health problems between baseline and end-line of 6 pp. Women, who were somewhat less likely to report going to a health facility at baseline (87% vs 92% for men) were the same as men at end-line (about 95% for both genders). Women reported an increase between baseline and end-line for going to a PHU (12 pp) but decreases in going to a District Hospital (-21 pp) and to a hospital in Freetown (-5 pp). Men, by contrast, reported no change in going to the PHU or to a District hospital, but a larger decrease than women in going to a hospital in Freetown (-16 pp). So, there are gender differences in health treatment seeking behavior. A majority of respondents reported seeking care at a health facility more than two times, and this increased by 10 pp between baseline and end-line.

**At end-line, 95% of EVD survivors report going to a health facility to receive care, most to a PHU (71%)**

**Table 7.** How health problems were treated in the previous 3-months

Variable	Response option	Baseline	End-line	Difference
Where they sought care? (of those who had health problems; N = 554 at baseline and 569 at end-line) (p = .002)	Health facility	89%	95%	6 pp
	Somewhere other than a health facility (pharmacy, traditional healers, religious or community leaders)	8%	3%	5 pp
	Did not seek care	3%	1%	-2 pp
For the location outside the health facility, where did you go to get treatment for your health problem? (of those who had health problems; N = 43 at baseline and 24 at end-line)	Community health worker	30%	33%	NS
	Pharmacy	93%	75%	-18 pp (p = .047)
	Country doctor / Traditional healer	2%	0%	NS
	Pastor / Imam	0%	4%	NS
	Community leader	0%	4%	NS
	PHU	66%	71%	5 pp (p = .045)
	District hospital	42%	29%	-13 pp (p = .000)

For the health problem you had, what type of health facility did you go to? (of those who had health problems; N = 495 at baseline and 540 at end-line)	Hospital in Freetown	17%	6%	-11 pp (p = .000)
How many times did you go to treat the health problem(s)? (of those who had health problems; N = 495 at baseline and 540 at end-line) (P = .007)	Once	16%	11%	-5 pp
	Twice	33%	29%	NS
	More than two times	51%	61%	10 pp
Were you referred to a higher-level facility to get better treatment? (of those who had health problems; N = 495 at baseline and 540 at end-line)	Yes	31%	29%	NS
Were you able to go to the referral facility to get the treatment? (of those referred; N = 151 at baseline and 159 at end-line)	Yes	99%	98%	NS

Survivors in all four regions are equally likely to go to a health facility for treatment in both baseline and end-line samples.

IDIs with a variety of respondent types support that health facilities have an increased capacity to support EVD survivors, pointing out such key things as improved outcomes, improved handling of individuals who need special care, and handling survivors whose personal circumstances change, for example if a woman becomes pregnant, she will need different counseling and treatment options.

*“...the health sector has achieved so much in terms of improving our health status as survivors because as I said comparing to eight months back, we have a vast difference to the time we were having the kind of complications that were reported, there is a far difference... So, that tells you how really the health system has improved greatly in the CPES program”*

**Male SLAES IDI respondent, Western Area**

*“As a focal person from DHMT representing EVD survivors, I always follow with health workers to ensure that specialized cases referred to the right place.”*

**Male DHMT IDI respondent, Moyamba**

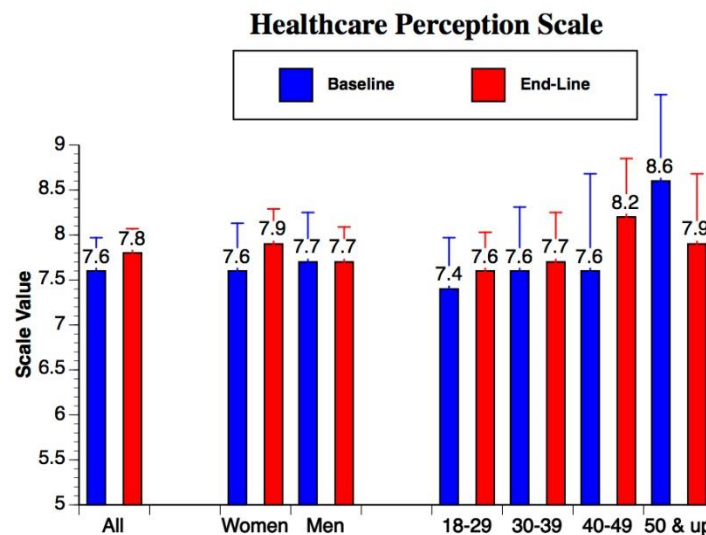


*“we provide services such as antenatal care and other illness, for antenatal care givers, our health workers know that women who have survived Ebola could get pregnant, thus should be in a better position to provide them quality treatment.”*

**Male DHMT IDI respondent, Port Loko**

**Research Question #6:** Are EVD survivors satisfied with the services that they are receiving?

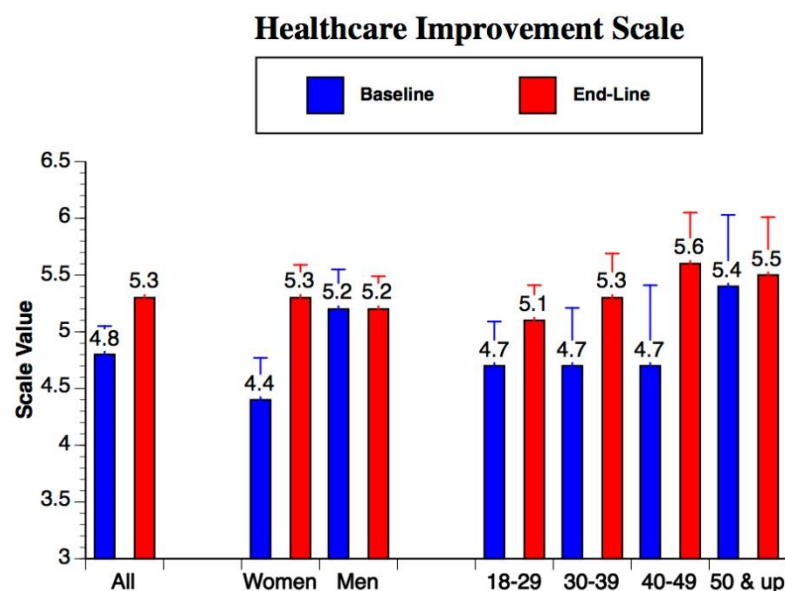
There were seven Likert-scale questions asked about respondents’ perceptions of the healthcare they had received at both baseline and end-line, and three that were asked only at end-line (Appendix E). The overall rating on the 7-Question Healthcare scale did not change between baseline and end-line (Figure 4), so the overall perceived quality of health care did not change even though there was change in each of the individual questions that make up the scale. This lack of change from baseline to end-line was true for both genders and all four age groups. In fact, at end-line, youth were identical to adults in how they scored on this scale. There was a general trend towards improvement, just not enough to be statistically significant. There is substantial room for improvement in this scale, as the maximum possible score is 14 (if all respondents “strongly agreed” with the positive perception), so the end-line mean is only a little over half of the potential maximum score.



**Figure 4.** Healthcare Perception scale for all respondents and disaggregated by gender and age group. 95% CI error bars are included.

For each of the healthcare perception questions, respondents were also asked if they thought the healthcare was improving or not, so a 7-Question healthcare improvement scale was created (Figure 5). This scale increased between baseline and end-line by 0.5 points (10%), but the increase was mostly measured for women among whom the improvement was substantial (20%) from a low

baseline of 4.4 to become about equal to male perceptions at end-line (5.3 points). As with the previous scale, there is much room for improvement in this scale, which also has a maximum of 14 points.



**Figure 5.** Healthcare Improvement scale for all respondents and disaggregated by gender and age group. 95% CI error bars are included.

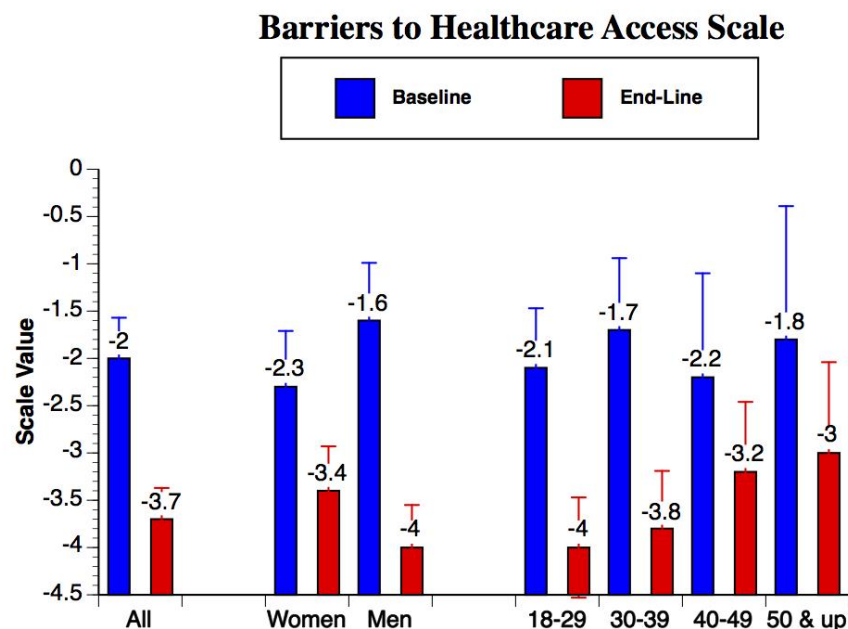
There was a great deal of regional variation in the perception of healthcare received, with scale scores ranging from a low of 2.8 in the South to 11.0 in the North at baseline, and the amount of change from baseline to end-line varied from -2.7 scale points in the North to 4.2 points in the West (Appendix I). At end-line, the regions were more similar in this scale, ranging from 4.2 in the East to 8.3 in the North. To a large degree, the healthcare improvement scale tracked with the healthcare perception scale. For example, in the West the healthcare perception scale increased by 4.2 points and the improvement scale increased by 3.1 points, whereas in the North region, the healthcare perception scale declined by 2.7 points and the improvement scale also declined by 0.7 points. The other two regions showed similar trends but had one of the two healthcare scale variables being not statistically significant different between baseline and

end-line.

#### Research Question #7: What barriers do EVD survivors face in accessing health services?

Most of the perceived “big problem” barriers (Appendix G) to obtaining healthcare declined from baseline to end-line, some by as much as 20 pp. This is reflected in the 10-Question barrier perception scale, in which there was a decline of 1.7 points (85%), with the largest declines measured among young (18 to 39 years old) men (Figure 6). However, even at end-line, six of the 10 barriers continue to be seen as a “big problem” by 35% or more of respondents. The largest perceived barriers at end-line had to do with the

availability of drugs at facilities, distance and transport to facilities, and the quality of care and availability of providers at health care facilities.



**Figure 6.** Barriers to healthcare access scale for all respondents and disaggregated by gender and age group. 95% CI error bars are included.

There was high regional variation at baseline in the barrier scale from -4.8 in the North to 1.1 in the South (Appendix I). Three of the regions showed strong downward trends (fewer barriers) of from -3.0 to -6.3 scale points, but the barrier scale increased by 1.5 points in the North.

IDI respondents also speak of barriers to accessing healthcare and point out that stigma is a form of barrier, and that it can come from health professionals as well as from community members. Many of the barriers that were asked about in the survey were also mentioned in the IDI, for example, lack of medicine in local health facilities, and difficulties in transportation in rural areas.

*“Well one of the barriers is coming from the medical practitioners, because us the survivors are always advocating and anticipating for confidentiality but we often find out that when we would have explained our problem to the medical personnel; we realize that the first point of exposure is come from them they are the only person the survivors talk to. So, if another person hears the news that is how stigma starts...”*

**Male SLAE IDI respondent**

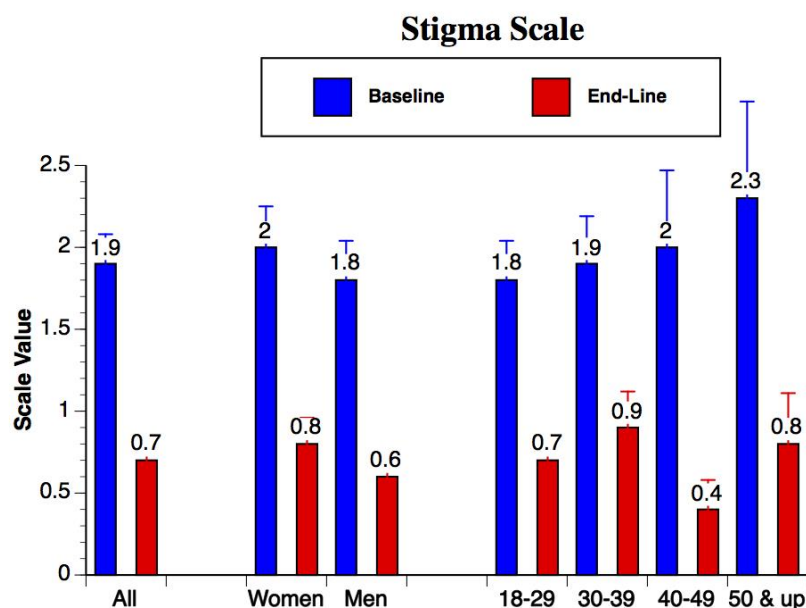
*“...when they come into the clinic, the hospitals most of the times they say medicines are not available, medicines are not available, they have not yet supply us, they have not yet supply us...”*

**Male SA IDI respondent Western Area**

*“Well, the transportation problem is one... like for me that come from Mount Aureol, if someone has sick and you meet him/her sick, for you to climb down that hill at first until you to East End Police where Dwazark motor vehicles are, and take transport to come here, Ah...! That one is difficult for us the transportation issue...”*

**Male SA IDI respondent Western Area**

## Research Question #8: Do EVD survivors face any stigma related to their EVD status?



**Figure 7.** EVD Stigma scale for all respondents and disaggregated by gender and age group. 95% CI error bars are included.

All eight stigma questions (Appendix H) show substantial declines in those reporting having experienced the stigma from baseline to end-line of from 9 to 25 pp. This positive trend is reflected in the improvement in the number of Stigma types that respondents have experienced, which declined from 1.9 to 0.7 (decline of 1.2 types or 63%) (Figure 7). When analyzed individually, there has been no significant change in whether people think stigma is improving or not for any of the eight types of stigma measured (Appendix H), which is likely at least partly the result of the fact that these questions were only asked of those who reported experiencing the stigma, so the sample sizes are small and the respondents asked the question had experienced the stigma. However, the values for improvement perceptions are generally high (for example, from 86% to 95% of respondents said they thought there was improvement in the stigma even at baseline, so

both types of questions provide support for the decline of stigma against EVD survivors over time.

Women generally faced slightly more stigma than men, but both genders note decreased stigma by end-line. Older survivors also faced more types of stigma at baseline than younger survivors, but these gaps narrow in the end-line survey. Regionally, the number of experienced stigma events at baseline ranged from 0.9 in the North to 4.8 in the East, but every region reported a decline in stigma events of from -0.3 in the North to -4.0 in the South (Appendix I).

It is important to point out that serious stigma remains even at end-line, for example, 5% of respondents reported physical assault and 12% report being verbally harassed because of their EVD status. However, reports of stigma by health workers has greatly diminished to only 1-2% of respondents reporting problems with health workers on those three questions at end-line.

The IDI also provide some key insights into stigma, including that some health workers are implicated in causing stigma and that not all people in Sierra Leone understand the laws forbidding stigma. However, they also point out the important role that SLAES and other partners provide in helping EVD survivors overcome stigma.

#### Key Insights from IDI with SLAES about stigma

- Some of the SLAES said health workers are still in the habit of pointing fingers at them (Ebola survivors) and calling them names, which they said makes them feel stigmatized and even prevents them from going to the health facility for treatment when they are sick.
- A majority said the government should make known to the general public that the by-laws for stigmatization against Ebola survivors still exist because some health workers are still in the habit of stigmatizing Ebola survivors.

#### Research Question #9: What psychosocial support are EVD survivors receiving from CPES?

Data in Table 8 are very positive. Nearly all EVD survivors have received psychosocial support including both psychological first aid and counseling, and they have received this support multiple times. Almost all respondents have also met with their Survivor Advocate multiple times in face-to-face encounters, and use them for a variety types of support, but especially for counseling and

*“...the Ministry of Social Welfare, Gender and Children’s Affair (MSWGCA), are the ones that are mentoring and doing psychosocial counselling specifically to members who lost their loved ones, people who were not accepted back in their jobs, when they stigmatized and discriminate us the more, and we also as SLAES executives, if we find out that a particular survivor needs counselling personally for any of these we will come in and help in that...”*

**Male SLAES IDI respondent, Moyamba**

accessing care at a healthcare facility. Overall, survivors are nearly universally happy with the assistance they have received from SAs. There are essentially no differences in these variables when disaggregated by region and gender, and at end-line, youth are essentially the same as adults in the psychosocial care they have received.

**Table 8.** Psychosocial support and counseling from Survivor Advocate and/or PHU

Variable	Response option	Baseline	End-line	Difference
Thinking back to the time from when you were discharged to when this program started – when last rainy season started - have you received any psycho social support/counseling on EVD?	Yes	98%	98%	NS
Did you receive psychological first aid – this is the group meetings where someone helps the community discuss EVD and survivors	Yes	98%	99%	NS
How many times (received psychological first aid)?	1-2 times	7%	9%	NS
	3+ times	24%	23%	NS
	Many times	69%	69%	NS
Did you receive individual counselling – either at home or in the clinic with a professional counsellor? (p = .008)	Yes	96%	98%	2 pp
How many times? (p = .017)	1-2 times	9%	11%	NS
	3+ times	23%	28%	5 pp
	Many times	68%	61%	-7 pp
Overall, are you happy with the assistance provided by your Survivor Advocate?	Yes	99%	98%	NS
In the last 3 months, how often have you interacted with your Survivor Advocate? (p = .001)	None	2%	4%	NS
	1-2 times	9%	13%	4 pp
	3+ times	21%	26%	5 pp
	Many times	67%	57%	-10 pp
What was the reason for interacting with the Survivor Advocate?	Assistance going to a health facility (p = .000)	85%	72%	-13 pp
	Needed additional care at higher-level facility (p = .004)	29%	35%	6 pp
	Needed counseling	85%	88%	NS
	Needed help settling disputes between survivor and community, family, etc.,	14%	13%	NS
	Other assistance needed (p = .000)	10%	3%	-7 pp
Did you physically meet with the survivor advocate?	Yes	98%	99%	NS

The IDI highlight both the need for psychosocial counseling and the emotional trauma suffered by many EVD survivors from the loss of family members and the stress caused by stigmatization that they faced in the aftermath of contracting the disease.

### Key Insights from IDI with SLAES about psychosocial counselling

- A majority of SLAES respondents suggested the need for psychosocial counselling support to continue because most of their fellow survivors need it.

*“...the partners had forums that were a monthly forum in different communities that the survivor advocates and the survivor’s advocate supervisor were organizing at community to give some psycho-social counseling to survivors in a big forum meeting. In that meeting, the advocates gather in each community and try to counsel them, create some funs to ease some of their stress down and that greatly helped throughout the program.”*

**Male SLAES IDI respondent, Bombali**

*“Well we had mental health specialists in the hospitals, we had mental health Nurses and Doctors who were able to take care of mental health because we had a situation of survivor in Port Loko who had almost gone mad but with strong intervention of the mental health Nurses who came strongly to the aide and see how that situation could be taken care of and that was done, and the person is now normal as I am talking to you”*

**Male SLAES IDI respondent, Western Area**

*“We tried to console them, embrace them so that they will not stop to come here whenever they have any difficulty, we shall continue to counsel them because they believe in us as health workers to solve their problems.”*

**Male PHU staff IDI respondent, Port Loko**



**Research Question #10:** What is the current sexual behavior of EVD survivors and what risk is there in a resurgence of the virus?

Table 9 shows that there has been a decline of 11 pp in the percent of respondents who reported being sexually active in the previous 6 months. The decline in sexual activity is solely attributable to women (-17 pp) as the decline for male respondents is not statistically significant, and the decline is most

pronounced in the Southern (-28 pp) and Western (-23 pp) regions. The decline in sexual activity among women is surprising since there was no change in their marital status between pre and post, and the overall level of their disabilities declined. Only one woman in the end-line survey indicated that she had experienced sexual health problems. Among women who reported being sexually active, there was a substantial decline in condom use (from 38% to 23%), and it is conceivable that as their partners became semen tested, those whose partners tested negative remained sexually active and stopped using condoms while those whose partners tested positive stopped being sexually active. The decline in sexual activity was also greater for younger rather than older respondents, although younger respondents still report being more sexually active than older respondents.

**Table 9.** Sexual behavior and semen testing

Variable	Response option	Baseline	End-line	Difference
In the past 6 months, have you had sex? (p = .000)	Yes	79%	68%	-11 pp
Women-Had sex in last 6 months (p = .000)	Yes	70%	53%	-17 pp
Men-Had sex in last 6 months	Yes	88%	84%	NS
Had sex in last 6 months (Aged 18 to 29)	Yes	87%	72%	-15 pp
Had sex in last 6 months (Aged 30 to 39)	Yes	87%	78%	-9 pp
Had sex in last 6 months (Aged 40 to 49)	Yes	68%	65%	NS
Had sex in last 6 months (Aged 50 and older)	Yes	43%	39%	NS
The last time you had sex, did you use a condom? (N = 597; 471) (p = .000)	Yes	46%	31%	-15 pp
How often was a condom used when you have had sex? (N = 597; 471) (p = .000)	Often	25%	14%	-11 pp
	Sometimes	48%	31%	-17 pp
	Never	25%	55%	30 pp
Have you ever participated in semen testing for EBOLA viral persistence? [Men only; N = 327; 284] (p = .000)	Yes	87%	96%	9 pp
When was the last time you were tested for EBOLA viral persistence? [Men who had been tested only; N = 284; 273] (p = .000)	1 month ago or less	15%	5%	-10 pp
	2 or more months ago	65%	66%	NS
	Don't know	20%	29%	9 pp
Did you receive the results of your last semen test for EBOLA viral persistence? [Men who had been tested; N = 228; 194]	Yes	80%	83%	NS
Did you receive any pre/post counselling on viral persistence? [Men; N = 327; 694] (p = .000)	Yes	91%	80%	-11 pp

Among the sexually-active respondents, condom use has also declined both in use at last sex (-15 pp) and in the frequency of use (-28 pp for often or sometimes use). This decline is worrisome, but also consistent with data provided earlier that knowledge that condoms can help prevent the spread of Ebola virus has also declined. The decline in condom use is observed at about the same amount (13 to 18 pp) in all four regions.

For men, semen testing for Ebola viral persistence is offered and the percentage of men who had been tested is both high and increased to 96% at end-line (Table 9). Semen testing was quite low in the South region at baseline (58%), but this increased to 97% at end-line. However, there were only 33 men in these samples, so sampling error may be a significant factor in the low baseline number and large change from baseline to end-line.

**At end-line, 77% of all men aged 15 and older had “ever participated” in semen testing for Ebola viral persistence, and for men who reported they had had sex in the previous 6-months, the “ever participated” level increased to 95%. Of those men 15 and older who had been tested, 83% had received the results of their last semen test.**

Having been tested in the previous month or less has declined by 10 pp, and a significant number of men don't recall when they were last tested. And while most men report having received the results of their test (and counseling about the results), it is not possible to know from our data if the decline in condom use is related to men who tested negative stopping use or men just abandoning condom use regardless of their EVD status. However, at baseline, men who had been tested within the previous month were less likely to have used a condom at last sex (49%) than men who had been tested two or more months ago (54%) or men who didn't remember when they had been tested (59%). This was reversed at end-line, with men tested within the previous month, condom use at last sex had increased to 54%, men who had been tested two or more months ago had declined to 38%, and men who didn't remember when they had been tested declined to 35%. Testing is an opportunity to remind men about the importance of condom use, but unfortunately, it is not possible to tell if condom use is solely related to their semen testing positive, or that counselors promoted the other health benefits of condom use in preventing unwanted pregnancy and STIs.

## Feedback on the CPES program:

Table 10 provides some input from the PIS end-line respondents on how they felt they were able to access the CPES program, with most respondents saying they knew who to contact and that they would contact their SA, and most of the rest would contact SLAES.

Qualitative IDIs with SAs, provided considerable insight and feedback from their perspective on the CPES program. The SA perform many tasks, including:

- Conduct regular home visits to check on survivors and take them to health centers if needed;
- Conduct psychosocial counseling to help survivors cope with the varied issues that they face;
- Conduct weekly planning meetings in communities with survivors to discuss issues they are facing;
- Conduct social mobilization to keep abreast of the needs of survivors as they evolve, or their circumstances change (for example, if a woman becomes pregnant).

Table 10. Feedback on the CPES program at end-line	
Variable	Responses
If you had any problems or feedback on the program, did you know who to contact?	Yes = 95% No = 5%
Who would you contact for problems or feedback on the program?	SA = 85% SLAES = 8% Referral Coordinator = 3% NGO Partner = <1%

### Key insights about CPES from in-depth interviews with SAs

- The majority of SAs called for livelihood support for EVD survivors.
- Most SAs said they want the government to make sure that drugs for survivors are always available in the health centers.
- Most SAs also called the attention of government and NGOs that they have among them school going children and orphans that needs educational support.
- Generally, SAs said they want the NGOs to handle treatment of EVD survivors. When the NGOs were handling it, it was going well.
- Some SAs emphasized that women need financial support to undertake business to take care of their basic financial needs.
- Almost all SAs called on the government and NGOs to provide jobs for them.
- A majority of SAs called the attention of government not to forget about them now that CPES has transitioned from the first phase.

*“But the main challenges and things needed are livelihood support food, financial support, and school fees because most of those paying their school fees are dead and for me, I have four men among us but the balance are women and they are all widows, they are aged women. So, their own cry every day is how they will be able to pay for their children. Initially, we were getting that kind of support from PIH...”*

**Male SA IDI respondent, Port Loko**

Qualitative IDIs with PHU staff also provide interesting insights from their perspective. Most EVD survivors have established reporting channels with IPs, and interviewees who had reported issues through these channels had their complaints acted upon by the authorities. They express very positive interactions with survivors and

recognize the important role they have to play in improving EVD survivor lives. Their functions included:

*“Sometimes when they supply Free Health Care Drugs, it will take 4 to 6 months before they supply another drugs, and during that period, we refer EVD survivors to another hospital because we don’t have the drugs available to treat them”.*

**Male PHU Staff IDI respondent**

- Provide care and treatment of EVD survivors as best they are able;
- Providing drugs, as they were available, and instructing survivors on their use (especially for injections).
- Refer patients to district hospitals if proper treatment/medicine is not available locally.
- Create and maintain records of EVD survivor visits.

*“Movement of people from one PHU centre to another is a major factor for drugs to finish at PHU centre; when you advised them to stay at their own health centres, they will say it is their right to get service where ever they want.”*

**Male PHU IDI respondent, Moyamba**

*“Like in the area of implementation, most cases when they started, we were having problems with the implementing partners, despite the fact that we were told that CPES is our baby but there were certain things that we thought we should be involved in but we were side lined, are you getting me?”*

**Male SLAES IDI respondent, Kono**

### Key insights from in-depth interviews with PHU Staff about their work with EVD survivors

- Most of the PHU staff expressed appreciation of the government for the implementation of the CPES Program. They said initially survivors were scared to come to the hospital for treatment, but government did not discriminate in treatment, as all survivors were given equal opportunity for free treatment.
- Most of them also explained that they were not able to provide certain treatment to all survivors because some would report sick but when tested, it was determined that they were not sick, just under stress.
- A majority of the PHU staff expressed that for drugs that are not available at the facility, they would give out a prescription to the SA who would then accompany the survivor to a pharmacy to get their supply of drugs.
- They also mentioned that they only refer cases that they cannot manage at the health facility. For example, pneumonia and typhoid because drugs to treat those conditions are expensive. If there are no drugs available, they refer the survivors to district hospitals.
- Some PHU staff expressed that initially, gloves were not sufficient for treatment of survivors. Later, the government and other partners supplied protective gear. They also mentioned that some important drugs were not available at the hospitals, and there are times when they have no drugs to treat patients. They said, it takes government up to 3 to 4 months before they supply new drugs at PHU centres.
- Majority of the PHU staff mentioned that their interaction with the SAs, SLAES and the IP were good. Most of them however, expressed that they never saw any counsellor from the MSWGCA involved with the CPES program.
- Similar to the IDI with SA, the lack of training and skills for jobs is a key issue, especially in agricultural areas.
- There is concern that the Government has stopped funding health care for EVD survivors, and so some have stopped coming to the PHU for care.

### Key insights from in-depth interviews with DHMT

- A majority of DHMT staff mentioned that, the DHMT participated in mapping out the number of Ebola Survivors in the country and identified the health facilities that they could go to for treatment;
- Training was conducted for health facilities staff as part of their roles in the CPES programme;
- District Hospitals were treating cases that could be treated and had a referral pathway for particular conditions that they could not treat;
- Some said basic drugs were available in the facilities, but some other drugs were only accessed at the pharmacies where the survivors are directed to access them, and therefore, stated that survivors were able to access the needed healthcare.
- Some DHMT staff also suggested that it would be good to merge the issues of the survivors into the regular health system;
- Almost all the respondents from the DHMT reported that the psychosocial and clinical supports both worked well during the CPES implementation. The psychosocial support gave survivors confidence to go for treatment at health facility while the health facility prioritizes health care services for survivors.
- Most DHMT staff interviewed expressed that DHMT should have been given the support to play a supervisory role but that didn't occur. The supervision was done by the CPES beneficiary and the IP in the district. They only give report to DHMT after activity implementation.
- Some of the DHMT staff interviewed mentioned that they made sure to keep in touch with the facilities across the District as a way of overseeing that the correct things are being done at their facilities.

Interviews with staff from the MSWGCA indicated that they saw their role primarily as supervisory and collaboration with CPES and the IPs by providing referral coordinators, clinical training, coordinating work planning among partners, and financial monitoring.

### Key Insights from IDI with Ministry of Social Welfare Gender and Children's Affairs

- Respondents from MSWGCA disclosed that even though lots of sensitization has been going on, most survivors in the district who lost their entire family during the Ebola epidemic still remember their relatives in tears. According to them, when they visit survivors, sometime they are in a 'bad mood'. It will take them time to talk to them give them stories just to encourage and put them in a good mood. The Ministry therefore recommended that the psychosocial counselling should continue for the survivors as it will help to ease their trauma.
- Respondent suggested that now that the CPES program is ending, they should have given them three to six months' notice with a one-off payment, especially to facilitate access to medicines that are sometimes not available in the PHUs or even the hospitals.
- Respondents said that the Government should work with partners to ensure that the needed drugs for survivors are available nation-wide. They said their lives were complicated and they needed better access to health care, nutrition, counselling, and a loving community.

## Discussion and Conclusions

**Limitations of the study:** The longitudinal survey data is correlational, not experimental, so it is not possible to infer that CPES caused the positive changes that were measured. Causal inferences are only possible in experimental

research designs that include a valid control group, which can be difficult to implement in a field setting, expensive at a national scale, and often have inherent ethical dilemmas. For example, the so-called "gold standard" of randomized control trials (RCT) require that subjects be randomly assigned to treatments, which can endanger the health of the controls, which is especially

*"...during the first six to ten months or twelve months' programme; yeah the Ministry played a great role because we really did not provide direct service but the service providers we make sure that whatever service that they provide for the survivors or whatever we always make sure that we contact them and even try to link with the survivors."*

**Male MSWGCA IDI respondent, Kono**



problematic if there is existing evidence of the efficacy of the intervention. However, the intense effort put forth by CPES and corroborating evidence from IDI, is suggestive that CPES was positively related to the quantitative changes that were measured.

Data are disaggregated for analysis by three sub-groups (1) gender, (2) four regions, and (3) four age groups to try to understand trends over time in each group. However, analyses of the disaggregated data need to be viewed with caution, especially for the last two comparisons because at least one sub-group in each has a small sample size. Specifically, The South region only had 76/77 respondents in each time period, and the oldest age group (50 and older) only had 89/93 respondents in each time period. These small samples make the sub-group analyses susceptible to a larger sampling error<sup>16</sup>, and are likely explanations for some of the large variations measure in them.

The timing of the baseline and end-line surveys create several challenges for interpreting these results. First, the baseline was implemented 10 months after the initiation of the CPES program, and so some of the hoped-for changes in dependent variables may already have occurred prior to the baseline survey. Second, the relatively short time period between baseline and end-line survey (of 7-10 months) allows for only a limited time for the CPES program to have its impact and be measured. Both of these timing issues increase the risk of a Type 2 statistical error or concluding that there has been no impact when in fact there has been, but the change is just too small to measure statistically or that it occurred before we could measure it. This makes it impressive that substantial progress was measured, especially in the decline in perceived barriers to healthcare access, stigma experienced, and disability reported. This may also explain why other variables, such as knowledge and perceptions of the quality of the healthcare received have not improved by statistically significant amounts between surveys.

Although the evaluation did not do a detailed assessment of the management practices of partners working with EVD survivors, IDIs with SLAES, PHU staff, DHMT and MSWGCA revealed that they were trained to effectively manage the affairs of EVD survivors. However, there were some issues in IP management that impacted the study. For example, some of the IPs were hampered in supporting Focus1000 in the end-line survey because Phase 1 had ended and they were closing their offices. This meant enumerators had to persuade these IPs to help them recruit survivors before interviews could be conducted. The longitudinal study design used in this impact evaluation required Focus1000 to locate randomly selected respondents from a sampling frame of EVD survivors compiled by IPs in each district. Ideally, the sampling frame would have included complete contact information for all respondents. However, this data was not readily available at the time of field data collection was scheduled to commence because many of the IPs charged with recruiting the survivors found it difficult to bring them together due to poor roads and transport issues and a lack of

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<sup>16</sup> Sampling error is a statistical term and does not imply any “wrongdoing” by the investigators but is simply an acknowledgement that small samples have a higher likelihood, by random chance, of drawing a non-representative sample relative to a large sample.

cell phone coverage. This caused respondent recruitment to be delayed and likely contributed to the slight differences in sample frames between baseline and end-line.

**Strengths of the study:** This study has two important strengths. First, the baseline and end-line samples are very similar to each other on the socioeconomic variables that were measured. This makes comparisons of baseline to end-line fair and negates the need to conduct multivariate tests that control for differences in SES. Second, the use of both quantitative data and qualitative data allows us to triangulate results. To a large extent, the qualitative data supports the findings of the survey data, lending support to the hypothesis that the CPES program was positively related to the outcomes. In a few instances, the two types of data seem inconsistent, but it is not surprising that different groups of people, EVD survivors and PHU staff, for example, may have differing perceptions of the program.

**Complexity of results:** The quantitative PIS data paints a complex, but generally positive and improving picture for Ebola survivors in Sierra Leone. For example, while knowledge variables remained somewhat static between baseline and end-line, baseline levels were fairly high (perhaps in part due to the fact that the CPES campaign had been underway for 10 months at the time of the baseline) and two knowledge variables declined while another two improved. Another example of the complexity would be that even while the percent of survivors that reported some form of health problem they had experienced over the previous 3-months, and the average number of problems they report have both increased, their level of disability and the number of days that their disabilities impacted their regular work routines declined. It is likely that changes in health-seeking behavior are related to declines in disability, so respondents sought care at more local health facilities than referrals to Freetown. Although the scale used to measure perceived quality of healthcare showed no change over the period of study the perception that healthcare was improving did increase. Another complexity is seen in the data on stigma as while the number of types of stigma survivors report having been exposed to declined, the measures of the perception that stigma was improving were unchanged. This last result is likely related to the fact that only respondents who said they had experienced the stigma were asked if they thought it was improving or not.

Other PIS data are not ambiguous. Perceived barriers to obtaining healthcare declined substantially during the course of the study, and while many barriers still remain, this trend is very positive and likely was related to the CPES program as IDI also supported this. Another clear trend was that the psychosocial support provided by CPES was nearly universally received, respondents reported receiving it multiple times, and survivors were universally happy with it. Survivors have endured great trauma and stress in the course of dealing with and surviving the disease, and the counseling appears to have provided immense relief by helping survivors deal with that.

**Negative trend in condom use:** Perhaps the most concerning results from the PIS data is that both the knowledge that condoms are an effective means of preventing the spread of EVD and the reported use of condoms have declined. This raises the potential risk for another disease outbreak, if not of EVD, possibly of some other sexually-transmitted infection (STI). However, both survey

questions used to measure these variables have some ambiguity, as they are not defined by a time (say 90 days post survival) or the knowledge of whether the survivor has had his semen tested and been counseled that he is virus free, and so it is no longer necessary to use condoms, except to prevent unwanted pregnancies or other STIs. The Ebola virus is known to persist for up to nine months post recovery (CDCP, 2018), and further, even if a sample of semen tests negative, that may not be conclusive proof that the patient is no longer an infection risk during sexual contact. There are ongoing studies in Sierra Leone to try to clarify these issues (CDCP, 2018).

**Qualitative results complement and extend survey results:** The qualitative IDIs give considerable insight to the state of EVD survivors at the conclusion of the first phase of the CPES program in October, 2017. Most of the respondents expressed satisfaction with and appreciation of the government for implementing CPES. Initially, many survivors were scared to come to a hospital for treatment, but because the CPES program did not discriminate, and all survivors were given equal opportunities to access free health care services, this fear subsided over time.

IDI respondents mentioned that the main health problems faced by EVD survivors include (1) joint pain, (2) eye sight defects, (3) abdominal pain, (4) headaches, and (5) menstrual problems by women. These reports of current health concerns are largely consistent with the problems reported in the quantitative PIS data, and it is unfortunate that an increase in the number of health problems between baseline and end-line was measured, although the degree of disability survivors report declines over the same period.

As in any country, Ebola is not the only disease that the population and health care providers need to address. Malaria, pneumonia and typhoid are examples of other diseases that survivors contract and health providers reported that they must deal with. Most IDI respondents indicate that malaria drugs are readily available, but drugs to treat other illnesses are not always available at facilities, and in such cases, health providers give out prescriptions to the SAs, who will accompany the individual survivor to a pharmacy to get the drugs. They also mentioned that they refer certain cases that they cannot manage or treat at the health facilities, for example, because drugs to treat those diseases are expensive.

DHMT staff said (in IDIs) that addressing normal illnesses is the aspect of care for Ebola survivors that they thought had been working well because there were treatments for common illnesses available at all facilities. Thus, survivor complaints about generalized body pain, headaches, joint pain, malaria, fever, chills and other similar issues were readily treated. They mentioned one major concern, which is that Ebola survivors were not initially part of the Free Health Care Plan. That is why their complaints are different from the rest of the population, and certain drugs are difficult to get for them. EVD-specific drugs were different from the normal free health care drugs that were available. EVD survivors had different illnesses from the non-EVD population that involved specialized care like surgery, potency problems, vaginal discharge by women, and hearing problems. There were no drugs available for these types of cases in the free health care system, but they needed to be referred to specific pharmacies where the drugs were available for them to freely access. That was a major challenge until they created a pharmacy where EVD survivors could be referred to access the drugs and the ESCC implementing agencies reimbursed the costs.

*“some patients have died because medicine, such as doxycycline and I.V., are the drugs that mostly not available at health facility”*

**Male PHU staff IDI, Port Loko**

DHMT respondents also said that while NGOs have established agreements with certain pharmacies that the NGO would reimburse the pharmacies for the cost of medicine that is provided to survivors, they are worried about continuity because NGOs often have a specific duration of operation. The free health care was initiated for pregnant women, lactating mothers and under five children. So, the government and partners should continue efforts to broaden the free-health care system to include Ebola survivors, and potentially make provision for drugs that can take care of specialized cases affecting EVD survivors.

DHMT recommended that the health care service for EVD survivors should be blended in the normal health system because they ‘are our sisters and brothers’. They also recommended the continuity of the Free Health Care System because most of the survivors are poor and cannot afford to pay for services.

**Progress on CPES goals:** In conclusion, CPES made substantial progress on several of its goals and objectives. This accomplishment is impressive especially because of the short time-frame between the baseline and end-line surveys. Access to healthcare for all EVD survivors has been improved so that at end-line, 95% of survivors were receiving care at a health facility. This was achieved by reducing financial, logistical, and psychosocial barriers. Further, the perception that the quality of care for EVD survivors has improved by increasing the capacity of existing facilities and systems to provide better care across the health service delivery chain, including a referral system to make sure survivors are treated at a facility that has appropriate treatments and drugs available (also by making drugs available through pharmacies). Although many EVD survivors report continued health challenges, their overall level of disability has declined enabling them to have more days of pursuing their normal activities. EVD survivors were supported in their recovery of functional capacity through effective delivery of healthcare and psychosocial services. Perhaps most notable was the success in using SAs and SLAES to deliver individualized services and counselling. EVD survivors have been supported in the re-integration into their communities through a reduction in stigma. While additional progress on many of these goals/objectives is needed, important progress has been made.

*“We were having specialized cases that were reported from PHU level to secondary to tertiary level which the program actually took care of. People were having problems with their eyes, stomach and even the mental which the partners paid for in whatever cost attached when referred, but now that the program is folding up we don’t know what will be the fate...”*

**Male SLAES IDI, Western Area**

There is less or conflicting evidence that CPES has made progress on two other goals/objectives. The goal to reduce the risk of EVD resurgence through sexual risk-reduction counselling and access to viral persistence testing shows mixed results with a high and increasing prevalence of semen testing and test result counselling being measured. However, there is also a decline in the use of condoms by sexually-active survivors, and the understanding that condoms are an effective means of reducing EVD infection risk. Further, there is only indirect data to support that CPES improved EVD survivors’ livelihoods. The reduction in disability that was measured also reduced the number of days survivors are not able to perform their normal routines, including work. However, no change in the percentage of respondents who reported working for a business or any decrease in respondents who reported they had no means of support between baseline and end-line was measured. However, many IDI respondents called for increased focus on survivor livelihoods, especially for women and people living in rural agricultural areas. This finding of little impact on livelihoods is not surprising as Phase 1 of CPES focussed primarily on health outcomes rather than on livelihood outcomes.

## Recommendations:

Fifteen recommendations emerge from this study, including:

### **Recommendations for improving health care access:**

1. There is a need for and value of continued free healthcare for a population whose livelihoods have been interrupted or destroyed by the disease and/or stigmatization that arose out of that experience.
2. The health care service for EVD survivors should be integrated into the normal health system.
3. A means for providing access to the specialized drugs and treatment needed by survivors is needed into the future even if CPES moves into a second phase.
4. The health community should continue to build trust in the health delivery system (hospitals, clinics, etc.), as that trust will facilitate treatment response should another Ebola, or similar disease, outbreak occur.
5. Even though perceived barriers to accessing healthcare have declined, they are still prevalent and so continued emphasis on eliminating barriers is required.
6. Transportation to access health facilities continues to be a major barrier and finding affordable means for survivors to travel to appropriate facilities should continue to be a priority. EVD survivors are a known “vulnerable group”, but there may be other similar groups who share similar barriers to health care access and working towards solving problems such as lack of transportation may improve access for more than just the one vulnerable group.
7. The EVD survivor community is worried about continuity of care following the conclusion of CPES Phase I, and communication efforts should be undertaken to assure and instruct survivors in how their future care will be handled.

### **Recommendations for the prevention of EVD spread by sexual contact:**

8. There should be continued emphasis on semen testing for men until the science is clear on when they are no longer infective. There is an ongoing Ebola Virus Persistence study in Sierra Leone to determine the length of time EV remains viable in survivor body fluids (including semen, breast milk and ocular fluids). So far, the study has found *“that Ebola can remain in the semen for up to at least 9 months. Previous studies had detected Ebola virus in semen for up to 6 months. CDC is conducting further tests to determine if the virus is live and potentially infectious this long after recovery. The study also shows that the virus in semen reduces over time. Because of the possible risk of sexual transmission, CDC advises male Ebola survivors to abstain or use condoms unless they know their semen is negative for Ebola”* (CDCP, 2018).
9. There should be an increased emphasis on condom use to help prevent future transmissions. Condom use seems to be positively correlated with semen testing, so counselling on condom use when semen testing is done should be continued. This effort could be coordinated with other programs, such as those addressing HIV and STI prevention, and programs using community health workers to implement them.

10. In CPES Phase 2, ensure that counseling for discordant EVD status couples is included in services, and that it emphasizes the need for semen testing, abstinence and condom use as appropriate.

**Recommendations for other types of support:**

11. Survivors greatly benefited from the psychosocial support they received from various components of the CPES Program given the emotional as well as physical trauma many have suffered. They would benefit from continued psychosocial support.
12. Even though rates of stigma experienced have declined, it remains prevalent and so continued emphasis on eliminating stigma is required.
13. Given the key role that SAs played, they need to be acknowledged for their service and supported in ways that may allow them to continue to support survivors if CPES continues in a second phase. A majority of SAs called for the government not to forget about them now that CPES has closed. The reliance on volunteers, such as SAs, to provide access to health care services at the community level creates challenges in training, management of workload, and providing incentives that need to be addressed in future programming.
14. Government ministries and NGOs need to be made aware that school-aged children and orphans need educational and psychosocial support.
15. Survivors continue to need increased support for their livelihoods, and this may be most important in rural agricultural areas where skills training is minimal. Women also need financial support to undertake business to take care of their basic financial needs.

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## Appendix A: CPES End-line Survey Questionnaire

Date (MM/DD/YYYY): \_\_\_\_\_ GPS Coordinates: \_\_\_\_\_ Team Number: \_\_\_\_\_

Enumerator Name number: \_\_\_\_\_

Survivor ID Number: \_\_\_\_\_ Implementing Partner\*: \_\_\_\_\_

\_\_\_\_\_ District\*: \_\_\_\_\_ Chiefdom\*: \_\_\_\_\_ Community: \_\_\_\_\_

\_\_\_\_\_ Rural ☐ Urban: ☐

Closest PHU: \_\_\_\_\_

Distance from PHU: \_\_\_\_\_ (miles)

Time taken to get to PHU: \_\_\_\_\_ (minutes)

\*Fields with drop-down options

### 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, doctor etc.): ☐

☐ 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.	<b>PART 1: Knowledge and Awareness on Ebola:</b> Now, I would like to ask you some questions about what you know about some things related to your health	Response		
		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

No.	<b>PART 3 (Current): Health Services Received :</b> Now, I would like to ask you some questions about health services that you may have received in the past 3 months.	Response		
		Yes (1)	No (0)	Don't know (99)
HS1_3mo	Have you had any health problems in the last <b>3</b> months? [If Yes, go to HS2_3mo else skip to Part 4]	1	0	
HS2_3mo	What type of health problem did you have? [Mark all relevant options] <input type="checkbox"/> Joint Problems <input type="checkbox"/> Eye related problems <input type="checkbox"/> Hearing related problems <input type="checkbox"/> Abdominal problems <input type="checkbox"/> Numbness, dizziness, pins & needles <input type="checkbox"/> Head ache <input type="checkbox"/> Emotional problems (poil hat, frustrated, vexed) <input type="checkbox"/> Sexual health problems (such as impotence for men) <input type="checkbox"/> Reproductive health problems (Difficult in become pregnant, prolonged bleeding, increased pain in menses) <input type="checkbox"/> Problems during pregnancy (preterm birth, still birth, increased PIH) <input type="checkbox"/> Fever <input type="checkbox"/> Pain <input type="checkbox"/> Dental problems Other (specify) _____ <input type="checkbox"/> Don't know			
HS3a_3mo	When you had these health problems, where di d you seek care? <input type="checkbox"/> Health facility [Set the skip pattern for HS5a_3mo]			

	<input type="checkbox"/> Somewhere outside the health facility, including pharmacy, traditional healers, religious or community leaders, or others [Set the skip pattern for HS4_3mo] <input type="checkbox"/> I did not seek care [Set skip pattern for HS3b_3mo]			
HS3b_3mo	If you did not seek care, please explain why not _____ [ Answer and move to Part 4]			
HS4_3mo	For the location outside the health facility, where did you go to get treatment for your health problem? 1 Community Health Worker 2 Pharmacy 3 Country doctor/traditional healer 4 Pastor/Imam 5 Community leader Other (specify)_____ 6 Nowhere			
HS5a_3mo	For any of the health problems in question HS2_3mo, what type of health facility did you go to? [Multiple selection] 1 PHU 2 District hospital 3 Hospital in Freetown 4 Other 99 Don't know			
HS5b_3mo	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			
HS5c_3mo	Were you referred to a higher level facility to get better treatment? [If No or Don't know, go to Part 4]	1	0	99
HS5d_3mo	Were you able to go to the referral facility to get the treatment? [If No or Don't know, go to HS5e_3mo, else go to HS5f_3mo]	1	0	99

HS5e_3mo	Please explain why not 1. Getting permission (from relative, spouse etc.) to go for treatment 2. 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 [Go to Part 4]			
HS5f_3mo	Was the referral facility able to provide the treatment you needed? [If No or Don't know, go to HS5g_3mo. Otherwise go to Part 4]	1	0	99
HS5g_3mo	Were you referred to another facility?	1	0	99

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.	<b>PART 4: Quality of Health Care:</b>	Response	
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	These questions relate to the care you received in the past 3 months. 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						
QOC1a	Has there been any improvement since then?						
QOC2	You were able to get health care when you needed it						
QOC2a	Has there been any improvement since then?						
QOC3	You had easy access to the health specialists when you needed them						
QOC3a	Has there been any improvement since then?						
QOC4	Where you went to get health care, people had to wait too long for emergency treatment						
QOC4a	Has there been any improvement since then?						
QOC5	You paid a large amount when you visit GOVERNMENT (not survivor specific) health facilities which you were not reimbursed for						
QOC5a	Has there been any improvement since then?						
QOC6	You paid a small 'tip' to receive health care in a timely fashion -						
QOC6a	Has there been any improvement since then?						
QOC7	Your health care workers treated you in a friendly and courteous manner						
QOC7a	Has there been any improvement since then?						
QOC8	You were satisfied with the services you received						
QOC8a	Has there been any improvement since then?						
QOC9	You had a regular place to go for healthcare						
QOC9a	Has there been any improvement since then?						
QOC10	How comfortable do you feel going to a healthcare facility by yourself?	Very uncomfortable	Uncomfortable	Neither comfortable nor	Comfortable	Very comfortable	

				uncomfortable			
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No.	<b>PART 5: Stigma Scale:</b> 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 to the last 3 months.	Response		
		Yes (1)	No (0)	Don't know (99)
STIG1	People talked badly about you because of your EBOLA survivor status			
STIG1a	Has there been any improvement since then?			
STIG2	Someone else disclosed your EBOLA survivor status without your permission			
STIG2a	Has there been any improvement since then?			
STIG3	You were verbally insulted, harassed and/or threatened because of your EBOLA survivor status			
STIG3a	Has there been any improvement since then?			
STIG4	You were physically assaulted because of your EBOLA survivor status			
STIG4a	Has there been any improvement since then?			
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			
STIG5a	Has there been any improvement since then?			
STIG6	You were denied health services because of your EBOLA survivor status			
STIG6a	Has there been any improvement since then?			
STIG7	Healthcare workers talked badly about you because of your EBOLA survivor status			
STIG7a	Has there been any improvement since then?			
STIG8	A health worker disclosed your EBOLA survivor status without your permission			
STIG8a	Has there been any improvement since then?			

No.	<b>PART 6: Psycho-social Support &amp; Counselling</b> The next questions are about the counselling support you have received so far from your assigned Survivor Advocate and PHU.	Response		
		Yes (1)	No (0)	Don't know (99)

CPES1	Thinking back to the last 3 months, have you received any psycho social support/counselling on EBOLA? [if No or Don't know, skip to CPES4]			
CPES2a	Did you receive psychological first aid – this is the group meetings where someone helps the community discuss EBOLA and survivors [If No or Don't Know, skip to CPES3a]			
CPES2b	How many times? 1. None 2. 1-2 3. 3+ 4. Many 99. Don't Know			
CPES3a	Did you receive individual counselling – either at home or in the clinic with a professional counsellor? [If No or Don't Know, skip to C]			
CPES3b	How many times? 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 Advocate.			
CPES4	Overall, are you happy with the assistance provided by your Survivor Advocate?			
CPES5	In the last 3 months, how often have you interacted 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] 1. Assistance going to a health facility 2. 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)			
CPES7	Did you physically meet with the survivor advocate?			

No.	<b>Part 7: Barriers to Access:</b> Many different factors can prevent people from getting medical advice or treatment for themselves. The next questions are about your experiences in the past 3 months. 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			

No.	<b>PART 8: Sex and Sexual behaviour:</b> The next questions ask about sexual behaviour. There is no right or wrong answer. Your response will not be linked to you in any	Response		



	way or shared with anyone, including your partner, family, or others.				
		Yes (1)	No (0)	Don't Know (99)	
SB1	In the past 6 months, have you had sex? [If No or Don't Know, skip to Part 9]	Yes (1)	No (0)	Don't know (99)	
SB2	The last time you had sex, did you use a condom?	Yes (1)	No (0)	Don't know (99)	
SB3	How often was a condom used when you have had sex?	Often (1)	Sometimes (2)	Never (3)	Don't know (99)
SB4	Have you ever participated in semen testing for EBOLA viral persistence? [Applies to men only] [If No or Don't Know, skip to Part 9]	Yes (1)	No (0)	Don't Know (99)	
SB5	When was the last time you were tested for EBOLA viral persistence? [Applies to men only] [If Never or Don't Know, skip to Part 9]	1 month/less ago (1)	2 or more months ago (2)		Don't know (99)
SB6	Did you receive the results of your last semen test for EBOLA viral persistence? [Applies to men only]	Yes (1)	No (0)	Don't know (99)	
SB7	Did you receive any pre/post counselling on viral persistence? [Applies to men only]	Yes (1)	No (0)	Don't know (99)	

## 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:		Response				
		None (1)	Mild (2)	Moderate (3)	Severe (4)	Extreme or cannot do (5)
S1	Standing for long periods such as 30 minutes?					
S2	Taking care of your household responsibilities?					
S3	Learning a new task, for example, learning how to get to a new place?					
S4	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?					
S5	How much have you been emotionally affected by your health problems?					
In the past 30 days, how much difficulty did you have in:						
S6	Concentrating on doing something for ten minutes?					
S7	Walking a long distance such as one mile [or equivalent]?					
S8	Washing your whole body?					
S9	Getting dressed?					
S10	Dealing with people you do not know?					
S11	Maintaining a friendship?					
S12	Your day-to-day work/school?					
H1	Overall, in the past 30 days, how many days were these difficulties present?	<b>Record number of days</b> ____				
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?	<b>Record number of days</b> ____				

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 because of any health condition?	<b>Record number of days</b> ____
----	--	-----------------------------------

<b>Washington Group Items</b> (Note: All respondents will answer the questions in <b>bold</b> . Only subsample respondents will receive the full 37-item scale)						
Now I am going to ask you some additional questions about your ability to do different activities, and how you have been feeling. [Although some of these questions may seem similar to ones you have already answered, it is important that we ask them all.]”						
W1	Do you wear glasses?	Yes (1)	No (2)	Refused (7)	Don't Know (9)	
		No Difficulty (1)	Some difficulty (2)	A lot of difficulty (3)	Cannot do at all/ unable to do (4)	Refused (7) / Don't Know (9)
W2	<b>Do you have difficulty seeing [even when wearing your glasses]? Would you say...</b>					
W3	Do you have difficulty clearly seeing someone's face across a room [even when wearing your glasses]? Would you say...					
W4	Do you have difficulty clearly seeing the picture on a coin [even when wearing your glasses]? Would you say...					
W5	Do you use a hearing aid?	Yes (1)	No (2)	Refused (7)	Don't Know (9)	
W6	<b>Do you have difficulty hearing [even when using a hearing aid(s)]? Would you say...</b>	No Difficulty (1)	Some difficulty (2)	A lot of difficulty (3)	Cannot do at all/ unable to do (4)	Refused (7) / Don't Know (9)
W7	How often do you use your hearing aid(s)? Would you say...	All of the time (1)	Some of the time (2)	Rarely (3)	Never (4)	Refused (7) / Don't Know (9)

		No Difficulty (1)	Some difficulty (2)	A lot of difficulty (3)	Cannot do at all/ unable to do (4)	Refused (7) / Don't Know (9)
W8	Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even when using your hearing aid(s)]? Would you say...					
W9	Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [even when using your hearing aid(s)]? Would you say...					
<b>W10</b>	<b>Do you have difficulty walking or climbing steps? Would you say...</b>					
		Yes (1)	No (2)	Refused (7)	Don't Know (9)	
W11	Do you use any equipment or receive help for getting around?					
W12	Do you use any of the following:					
W12A	Cane or walking stick?					
W12B	Walker or Zimmer frame?					
W12C	Crutches?					
W12D	Wheelchair or scooter?					
W12E	Artificial limb (leg/foot)?					
W12F	Someone's assistance?					
W12G	Other (please specify): _____					
		No Difficulty (1)	Some difficulty (2)	A lot of difficulty (3)	Cannot do at all/ unable to do (4)	Refused (7) / Don't Know (9)

W13	Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of your aid]? Would you say...				(skip to W15)	
W14	Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [without the use of your aid]? Would you say...					
W15	Do you have difficulty walking up or down 12 steps? Would you say... (Skip to W18 if W11=No or if W12D = Yes)					
W16	Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using your aid? Would you say...				(skip to W18)	
W17	Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using your aid? Would you say...					
W18	<b>Using your usual language, do you have difficulty communicating, for example understanding or being understood? Would you say...</b>	<b>No Difficulty (1)</b>	<b>Some difficulty (2)</b>	<b>A lot of difficulty (3)</b>	<b>Refused (7)</b>	
W19	Do you use sign language?	Yes (1)	No (2)	Refused (7)	Don't Know (9)	
W20	<b>Do you have difficulty remembering or concentrating? Would you say...</b>	<b>No Difficulty (1)</b>	<b>Some difficulty (2)</b>	<b>A lot of difficulty (3)</b>	<b>Cannot do at all/ unable to do (4)</b>	<b>Refused (7) / Don't Know (9)</b>
W21	Do you have difficulty remembering, concentrating, or both? Would you say...	Difficulty remembering only (1)	Difficulty concentrating only (2) (skip to W24)	Difficulty with both remembering and concentrating (3)	Refused (7)	Don't Know (9)

W22	How often do you have difficulty remembering? Would you say...	Sometimes (1)	Often (2)	All of the time (3)	Refused (7)	Don't Know (9)
W23	Do you have difficulty remembering a few things, a lot of things, or almost everything? Would you say...	A few things (1)	A lot of things (2)	Almost everything (3)	Refused (7)	Don't Know (9)
W24	<b>Do you have difficulty with self-care, such as washing all over or dressing? Would you say...</b>	<b>No Difficulty (1)</b>	<b>Some difficulty (2)</b>	<b>A lot of difficulty (3)</b>	<b>Cannot do at all/ unable to do (4)</b>	<b>Refused (7) / Don't Know (9)</b>
W25	Do you have difficulty raising a 2 liter bottle of water or soda from waist to eye level? Would you say...					
W26	Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles? Would you say...					
W27	How often do you feel worried, nervous, or anxious? Would you say...	Daily (1)	Weekly (2)	Monthly (3)	A few times a year (4)	Never (5) Refused (7) / Don't Know (9)
W28	Do you take medication for these feelings?	Yes (1)	No (2)	Refused (7)	Don't Know (9)	
W29	Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings? Would you say...	A little (1)	A lot (2)	Somewhere between a little and a lot (3)		Refused (7) / Don't Know (9)
W30	How often do you feel depressed? Would you say...	Daily (1)	Weekly (2)	Monthly (3)	A few times a year (4)	Never (5) Refused (7) / Don't Know (9)
W31	Do you take medication for depression?	Yes (1)	No (2)	Refused (7)	Don't Know (9)	
W32	Thinking about the last time you felt depressed, how depressed did you feel? Would you say...	A little (1)	A lot (2)	Somewhere between a little and a lot (3)	Refused (7)	Don't Know (9)

W33	In the past 3 months, how often did you have pain? Would you say...	Never (1) (Skip to W35)	Some days (2)	Most days (3)	Every day (4)	Refused (7) / Don't Know (9)
W34	Thinking about the last time you had pain, how much pain did you have? Would you say...	A little (1)	A lot (2)	Somewhere between a little and a lot (3)	Refused (7)	Don't Know (9)
W35	In the past 3 months, how often did you feel very tired or exhausted? Would you say...	Never (1) (Skip to end)	Some days (2)	Most days (3)	Every day (4)	Refused (7) / Don't Know (9)
W36	Thinking about the last time you felt very tired or exhausted, how long did it last? Would you say...	Some of the day (1)	Most of the day (2)	All of the day (3)	Refused (7)	Don't Know (9)
W37	Thinking about the last time you felt this way, how would you describe the level of tiredness? Would you say...	A little (1)	A lot (2)	Somewhere between a little and a lot (3)	Refused (7)	Don't Know (9)

No.	<b>PART 10: Program Implementation</b> Finally, we would like to ask you some questions related to the program.	Response		
		Yes (1)	No (0)	Don't know (99)
PI1	If you had any problems or feedback on the program, did you know who to contact? [If No or Don't know, go to end of survey.]			
PI2	Who would you contact for problems or feedback on the program? 1. Survivor Advocate 2. SLAES 3. Referral Coordinator 4. NGO Partner (GOAL, PIH, JSI, etc.)			

	5. Other: _____ 6. Don't know			
PI3	Did you ever contact anyone about problems or feedback? [If No or Don't know, go to end of survey.]			
PI4	What was the outcome of your reporting of a problem or providing program feedback? (text field)			

This completes the questionnaire. Thank you!



## Appendix B: CPES Baseline and End-line Qualitative Data Collection Guides

**Instructions to facilitators:** Before you begin, you must read the information sheet 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)    Survivor Advocate    DHMT    SLAES

IF DHMT, current role: \_\_\_\_\_

Sex (Please circle one):                      Man                      Woman

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.

## Survivor Advocates

### Let's begin by talking about your activities as a Survivor advocate...

1. What are some of your activities as a Survivor Advocate?
  - a. Tell me about your activities in the last month. (Probe for type of activity and examples for each on how they are done)
  - b. What are the aspects of your role as a Survivor Advocate that you like the most? (Probe for specific examples and why you like them)
  - c. Are you able to perform this role as expected? Why or why not?
  - d. Which activity (ies) do you find easy to do? And why?
  - e. Which activity (ies) do you find difficult to do? And why?

Let's now talk a little bit about the needs of survivors you work with.

2. What are some of the survivors' needs? Can you give me some examples?
  - a. What health services do they need in general?
    - How often do they need these services?
    - And where do they access them?
  - b. What psycho-social support and counseling do they need in general?
    - Probe for support & advise they need to deal with their stress/stigma
  - c. What are the livelihood needs of Ebola survivors? (probe for
  - d. income, employment & means of support)
  - e. Of all the needs mentioned, what specific needs apply to women and children? (probe for any other needs apart from those listed)
  - f. In your view, how can some of the needs you just mentioned be best met?
3. What are some of the problems survivors face 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. How can the problems mentioned be addressed?
  - b. Of these problems, what areas do they need more assistance?

4. Tell us some more about how you interact with the health system in your district. Please refer to both PHUs and the district hospital.
    - a. In what ways do you engage with them? Are you able to do this successfully? Why or why not? Please provide examples.
    - b. What about social workers and psycho-social support and counseling? In what ways do you engage with them? Are you able to do this successfully? Why or why not? Please give examples.
    - c. And other IP staff? In what ways do you engage with them? Are you able to do this successfully? Why or why not? Please provide examples.
    - d. Any other arms of the Government?
    - e. And SLAES?
  5. Overall, what changes (if any) would you like to see in the near future to improve the situation of survivors? Why?
  6. 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

### 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?
  - 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)
  - c. How do you record information about EVD survivors?
  - d. What were the health problems they faced?
  - e. 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?
    - Did it cover women and adolescents and children as well?
  - b. (If no, what services are you unable to provide?

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?

Now we are going to talk about how well your PHU is equipped to treat EVD survivors.

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, 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?
    - Survivor advocates?
    - SLAES members?
    - Social workers and psycho-social counselors?
    - CPES implementing partners in your district?
6. Overall, what changes (if any) would you like to see in the near future to improve the health situation of survivors? Why?
7. 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

## 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?
  - 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:
  - a. PHUs
  - b. district hospitals
  - c. provincial/national hospitals
4. In what ways are mental health and psycho-social issues addressed?
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?
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 the district hospitals and PHUs 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?

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) would you like to see in the near future to improve the health situation of survivors? Why?

11. I would like to ask one last question about program implementation. During the CPES implementation, were you **or your team** involved **or** consulted in project planning and decision-making?

- Probe for any information on why or why not
- Probe for information on decision-making processes and potential successes/challenges

12. 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. How is it different for women, adolescents and children?
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:
  - a. PHU
  - b. District hospitals
  - c. Regional/national hospitals
3. What happens when a patient needs more specialized care?
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
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. 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?
9. Overall, what changes (if any) would you like to see in the near future to improve the health situation of survivors? Why?

10. I would like to ask one last question about program implementation. During the CPES implementation, were you **or your team** involved **or** consulted in project planning and decision-making?

- Probe for any information on why or why not
- Probe for information on decision-making processes and potential successes/challenges

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

## MSWGCA

**Let's begin by talking about your work, especially with regards to CPES and provision of psychosocial and livelihood support services to EVD survivors in your district.**

1. Please tell us about the Ministry of Social Welfare's role in implementing CPES in this district.
  - a. How does the Ministry coordinate CPES activities in the district?
  - b. How does the Ministry oversee the role of SLAES in the services they provide?
2. What is the Ministry's role in ensuring EVD survivors receive the **psychosocial and livelihood support** services related to post Ebola for survivors?
  - a. Did survivors receive any cash transfers during CPES Implementation in your district? If so, how did it help (if it did) to improve the lives of survivors?
  - b. Are you aware of any financial management training that survivors benefitted from during CPES implementation? If so, how has it helped (if it did) to enhance the work that SLAES does?
3. What was the relationship of the Ministry of Social Welfare like with the MoHs, SLAES & IPs in the services provided to EVD survivors



(probe for level of coordination at national and district level)

4. What aspects of the **psychosocial and livelihood** care for Ebola survivors are:
  - Working well in your district? Give reasons
  - And what aspects are not working well? Give reasons
5. Tell me about the necessary resources that the district have for survivors? [examples – infrastructure, supplies, equipment, staff].
  - a. Are you able to provide livelihood services to all survivors? (probe for men, women, adolescents and children)
  - b. From your observation, how has this support help to improve (if any) the lives of survivors. Probe for type of services provided 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 Social Welfare Ministry has tried to resolve/deal with these challenges?
6. In your view, do all survivors have access to the livelihood & psychosocial care they need? Why or why not?
7. Overall, what changes (if any) would you like to see in the near future to improve the livelihood & psychosocial situation of survivors? Why?
8. 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

## APPENDIX C. EVD Knowledge

Variable	Response option	Baseline	End-line	Difference
Have you ever heard of a virus called Ebola?	Yes	100%	100%	NS
Can one reduce their chances of getting Ebola from a survivor by not having sex with him/her?	Yes	87%	79%	-8 pp (p = .000)
Can one reduce their chance of getting Ebola from a survivor by using condoms when having sex with him/her	Yes	95%	87%	-8 pp (p = .000)
Can an Ebola survivor appear healthy?	Yes	65%	72%	7 pp (p = .006)
Can an Ebola survivor who is pregnant pass Ebola to her unborn child?	Yes	5%	9%	4 pp (p = .000)
EVD knowledge scale (All respondents)	Mean (SE)	3.5 (.03)	3.4 (.04)	NS
EVD knowledge scale (Women)	Mean (SE)	3.4 (.04)	3.4 (.05)	NS
EVD knowledge scale (Men)	Mean (SE)	3.7 (.04)	3.5 (.05)	-0.2 (p = .010)
EVD knowledge scale (Aged 18 to 29)	Mean (SE)	3.5 (.04)	3.4 (.06)	NS
EVD knowledge scale (Aged 30 to 39)	Mean (SE)	3.6 (.05)	3.6 (.07)	NS
EVD knowledge scale (Aged 40 to 49)	Mean (SE)	3.5 (.07)	3.4 (.10)	NS
EVD knowledge scale (Aged 50 and older)	Mean (SE)	3.4 (.08)	3.4 (.11)	NS

## APPENDIX D. Physical Ability & Disability

Variable	Response option	Baseline	End-line	Difference
In the past 30 days, how much difficulty did you have in:				
Walking a long distance such as one mile [or equivalent]? (p = .000)	None	27%	55%	28 pp
	Mild	21%	19%	NS
	Moderate	21%	16%	-5 pp
	Severe	26%	10%	-16 pp
	Extreme or cannot do	6%	1%	-5 pp
Standing for long periods such as 30 minutes? (p = .000)	None	31%	50%	19 pp
	Mild	21%	18%	NS
	Moderate	23%	22%	NS
	Severe	21%	10%	-11 pp
	Extreme or cannot do	5%	0%	-5 pp
How much have you been emotionally affected by your health problems? (p = .000)	None	30%	40%	10 pp
	Mild	31%	27%	NS
	Moderate	18%	22%	NS
	Severe	18%	11%	-7 pp
	Extreme or cannot do	3%	0%	-3 pp
Taking care of your household responsibilities? (p = .000)	None	32%	64%	32 pp
	Mild	33%	19%	-14 pp
	Moderate	19%	14%	-5 pp
	Severe	15%	4%	-11 pp
	Extreme or cannot do	2%	0%	-2 pp
Concentrating on doing something for ten minutes? (p = .000)	None	52%	73%	21 pp
	Mild	23%	17%	-6 pp
	Moderate	14%	8%	-6 pp
	Severe	11%	2%	-9 pp
	Extreme or cannot do	1%	0%	-1 pp
Your day-to-day work/school? (p = .000)	None	48%	64%	16 pp
	Mild	26%	19%	-7 pp
	Moderate	17%	13%	-4 pp
	Severe	10%	4%	-6 pp
	Extreme or cannot do	0%	0%	NS
Learning a new task, for example, learning how to get to a new place? (p = .000)	None	49%	83%	34 pp
	Mild	29%	11%	-18 pp

	Moderate	13%	5%	-8 pp
	Severe	9%	1%	-8 pp
	Extreme or cannot do	1%	0%	-1 pp
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? (p = .000)	None	73%	87%	14 pp
	Mild	17%	9%	-8 pp
	Moderate	6%	3%	-3 pp
	Severe	4%	0%	-4 pp
	Extreme or cannot do	1%	0%	NS
Dealing with people you do not know? (p = .000)	None	77%	90%	13 pp
	Mild	15%	8%	-7 pp
	Moderate	5%	1%	-4 pp
	Severe	3%	0%	-3 pp
	Extreme or cannot do	0%	0%	NS
Washing your whole body? (p = .003)	None	82%	89%	7 pp
	Mild	12%	7%	-5 pp
	Moderate	5%	3%	NS
	Severe	2%	1%	NS
	Extreme or cannot do	0%	0%	NS
Maintaining a friendship? (p = .000)	None	84%	91%	7 pp
	Mild	11%	8%	-3 pp
	Moderate	3%	1%	-2 pp
	Severe	2%	0%	-2 pp
	Extreme or cannot do	0%	0%	NS
Getting dressed? (p = .005)	None	86%	90%	4 pp
	Mild	11%	6%	-5 pp
	Moderate	2%	3%	NS
	Severe	1%	0%	NS
	Extreme or cannot do	0%	0%	NS
Percentage that report at least one disability (p = .000)	Report no disability that is mild or more severe	12%	28%	16 pp
Disability 12-Question Scale (larger number indicates higher level of disability)	Mean (SE)	9.7 (.26)	5.3 (.22)	-4.4 (p = .000)
Disability scale (Women)	Mean (SE)	10.8 (.37)	6.1 (.31)	-4.7 (p = .000)
Disability scale (Men)	Mean (SE)	8.6 (.36)	4.3 (.30)	-4.3 (p = .000)
Disability scale (Aged 18 to 29)	Mean (SE)	8.7 (.36)	4.3 (.31)	-4.4 (p = .000)

Disability scale (Aged 30 to 39)	Mean (SE)	9.7 (.48)	4.7 (.36)	-5.0 (p = .000)
Disability scale (Aged 40 to 49)	Mean (SE)	11.7 (.79)	5.8 (.49)	-5.9 (p = .000)
Disability scale (Aged 50 and older)	Mean (SE)	11.2 (.77)	8.6 (.79)	-2.6 (p = .018)
Overall, in the past 30 days, how many days were these difficulties present?	Mean (SE)	4.5 (.21)	4.2 (.26)	NS
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?	Mean (SE)	3.3 (.14)	2.1 (.18)	-1.2 (p = .000)
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 because of any health condition?	Mean (SE)	3.9 (.17)	2.5 (.21)	-1.4 (p = .000)

## Appendix E. Washington Group on Physical Disability

Questions were asked in end-line survey only. All sample sizes are 694 unless otherwise noted.

Variable	Response #1	Response #2	Response #3	Response #4	Response #5
Do you wear glasses?	Yes = 12%	No = 88%			
Do you have difficulty seeing [even when wearing your glasses]?	No Difficulty = 84%	Some Difficult = 13%	A lot of difficulty = 1%	Unable to do = 1%	
Do you have difficulty clearly seeing someone's face across a room [even when wearing your glasses]?	No Difficulty = 85%	Some Difficulty = 13%	A lot of difficulty = 1%	Unable to do = 1%	
Do you have difficulty clearly seeing the picture on a coin [even when wearing your glasses]?	No Difficulty = 86%	Some Difficulty = 13%	A lot of difficulty = 1%	Unable to do = 1%	
Do you use a hearing aid?	Yes = 1%	No = 98 %	Refused = 0%	Don't know = <1%	
Do you have difficulty hearing [even when using a hearing aid(s)]?	No Difficulty = 94%	Some Difficulty = 5%	A lot of difficulty = 1%	Unable to do = <1%	
How often do you use your hearing aid(s)? (Of those who use Aids; N = 10)	All of the time = 30%	Some of the time = 10%	Rarely = 0%	Never = 50%	
Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even when using your hearing aid(s)]?	No Difficulty = 95%	Some Difficulty = 4%	A lot of difficulty = <1%	Unable to do = 1%	
Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [even when using your hearing aid(s)]?	No Difficulty = 90%	Some Difficulty = 8%	A lot of difficulty = 1%	Unable to do = 1%	
Do you have difficulty walking or climbing steps?	No Difficulty = 67%	Some Difficulty = 28%	A lot of difficulty = 5%	Unable to do = <1%	
Do you use any equipment or receive help for getting around?	Yes = 1%	No = 99%			
Those who reported they used equipment or help in getting around (N = 5) were asked:					
Do you use a cane or walking stick?	Yes = 80%	No = 20%			
Do you use a walker or Zimmer frame?	Yes = 0%	No = 100%			
Do you use crutches?	Yes = 0%	No = 100%			
Do you use a wheelchair or scooter?	Yes = 0%	No = 100%			

Do you use an artificial limb (leg/foot)?	Yes = 0%	No = 100%			
Do you use someone's assistance?	Yes = 20%	No = 80%			
Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of your aid]?	No Difficulty = 74%	Some Difficulty = 22%	A lot of difficulty = 2%	Unable to do = <1%	
Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [without the use of your aid]?	No Difficulty = 58%	Some Difficulty = 32%	A lot of difficulty = 9%	Unable to do = 1%	
Do you have difficulty walking up or down 12 steps?	No Difficulty = 61%	Some Difficulty = 33%	A lot of difficulty = 6%	Unable to do = <1%	
Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using your aid? (N= 5)	No Difficulty = 80%	Some Difficulty = 20%	A lot of difficulty = 0%	Unable to do = 0%	
Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using your aid? (N = 7)	No Difficulty = 60%	Some Difficulty = 20%	A lot of difficulty = 20%	Unable to do = 0%	
Using your usual language, do you have difficulty communicating, for example understanding or being understood?	No Difficulty = 98%	Some Difficulty = 2%	A lot of difficulty = <1%	Unable to do = 0%	
Do you use sign language?	Yes = 3%	No = 97%	Refused = <1%		
Do you have difficulty remembering or concentrating?	No Difficulty = 80%	Some Difficulty = 14%	A lot of difficulty = 2%	Unable to do = 0%	Refused = <1% Don't know = 4%
Do you have difficulty remembering, concentrating, or both?	Difficulty remembering only = 12%	Difficulty concentrating only = 3%	Difficulty remembering & concentrating = 7%	Refused = 23%	Don't know = 56%
How often do you have difficulty remembering?	Sometimes = 19%	Often = 1%	All of the time = 1%	Refused = 22%	Don't know = 57%
Do you have difficulty remembering a few things, a lot of things, or almost everything?	A few things = 21%	A lot of things = 3%	Almost everything = <1%	Refused = 20%	Don't know = 57%
Do you have difficulty with self-care, such as washing all over or dressing? (N = 552)	No Difficulty = 88%	Some Difficulty = 4%	A lot of difficulty = 1%	Unable to do = 0%	Refused = 2%

					Don't know = 6%
Do you have difficulty raising a 2-liter bottle of water or soda from waist to eye level?	No Difficulty = 84%	Some Difficulty = 11%	A lot of difficulty = 2%	Unable to do = 0%	Refused = 1% Don't know = 2%
Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?	No Difficulty = 88%	Some Difficulty = 10%	A lot of difficulty = 2%	Unable to do = <1%	Refused = 1% Don't know = <1%
How often do you feel worried, nervous, or anxious?	Daily = 4%	Weekly = 16%	Monthly = 15%	A few times per year = 27%	Never = 33%
Do you take medication for these feelings?	Yes = 14%	No = 79%	Refused = 3%	Don't know = 4%	
Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?	A little = 43%	Somewhere between a little and a lot = 8%	A lot = 13%	Refused = 17%	Don't know = 20%
How often do you feel depressed? (N = 578)	Daily = 41%	Weekly = 10%	Monthly = 8%	A few times per year = 0%	Never = 0%; Refused = 19%; Don't know = 22%
Thinking about the last time you felt depressed, how depressed did you feel?	A little = 35%	Somewhere between a little and a lot = 9%	A lot = 21%	Refused = 17%	Don't know = 19%
In the past 3 months, how often did you have pain?	Never = 15%	Some days = 71%	Most days = 9%	Every day = 3%	Don't know = 1%
Thinking about the last time you had pain, how much pain did you have?	A little = 51%	Somewhere between a little and a lot = 9%	A lot = 26%	Refused = 8%	Don't know = 8%
In the past 3 months, how often did you feel very tired or exhausted?	Never = 13%	Some days = 76%	Most days = 7%	Every day = 2%	Refused = <1% Don't know = 2%
Thinking about the last time you felt very tired or exhausted, how long did it last?	Some of the day = 65%	Most of the day = 11%	All of the day = 9%	Refused = 6%	Don't know = 8%
Thinking about the last time you felt this way; how would you describe the level of tiredness?	A little = 55%	Somewhere between a little and a lot = 9%	A lot = 22%	Refused = 6%	Don't know = 8%



## Appendix F. Perceived Quality of Healthcare

Variable	Response option	Baseline	End-line	Difference
The health care you were receiving was good (p = .000)	Strongly Disagree	5%	1%	-4 pp
	Disagree	9%	1%	-8 pp
	Uncertain	2%	12%	10 pp
	Agree	37%	50%	13 pp
	Strongly agree	48%	36%	-12 pp
Has it improved? (p = .000)	Yes	85%	81%	-4 pp
You were able to get health care when you needed it (p = .000)	Strongly Disagree	6%	0%	-6 PP
	Disagree	13%	3%	-10 pp
	Uncertain	2%	10%	8 pp
	Agree	36%	51%	15 pp
	Strongly agree	43%	36%	-7 pp
Has it improved? (p = .000)	Yes	84%	82%	NS
You had easy access to the health specialists when you needed them (p = .000)	Strongly Disagree	9%	7%	NS
	Disagree	13%	4%	-9 pp
	Uncertain	4%	11%	7 pp
	Agree	34%	46%	12 pp
	Strongly agree	41%	33%	-8 pp
Has it improved? (p = .000)	Yes	80%	79%	NS
Where you went to get health care, people had to wait too long for emergency treatment (p = .000)	Strongly Disagree	37%	33%	NS
	Disagree	24%	24%	NS
	Uncertain	4%	19%	15 pp
	Agree	24%	12%	-12 pp
	Strongly agree	11%	12%	NS
Has it improved? (p = .000)	Yes	78%	72%	-6 pp
You paid a large amount when you visit Government (not survivor specific) health facilities, which you were not reimbursed for (p = .000)	Strongly Disagree	58%	68%	10 pp
	Disagree	31%	15%	16 pp
	Uncertain	2%	10%	8 pp
	Agree	6%	4%	NS
	Strongly agree	4%	3%	NS
Has it improved? (p = .000)	Yes	79%	77%	NS
You paid a small 'tip' to receive health care in a timely fashion (p = .000)	Strongly Disagree	63%	67%	NS
	Disagree	29%	15%	-14 pp
	Uncertain	2%	10%	8 pp

	Agree	5%	2%	-3 pp
	Strongly agree	2%	5%	3 pp
Has it improved? (p = .000)	Yes	83%	78%	-5 pp
Your health care workers treated you in a friendly and courteous manner (p = .000)	Strongly Disagree	5%	2%	-3 pp
	Disagree	3%	1%	-2 pp
	Uncertain	4%	9%	5 pp
	Agree	35%	59%	14 pp
	Strongly agree	53%	28%	-25 pp
Has it improved since then? (p = .000)	Yes	91%	85%	-6 pp
You were satisfied with the services you received	Strongly Disagree	Not asked	1%	NA
	Disagree	Not asked	2%	NA
	Uncertain	Not asked	11%	NA
	Agree	Not asked	54%	NA
	Strongly agree	Not asked	32%	NA
Has it improved since then?	Yes	Not asked	82%	NA
You had a regular place to go for healthcare	Strongly Disagree	Not asked	1%	NA
	Disagree	Not asked	1%	NA
	Uncertain	Not asked	12%	NA
	Agree	Not asked	50%	NA
	Strongly agree	Not asked	36%	NA
Has it improved since then?	Yes	Not asked	84%	NA
How comfortable do you feel going to a healthcare facility by yourself?	Very uncomfortable	Not asked	9%	NA
	Uncomfortable	Not asked	6%	NA
	Neither comfortable nor uncomfortable	Not asked	9%	NA
	Comfortable	Not asked	27%	NA
	Very Comfortable	Not asked	50%	NA
Healthcare Perception 7-Question scale (larger number indicates more positive agreement)	Mean (SE)	7.6 (.19)	7.8 (.14)	NS
Healthcare scale (Women)	Mean (SE)	7.6 (.27)	7.9 (.20)	NS
Healthcare scale (Men)	Mean (SE)	7.7 (.28)	7.7 (.20)	NS
Healthcare scale (Aged 18 to 29)	Mean (SE)	7.4 (.29)	7.6 (.22)	NS
Healthcare scale (Aged 30 to 39)	Mean (SE)	7.6 (.36)	7.7 (.28)	NS
Healthcare scale (Aged 40 to 49)	Mean (SE)	7.6 (.55)	8.2 (.33)	NS
Healthcare scale (Aged 50 and older)	Mean (SE)	8.6 (.49)	7.9 (.40)	NS

Healthcare Improvement 7-Question scale (larger number indicates more improvement)	Mean (SE)	4.8 (.13)	5.3 (.10)	0.5 (p = .006)
Healthcare Improvement scale (Women)	Mean (SE)	4.4 (.19)	5.3 (.15)	0.9 (p = .000)
Healthcare Improvement scale (Men)	Mean (SE)	5.2 (.18)	5.2 (.15)	NS
Healthcare Improvement scale (Aged 18 to 29)	Mean (SE)	4.7 (.20)	5.1 (.16)	NS
Healthcare Improvement scale (Aged 30 to 39)	Mean (SE)	4.7 (.26)	5.3 (.20)	NS
Healthcare Improvement scale (Aged 40 to 49)	Mean (SE)	4.7 (.36)	5.6 (.23)	0.9 (p = .029)
Healthcare Improvement scale (Aged 50 and older)	Mean (SE)	5.4 (.32)	5.5 (.26)	NS

## Appendix G. Barriers to healthcare access

Variable	Response option	Baseline	End-line	Difference
Many different factors can prevent people from getting medical advice or treatment for themselves. The next questions are about your experiences in the past 3 months. When you are sick and wanted to get medical advice or treatment, is each of the following a big problem or not?				
Concern that there may be no drugs available at the health facility	Big problem	62%	49%	-13 pp (p = .000)
Having to take transport	Big problem	38%	49%	11 pp (p = .000)
The distance to the health facility	Big problem	48%	46%	NS
Concern with the quality of care available not good enough	Big problem	60%	46%	-14 pp (p = .000)
Concern that there may NOT be any health provider at the health facility	Big problem	58%	43%	-15 pp (p = .000)
Getting money needed for treatment	Big problem	52%	36%	-16 pp (p = .000)
Not wanting to go alone	Big problem	17%	18%	NS
Concern that there may not be a female health provider [for women participants] or a male health provider (for male participants)	Big problem	23%	13%	-20 pp (p = .000)
No child care available	Big problem	31%	12%	-19 pp (p = .000)
Getting permission (from relative, spouse etc.) to go for treatment	Big problem	13%	4%	-9 pp (p = .000)
10-Question Barrier Perception Scale (larger number indicates more “big problem” barriers perceived)	Mean (SE)	-2.0 (.22)	-3.7 (.17)	-1.7 (p = .000)
Barrier Perception scale (Women)	Mean (SE)	-2.3 (.30)	-3.4 (.24)	-1.1 (p = .004)
Barrier Perception scale (Men)	Mean (SE)	-1.6 (.31)	-4.0 (.23)	-2.4 (p = .000)
Barrier Perception scale (Aged 18 to 29)	Mean (SE)	-2.1 (.32)	-4.0 (.27)	-1.9 (p = .000)
Barrier Perception scale (Aged 30 to 39)	Mean (SE)	-1.7 (.39)	-3.8 (.31)	-2.1 (p = .000)
Barrier Perception scale (Aged 40 to 49)	Mean (SE)	-2.2 (.56)	-3.2 (.38)	NS
Barrier Perception scale (Aged 50 and older)	Mean (SE)	-1.8 (.72)	-3.0 (.49)	NS

## Appendix H. Stigma

Variable	Response	Baseline	End-line	Difference
People talked badly about you because of your Ebola survivor status	Yes	46%	23%	-23 pp (p = .000)
Has there been any improvement since then? (N = 348; 158)	Yes	87%	87%	NS
Someone else disclosed your Ebola survivor status without your permission	Yes	42%	17%	-25 pp (p = .000)
Has there been any improvement since then? (N = 308; 121)	Yes	86%	86%	NS
You were verbally insulted, harassed and/or threatened because of your Ebola survivor status	Yes	24%	12%	-12 pp (p = .000)
Has there been any improvement since then? (N = 184; 83)	Yes	86%	82%	NS
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	Yes	29%	10%	-19 pp (p = .000)
Has there been any improvement since then? (N = 219; 68)	Yes	94%	94%	NS
You were physically assaulted because of your Ebola survivor status	Yes	14%	5%	-9 pp (p = .000)
Has there been any improvement since then? (N = 106; 36)	Yes	93%	83%	NS
A health worker disclosed your Ebola survivor status without your permission	Yes	14%	2%	-12 pp (p = .000)
Has there been any improvement since then? (N = 103; 14)	Yes	88%	86%	NS
Healthcare workers talked badly about you because of your Ebola survivor status	Yes	13%	2%	-11 pp (p = .000)
Has there been any improvement since then? (N = 95; 13)	Yes	92%	92%	NS
You were denied health services because of your Ebola survivor status	Yes	11%	1%	-10 pp (p = .000)
Has there been any improvement since then? (N = 84; 8)	Yes	94%	100%	NS
Number of types of stigma people report experiencing (Max of 8)	Mean (SE)	1.9 (.09)	0.7 (.05)	-1.2 (p = .000)
Stigma number (Women)	Mean (SE)	2.0 (.13)	0.8 (.08)	-1.2 (p = .000)
Stigma number (Men)	Mean (SE)	1.8 (.12)	0.6 (.07)	-1.2 (p = .000)
Stigma number (Aged 18 to 29)	Mean (SE)	1.8 (.12)	0.7 (.07)	-1.1 (p = .000)
Stigma number (Aged 30 to 39)	Mean (SE)	1.9 (.15)	0.9 (.11)	-1.0 (p = .000)
Stigma number (Aged 40 to 49)	Mean (SE)	2.0 (.24)	0.4 (.09)	-1.6 (p = .000)
Stigma number (Aged 50 and older)	Mean (SE)	2.3 (.30)	0.8 (.16)	-1.5 (p = .000)

## Appendix I. Regional disaggregation for ten scale or time variables

Region	Time	Knowledge	Health Problems	Health Care Perception	Health Care Improvement	Stigma	Barrier	Disability	Days Disability Present	Days Totally Incapacitated	Days Reduced activities
<b>North</b> (N = 366; 313)	Baseline	3.6	1.3	11.0	6.5	0.9	-4.8	7.9	2.2	1.8	2.1
	End-line	3.7	2.7	8.3	5.8	0.6	-3.3	4.1	3.5	2.5	2.5
	<b>Change</b>	<b>NS</b>	<b>1.4</b>	<b>-2.7</b>	<b>-0.7</b>	<b>-0.3</b>	<b>1.5</b>	<b>-3.8</b>	<b>1.3</b>	<b>0.7</b>	<b>NS</b>
<b>East</b> (N = 115; 107)	Baseline	3.4	3.2	7.3	6.3	3.8	0.2	10.5	5.7	3.9	4.9
	End-line	3.7	3.4	4.2	5.7	1.1	-2.9	6.6	6.4	3.6	4.8
	<b>Change</b>	<b>0.3</b>	<b>NS</b>	<b>NS</b>	<b>-0.6</b>	<b>-2.7</b>	<b>-3.1</b>	<b>-3.9</b>	<b>NS</b>	<b>NS</b>	<b>NS</b>
<b>South</b> (N = 76, 77)	Baseline	3.6	3.4	2.8	3.8	4.8	1.1	9.6	5.8	6.6	7.3
	End-line	3.4	3.1	6.4	4.8	0.8	-1.9	8.3	4.4	1.4	1.9
	<b>Change</b>	<b>NS</b>	<b>NS</b>	<b>3.6</b>	<b>NS</b>	<b>-4.0</b>	<b>-3.0</b>	<b>NS</b>	<b>NS</b>	<b>-5.2</b>	<b>-5.4</b>
<b>West</b> (N = 200; 197)	Baseline	3.4	2.4	3.3	1.3	1.6	0.8	12.5	9.1	4.8	6.5
	End-line	3.0	2.8	7.5	4.4	0.7	-5.5	4.5	4.2	1.3	1.7
	<b>Change</b>	<b>-0.4</b>	<b>0.4</b>	<b>4.2</b>	<b>3.1</b>	<b>-0.9</b>	<b>-6.3</b>	<b>-8.0</b>	<b>-4.9</b>	<b>-3.5</b>	<b>-4.8</b>