



COMPREHENSIVE PROGRAM FOR EBOLA SURVIVORS BASELINE REPORT

April 2017



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Table of Contents

04

Page

Acronyms

05

Page

Introduction

11

Page

Research
Questions

13

Page

Methods &
Sampling

15

Page

Quantitative Data

22

Page

Qualitative Data

26

Page

Findings

58

Page

Limitations

60

Page

Conclusions

Acronyms

CHP	Community health post	LQAS	Lot quality assurance sampling
CPES	Comprehensive Program for Ebola Survivors	M&E	Monitoring and evaluation
CTO	Clinical training officers	MDM	Medicos del Mundo
DAS	WHO Disability Assessment Schedule	MOHS	Ministry of Health and Sanitation
DHMT	District health management team	MSWGCA	Ministry of Social Welfare Gender and Children's Affairs
ESCC	Ebola Survivors Care Consortium		
ETP&SS	Ebola Transmission Prevention and Survivor Services	NERC	National Ebola Response Centre
EVD	Ebola virus disease	PHU	Primary health unit
EVP	Ebola viral persistence	QOC	Quality of care
GoSL	Government of Sierra Leone	SA	Survivor advocate
IMC	International Medical Corps	SLAES	Sierra Leone Associate of Ebola Survivors
IP	Implementing partner	TWG	Technical working group
JSI	JSI Research & Training Institute, Inc.	USAID	United States Agency for International Development
		WHO	World Health Organization
		WHI	World Hope International

1

Introduction

Project Overview
Implementing Partners
Distribution of EVD Survivors
Project Objectives

Project Overview

In late 2015, His Excellency Ernest Bai Koroma, the President of Sierra Leone, introduced the Ministry of Health and Sanitation and Ministry of Social Welfare, Gender, and Children's Affairs-led, government-mandated Comprehensive Program for Ebola Survivors to improve the well-being of Ebola virus disease survivors by providing basic and specialized health care.

The Ministry of Health and Sanitation (MOHS) and the Ministry of Social Welfare, Gender, and Children's Affairs (MSWGCA) have embraced the responsibility of ensuring that the health system in Sierra Leone is equipped and able to respond to the specific needs of Ebola virus disease (EVD) survivors in a comprehensive manner.

Since 2016, the Comprehensive Program for Ebola Survivors (CPES) has been supported through a combination of the UK 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 & Training Institute, Inc. (JSI).

The ESCC project support to CPES is being implemented in 13 districts by the consortium implementing partners (IPs): GOAL, Partners in Health, Medicos Del Mundo, International Medical Corps (IMC), Save the Children, World Hope International, Welbodi, and Kings Sierra Leone Partnership, all of which work with the MOHS, MSWGCA, and the World Health Organization (WHO).¹

¹ The project has been supporting 13 districts, Bonthe district was excluded because there were no EVD survivors recorded there. Furthermore, until May 1st 2017 Western Area Rural and Western Area Urban districts have been considered as a composite district (Western Area) instead of two distinct districts.

Project Overview

CPES activities are led and coordinated by a district coordinator and implemented by a team of survivor advocates and their supervisors at the community level; clinical training officers (CTOs) at the primary care level; and referral coordinators at secondary and tertiary hospitals.

The intended beneficiary population of CPES is EVD survivors in Sierra Leone who, as a group, are represented by the civil society organization Sierra Leone Association for EVD Survivors (SLAES). SLAES 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 which strengthens service delivery to EVD survivors contributing to improving the overall survivors' well-being.



Implementing Partners

CPES implementation at the district level is supported by the Ebola Survivors Care Co.

District	Implementing partners
Bo	GOAL
Bombali	World Hope International
Kailahun	Save the Children
Kambia	GOAL + PIH (community level in 2016)
Kenema	GOAL
Koinadugu	Medicos Del Mundo
Kono	Partners In Health
Moyamba	Medicos Del Mundo
Port Loko	Partners In Health
Pujehan	Save the Children
Tonkolili	World Hope International
Western Area Rural (WAR) ²	IMC + Kings Sierra Leone Partnership and Welbodi Partnership (Tertiary Care)
Western Area Urban (WAU) ³	IMC + Kings Sierra Leone Partnership and Welbodi Partnership (Tertiary Care)

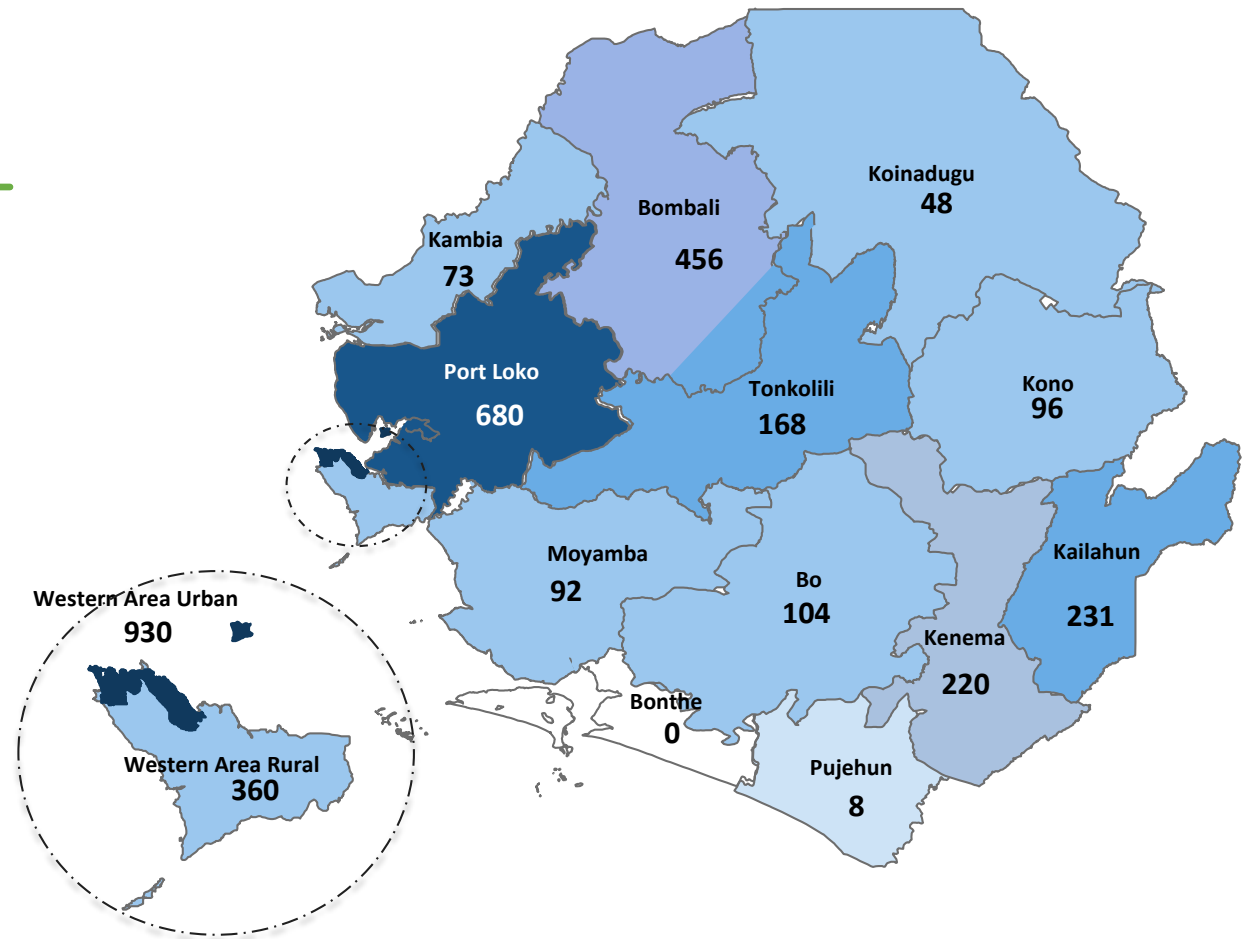
² As of May 1, 2017, IMC will be replaced by Save the Children and supported through the USAID ETP&SS JSI-managed project until September 30, 2017.

³ As of May 1, 2017, IMC will be replaced by GOAL and supported through the USAID ETP&SS JSI-managed project until September 30, 2017.

Distribution of EVD Survivors

There are a total of **3,466** EVD survivors registered by the National Ebola Response Centre (NERC) in Sierra Leone and handed over to MOHS, MSWGCAs, WHO and H.E. The President.

The distribution of these survivors varies across each district, with the highest concentration of survivors residing in **Western Area (Rural and Urban)**, **Port Loko**, and **Bombali Districts**.



Project 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 survivor health care into mainstream clinical services, owned and managed by MOHS.

The program contributes to attaining the Resilient Zero objective of the Presidential 10–24 Month Recovery Plan and aims to provide free health care for EVD survivors at MOHS facilities, including all clinic visits, in- and out-patient procedures, specialized care (ophthalmology, neurology, mental health, reproductive health for women, etc.), medications, and diagnostic testing.

Main Goals:

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

Key Objectives:

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

2

Research Questions

Research Aims & Main Research Questions

Research Aims & Main Research Questions

Research aims

Overall research activities seek to determine if the program achieves intended outcomes and impact by analyzing trends in disability experienced by EVD survivors, barriers to receiving health care, and satisfaction with service delivery. Specific interest is on viral persistence among male EVD survivors.

The evaluation of CPES uses a simple pre/post design by analyzing data from a baseline and endline survey to examine change in program implementation characteristics by the project's end in 2017.

Main research questions

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

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

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

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

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

3

Methods & Sampling

Overview of Methodology



Overview of Methodology

The baseline assessment used a mixed-methods approach, including a quantitative and qualitative data collection that focused on understanding survivor experiences directly as well as gathering perspectives and accounts from program implementing staff and stakeholders. Survey tools and interview guides developed were structured to reflect the CPES results framework and to answer the key research questions.

Ethics review and approval for this research was obtained from JSI's institutional review board and the Sierra Leone Ethics and Scientific Review Committee.

4

Quantitative Data

Quantitative Sampling

Quantitative Survey Instrument

Quantitative Data Collection & Management

Quantitative Data Analysis

Quantitative Sampling

This methodology was used to develop the sample for data collection based on the total population of male and female EVD survivors provided by the implementing partners in the 13 districts. As such, the 18+ male and female sample was representative of the EVD survivor population at the national level by gender.

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

*The study population for the survey was restricted to **male and female EVD survivors 18 years of age and older** in each of the project districts. The survey used **lot quality assurance sampling (LQAS)** methodology, which involves taking a small random sample in each set of groups within a given population.⁴*

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

⁴ More information on LQAS is available here – Lanata CF, Stroh G, Black RE. 1988. *Lot quality assurance sampling in health monitoring*. The Lancet 1988; 1: 122-123; Lanata CF, Black RE. 1991. *Lot quality assurance sampling techniques in health surveys in developing countries: advantages and current constraints*. World Health Stat Q. 1991;44(3):133-9 http://apps.who.int/iris/bitstream/10665/47594/1/WHSQ_1991_44_3_p133-139_eng.pdf; JSI, 2006. *Lot Quality Assurance Sampling, An Overview*. Presentation at LQAS Conference, Sheraton Kampala Hotel 3rd July 2006 http://uphold.jsi.com/Docs/Resources/Conferences/presentation_overview-lqas_2006.pdf.

Quantitative Sample

**758 total
EVD survivors**

Surveyed in February
2017

372 males & **386**
females, 18 years & older
from **12** districts

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

District	Males	Females	Total
Bo	19	19	38
Bombali	19	19	38
Kailahun	20	19	39
Kambia	19	19	38
Kenema	19	19	38
Koinadugu	19	19	38
Kono	19	19	38
Moyamba	19	19	38
Port Loko	100	115	215
Tonkolili	19	19	38
Western Area Rural	50	50	100
Western Area Urban	50	50	100

Quantitative Survey Instrument

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

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

Quantitative Data Collection & Management

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

Quantitative data analysis methods

The baseline survey was analysed using Stata 14 software and included descriptive statistics on key indicators/outcomes relevant to CPES/ESCC.

Because of the oversampling in some districts, data were weighted for analysis. **Results are presented by gender at the country level and, in some instances, for Western Area**, which combine results from Western Area Rural and Western Area Urban, the districts with the largest population of EVD survivors.

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

A **factor analysis** of the responses to all **8 stigma-related questions** in the survey revealed that all questions posed were important in influencing the overall stigma experienced by EVD survivors.

Calculated Scores



Quality of care

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

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

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

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

Calculated Scores



Stigma

EVD survivors were asked to report if they had ever experienced stigma in a variety of scenarios. Factor analysis of these yes/no responses to all 8 stigma questions revealed that all questions were important in influencing the overall stigma experienced by survivors. The **proportion of EVD survivors who experienced any stigma** was determined based on whether they responded “yes” to at least one of the stigma questions. We further looked at the **proportion of survivors who experienced stigma from a health worker** based on whether the respondent indicated “yes” to at least 1 of the 3 statements related to their interactions with health workers.

Disability Assessment

The WHO Disability Assessment Schedule (DAS⁵) (short) was used to measure the level of disability experienced by EVD survivors surveyed. Scores were calculated based on their responses to the 12 DAS questions indicating their level of difficulty completing daily tasks. Difficulty was scored with the following scale: none (0); mild (1); moderate (2); severe (3); extreme or cannot do (4). Scores from the 12 DAS questions ranged from 0 to 33, with a median of 9 and a mean of 9.68. Survivors were categorized as having a healthy life if they scored less than 25% on the DAS (composite score lower than 12).

⁵Kostanjsek, T., Chatterji, N., and Rehm, J. 2010. *Measuring Health and Disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0)*. World Health Organization. Accessed October 2016 at http://apps.who.int/iris/bitstream/10665/43974/1/9789241547598_eng.pdf?ua=1&ua=1.

5

Qualitative Data

Qualitative Data Sample

Qualitative Interview Guidelines

Qualitative Data Collection & Management

Qualitative Data Sample

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

- Survivor advocates
- PHU health staff (community health post [CHP] level)
- District health management team (DHMT) staff
- SLAES regional and district level member staff

A total of 21 interviews were conducted. Data collection took place in selected project areas with combinations of high and low survivor populations of survivors: Western Area Urban, Bombali/Port Loko, and Kono/Moyamba.

	Western Area Urban	Bombali/Port Loko	Kono/Moyamba
Survivor advocates	3	3	1
PHU health workers	3	3	2
SLAES	1	1	1
DHMT	1	1	1
Total	8	8	5

Qualitative Interview Guides

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

- ✓ EVD survivor needs, including those of women, adolescents, and children.
- ✓ Ability to provide health services.
- ✓ Constraints of health staff in providing services.
- ✓ Referral systems in place.
- ✓ Areas to improve program implementation.

Qualitative Data Collection & Management

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

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

6

Findings

Knowledge & Awareness

Health Services Received

Health Services Referrals

Perceived Quality of Care

Stigma

Psychosocial Support

Barriers to Accessing Care

Sexual Behavior

Viral Persistence

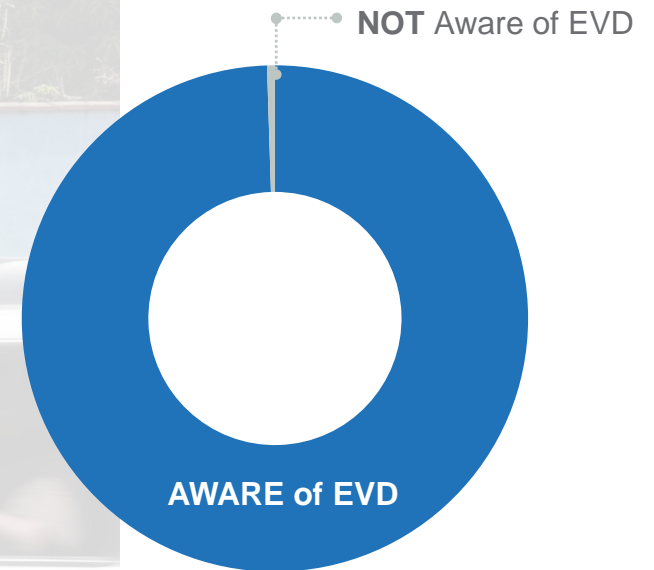
Health & Livelihood Needs

Knowledge & Awareness

When asked if they had ever heard of EVD, **almost all survivors (99.6%) indicated that they were aware of EVD.**

This high level of awareness was observed across all of the districts surveyed.

To further explore survivors' understanding of their health in relation to EVD, questions regarding the transmission of EVD were posed to survivors.



97.0% indicated that one could reduce the chance of contracting EVD by not having sex with a survivor. Fewer survivors in Western Area (79.6%), felt that statement to be true.

91.2% believed that using a condom during sex with a EVD survivor would reduce one's chance of contracting EVD.

Over half (59.9%) of all EVD survivors interviewed felt that an EVD survivor could appear healthy. 84.9% of survivors correctly indicated that EVD could not be passed from a pregnant woman to her unborn child, with more women responding correctly than men. Interestingly, there was a high percentage of survivors who did not know the answer to that question, particularly in Western Area (23% of females and 27% of males).

		Western Area		All Districts			n
		Males	Females	Males	Females	Total	
		%	%	%	%	%	
Can one reduce their chances of getting Ebola from a survivor by not having sex?	Yes	94	69.4	97.4	96.6	97.0	749
	No	6	30.6	2.6	3.4	3.0	
Can one reduce their chance of getting Ebola from a survivor by using condom?	Yes	100	97	93.2	89.2	91.2	756
	No	0.0	3.0	6.8	10.8	8.8	
Can an Ebola survivor appear healthy?	Yes	79.8	69.8	67.8	52.6	59.9	750
	No	20.2	30.2	32.2	47.4	40.1	
Can an Ebola survivor who is pregnant pass Ebola to her unborn child?	Yes	5.0	1.0	12.5	6.6	9.4	756
	No	72.0	72	83.5	86.3	84.9	
	Don't Know	23.0	27.0	4.0	7.1	5.6	

Health Services Received

Survivors were asked a series of questions regarding their use of the health system for EVD-related health issues. The assessment looked at services received at two time points:

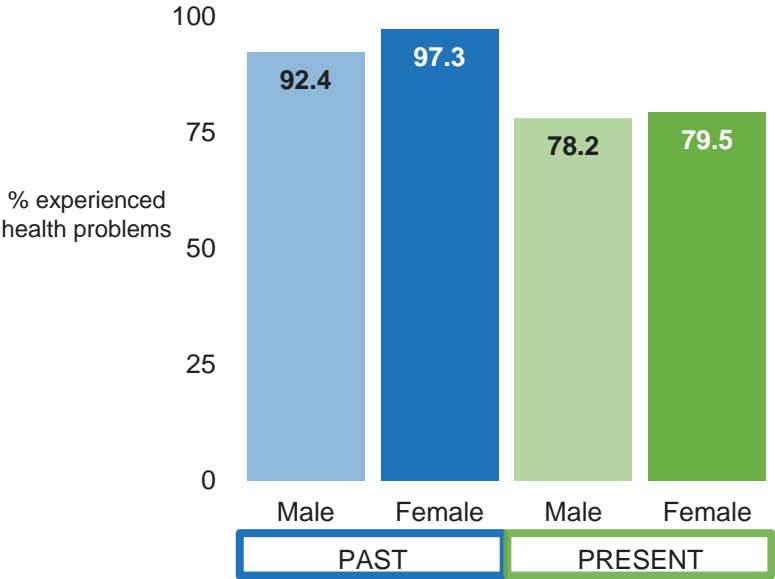
PAST

The time period from when the survivor was discharged from EVD treatment until the beginning of CPES (2014–April 2016).

PRESENT

In the previous three months before the survey was conducted (November 2016–February 2017)

Almost all EVD survivors (94.9%) indicated that they experienced health problems following discharge from the EVD treatment centre; a lower percentage (78.9%) indicated that they currently experienced health problems. Women more often indicated experiencing a health problem (past or present) than men.



Both male and female survivors reported experiencing a variety of and multiple health problems. The main health problems reported for both past and present were **headache, fever, pain, eye, and joint problems**.

Reproductive health, sexual health, and problems during pregnancy were cited less often, but more than 10% indicated experiencing “other” health problems, which included body rash/itching, general swollenness, and loss of appetite.

The frequency of these individual health problems was less for EVD survivors experiencing current health problems as compared to those who experienced past health problems.

Qualitative data found the commonly mentioned EVD-related health problems to be body aches, eye problems, and joint pain. Some also stated that survivors experienced abdominal pains and headaches, with a few mentioning hearing problems as a concern.

Sexual and reproductive health issues were brought up by many respondents, who cited impotence and menstrual problems.

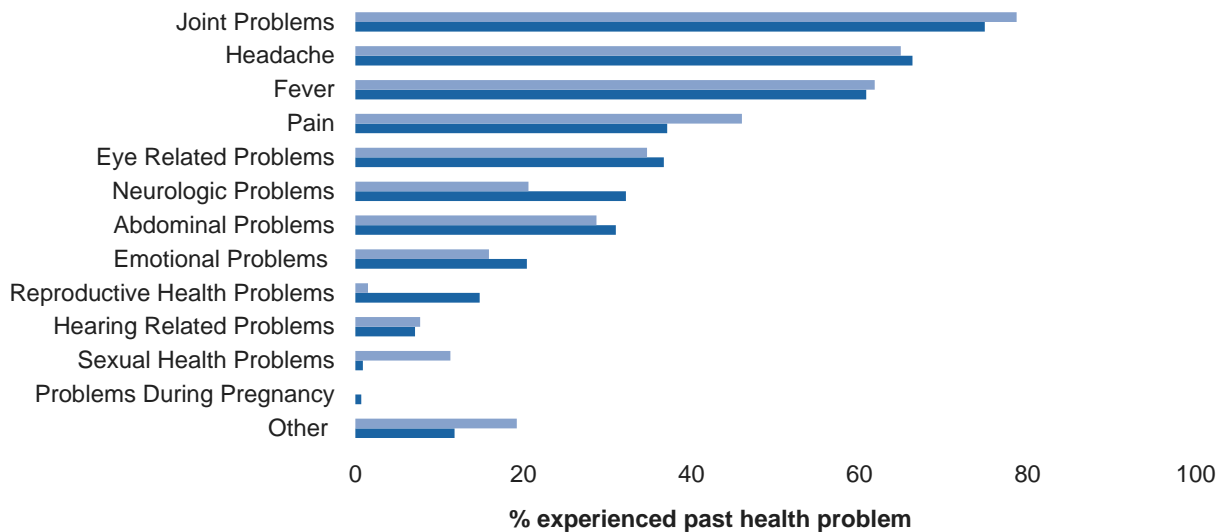
One respondent from SLAES spoke about the temporal nature of some illnesses and how the health conditions for certain survivors can drastically differ within a short period of time:

“It is really confusing, the situation get worse every day for survivors there are so many complications that affect them suddenly. Some of them may get up in the morning with good health but before the end of the day you may see them crying of pain or other illnesses. One afternoon I just went out to a field and I started feeling sudden fever [and] within ten minutes I fainted ... they call in for ambulance to take me to the hospital...”

–SLAES representative

PAST

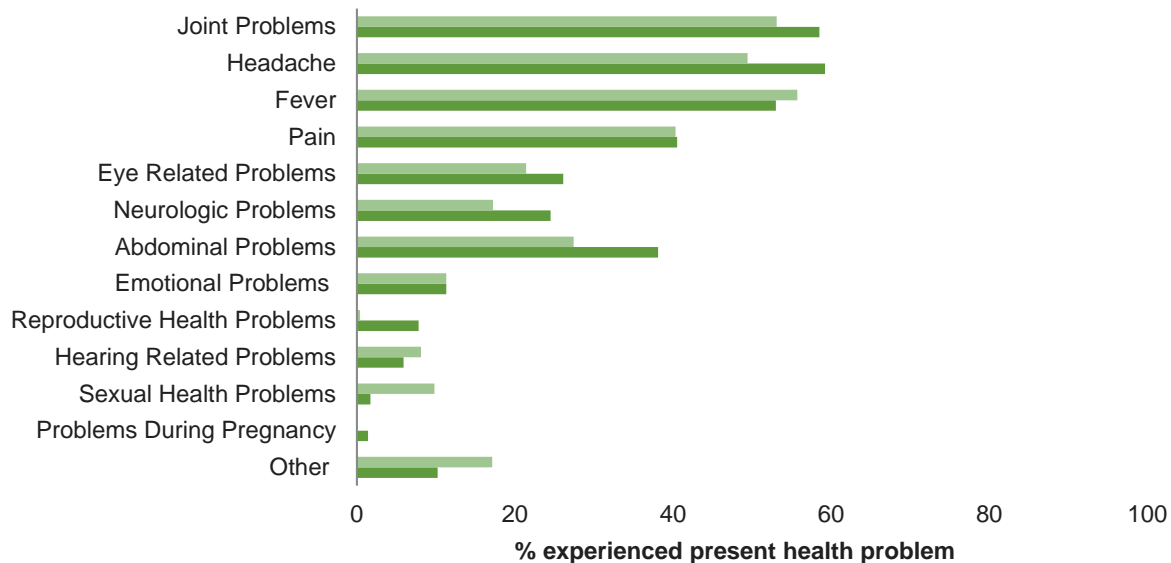
Male Female



Reported health problems from Ebola survivors

PRESENT

Male Female



Health Services Received

95.7% sought care for their past EVD-related health problems at a health facility. Interestingly, the respondents that indicated that they care for their EVD-related health problems were all men.

EVD survivors presently experiencing health problems sought care at a health facility slightly less often (88.7%) than those with past health problems. 8.7% of survivors with current health problems sought care outside the facility and only a few did not seek care at all (2.6%).

More women with present health problems sought care more often than men with present health problems.

PAST	Western Area		All Districts		
	Male	Female	Male	Female	Total
	%	%	%	%	n
Health facility	97.9	98.0	94.8	96.5	95.7 669
Outside health facility	1.0	2.0	4.5	3.5	3.9 21
Did not seek care	1.0	0.0	0.8	0.0	0.4 2

n=692

PRESENT	Western Area		All Districts		
	Male	Female	Male	Female	Total
	%	%	%	%	n
Health facility	92.0	77.4	89.0	88.4	88.7 496
Outside health facility	1.1	20.2	6.9	10.4	8.7 43
Did not seek care	6.8	2.4	4.1	1.2	2.6 16

n=555

The small proportion of EVD survivors who sought care outside the facility for past or present health problems most often chose to go directly to a pharmacy for treatment.

None of the survivors surveyed who sought care outside the facility for past or present health problems went to a country doctor/traditional healer or pastor/imam for care.

Health Services Received

PAST

Most EVD survivors (69.3%) who sought care at a health facility after discharge from the treatment facility went to a PHU; more than half (51.7%) indicated that they sought care at a district hospital; and very few sought care at a hospital in Freetown (tertiary hospital).

Interestingly, when asked how many times EVD survivors sought care for their past health problems, the vast majority (78.6%) indicated that they visited a facility 3 or more times. A small portion (5.3%) sought care only once after they were discharged from the treatment centre.

EVD Survivors in Western Area indicated much higher rates of seeking care at a tertiary hospital in Freetown, likely because of their proximity to those facilities as compared to survivors in other districts.

	Western Area		All Districts		
	Male	Female	Male	Female	Total
	%	%	%	%	%
PHU	81.5	44.6	49.6	61.2	55.7
District Hospital	1.2	47.7	61.0	53.8	57.2
Hospital in Freetown	65.4	38.5	2.0	1.3	1.7
Other	2.5	3.1	4.0	1.6	2.7

n=669

Health Services Received

PRESENT

Care seeking for survivors with present health problems was similar but the frequency of attending a facility was less than those dealing with past health issues.

Those with current health problems most often sought care at a PHU or district hospital (55.7% and 57.2% respectively).

A very small portion of EVD survivors with present health problems (1.2%) sought care at Freetown, with the major

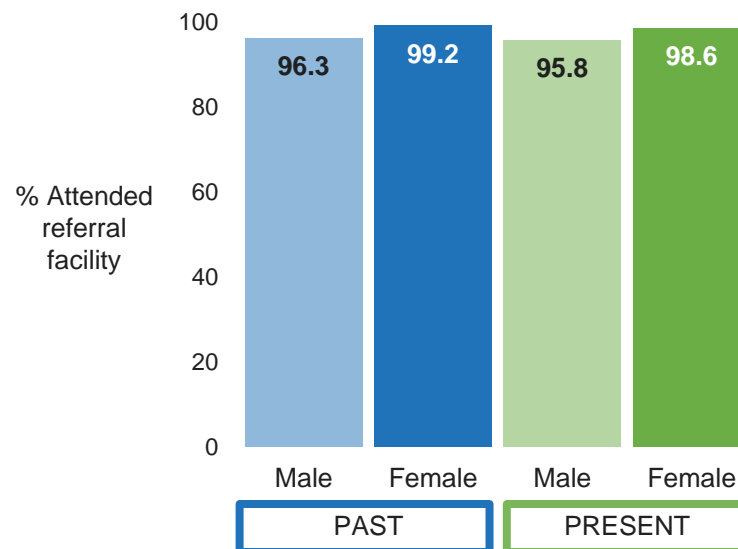
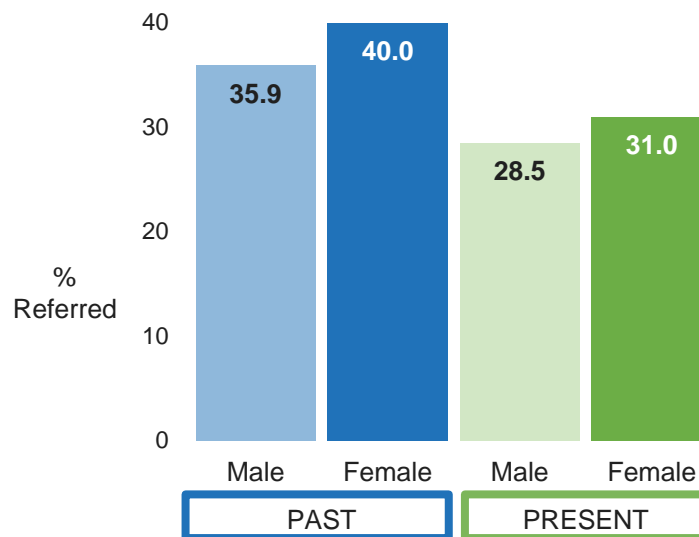
exception of those from Western Area.

Similarly, the majority of EVD survivors with present health problems indicated that they visited a facility three or more times to address their health needs.

	Western Area		All Districts		
	Male	Female	Male	Female	Total
	%	%	%	%	%
PHU	74.5	49.0	57.5	69.4	63.9
District Hospital	4.3	43.8	54.7	49.1	51.7
Hospital in Freetown	66.0	56.3	1.7	0.9	1.2
Other	2.1	1.0	8.4	2.6	5.3
n=496					

Health Services Referrals

Consistent with findings related to the number of times EVD survivors sought care at a facility, **40.1% were referred to a higher level facility for treatment** of health problems they experienced following discharge from the treatment centre, and **30.4% of EVD survivors with present health problems were referred to a higher-level facility** to receive appropriate care. Almost all of those who received referrals for past or present EVD-related health problems indicated that they were able to attend the referral facility.



Health Services Referrals

The high attendance of referred cases may be explained by the qualitative data, which found that CPES provided the transportation fare (in advance or as a reimbursement) or directly transported the survivors to the higher-level referral facility. Facility staff members worked with referral coordinators and survivor advocates (SA) to ensure that the survivor had the necessary transportation to go to the referral facility. In addition, the SA personally accompanied survivors to the hospitals and followed up with them afterward. A few facility staff mentioned that they too followed up on referred cases to check the progress of the individual's health.

Moreover, one respondent from SLAES stated that the tertiary hospital in Freetown provided lodging for those who needed to stay overnight, further reducing barriers to attending higher-level facilities.

For the very small proportion of EVD survivors who were unable to attend, the most common reasons listed was concern that the quality of care available at the facility was poor; worry that drugs would not be available; and inability to pay for treatment.

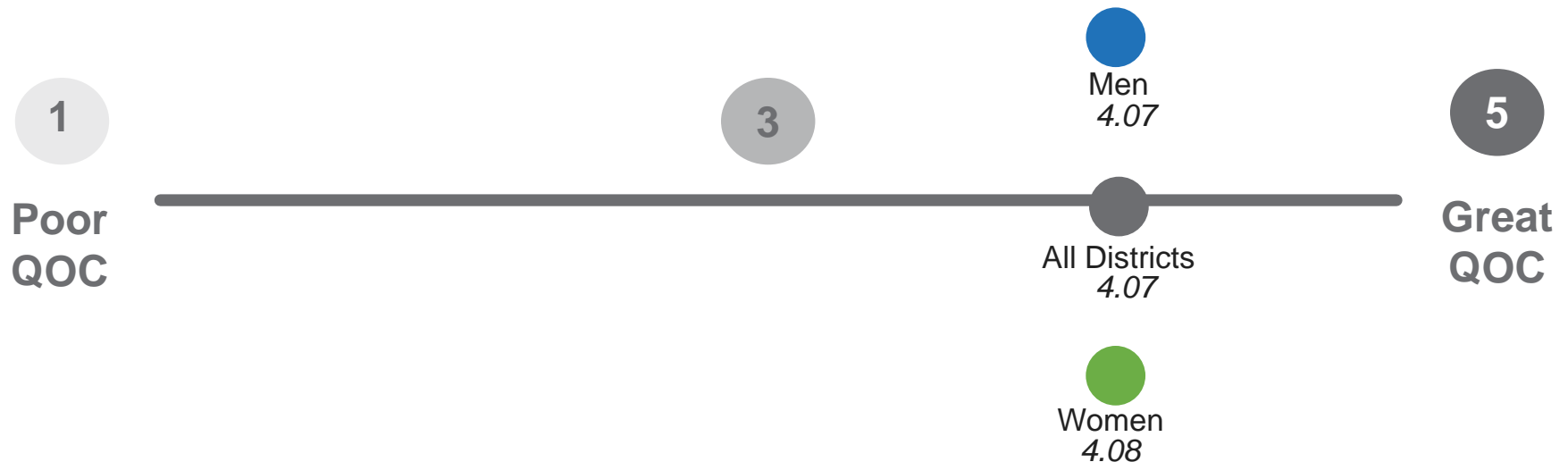
Facility staff reported through qualitative data that they would refer cases to higher-level facilities if they lacked the necessary equipment, specialized knowledge, or medicine to administer proper care. Respondents most often stated pharmacies as a key referral point if a facility was experiencing drug stock outs.

“...as a survivor advocate I am also to do visitation to all the survivors under my name at least one or twice in the month. The first visit should be home visit whether the client is sick or not I am supposed to do home visit ... The second visit is follow up visit; the follow up visit does not have fixed time but if a client is sick, you will have to visit frequently to know if they are responding to treatment or taking their drugs according to prescription...”

–Survivor advocate

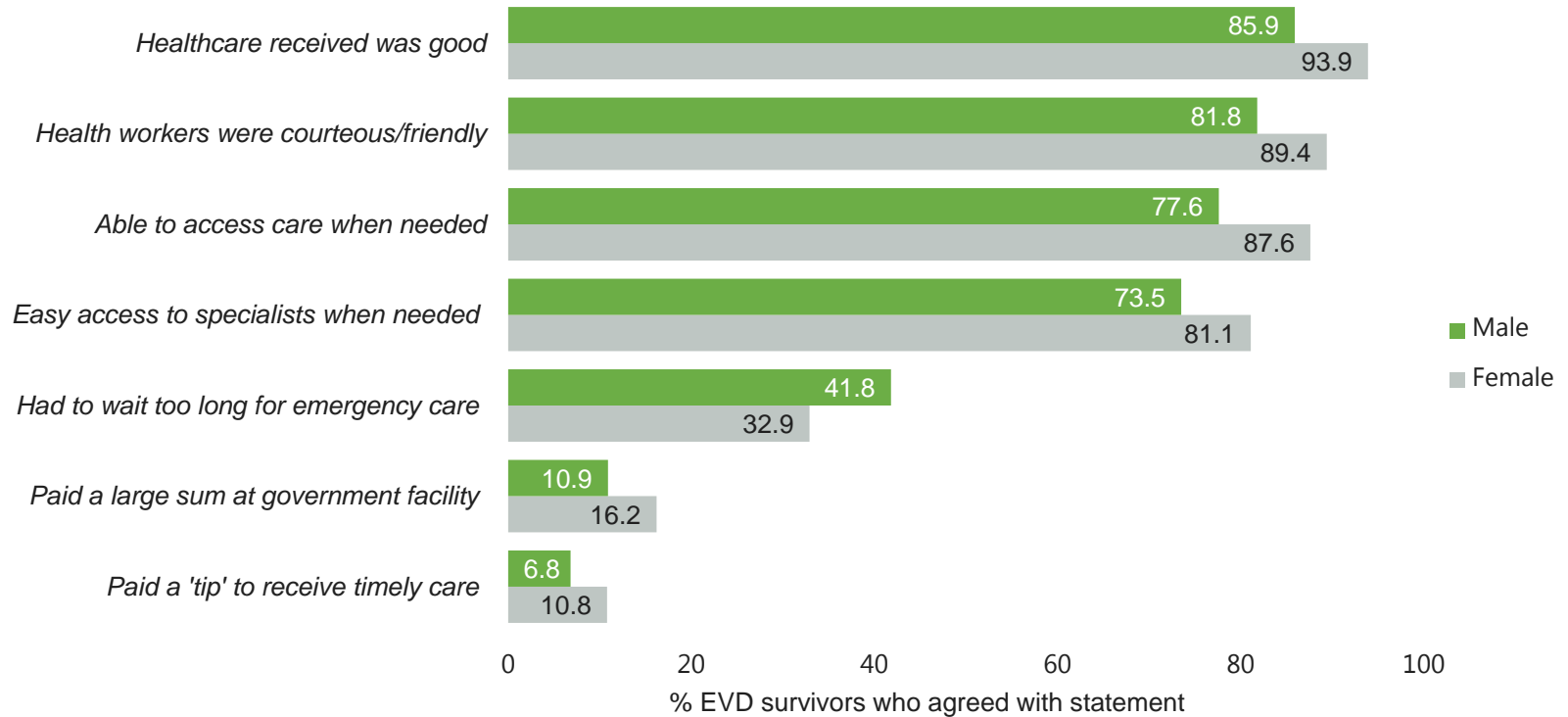
Perceived Quality of Care

The QOC score for the survivor population across all districts was quite high (4.07), with **67.9% of EVD survivors having a mean QOC score of 4.0** or higher, indicating that survivors felt that the quality of care they received was high. This was true for both males and females. The perception of quality of care received was a slightly lower in Western Area for both males and females.



Perceived Quality of Care

A breakdown of the percentage of respondents who “agreed” or “strongly agreed” with each of the quality of care statements is below.



Quality of Care

PHU staff, SAs, and DHMT members were generally positive about the QOC given to EVD survivors. However, virtually all respondents mentioned drug stockouts as a major issue. Many facilities did not have the medicine required, forcing workers to refer survivors to pharmacies or higher-level facilities. Two SAs stated that the consistent lack of drugs deterred some of their clients from attending the health facility when sick.

PHU staff felt that the frequent stockouts occur because the country's free health care initiative extended free coverage to the EVD survivors in addition to pregnant and lactating women and children under five years of age.

"...our survivors were finding it very difficult to access the health facility and there [are] some who don't go there because of transportation, others will say if went to the health facility they will not be able to give me the medications I needed..."

—Survivor advocate



Quality of Care

"For the medicines we don't have special package for survivors ... I asked her [the Minister MSWGCA] ... why they didn't give special package for survivors but she said why we didn't make special package is because the CPES program is piloted for two years, if we say we are going to make special, then after the two years when the CPES program must have closed where will the survivors be. But if it is included in the free health care, then even if CPES is stopped, the program will continue."

–PHU staff

According to PHU staff, the supply of medicine has not matched the growing demand, producing a strain on the inventory. One SA indicated that supply levels were intentionally kept low to ensure continuity of service delivery after the CPES program ends.

In instances where a facility was out of a particular drug, a couple of SAs and PHU staff said that some EVD survivors accused the facility staff of withholding drugs from them.

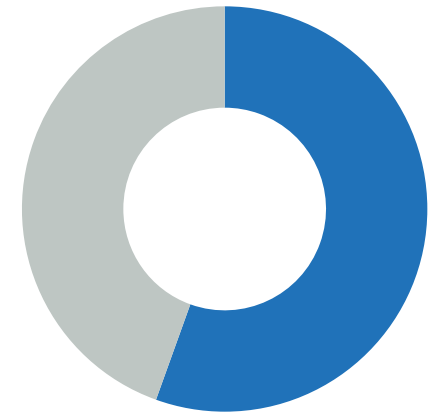
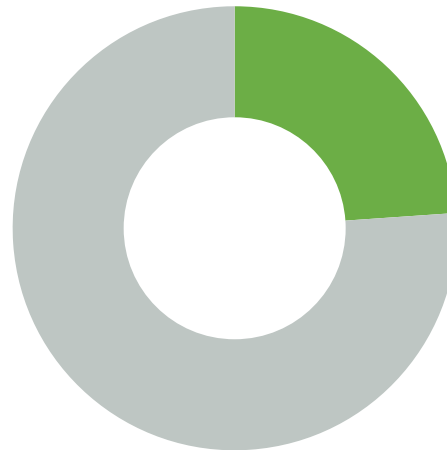
Stigma

While more than half of EVD survivors experienced some degree of stigma, less than a quarter indicated that they experienced stigma from a health worker (answering “yes” to at least one of the questions related to stigma at the PHU). Similarly, slightly more men (26.1%) indicated that they experienced stigma when they interacted with a health worker than did women (21.8%).

Overall, **55.5% of EVD survivors experienced some instance of stigma**, as indicated by a “yes” response to at least one of the stigma-related questions. Slightly more men (61.5%) experienced stigma than did women (50.5%).

Interestingly, more younger EVD survivors (18–39 years old) reported experiencing some form of stigma than did survivors in older groups.

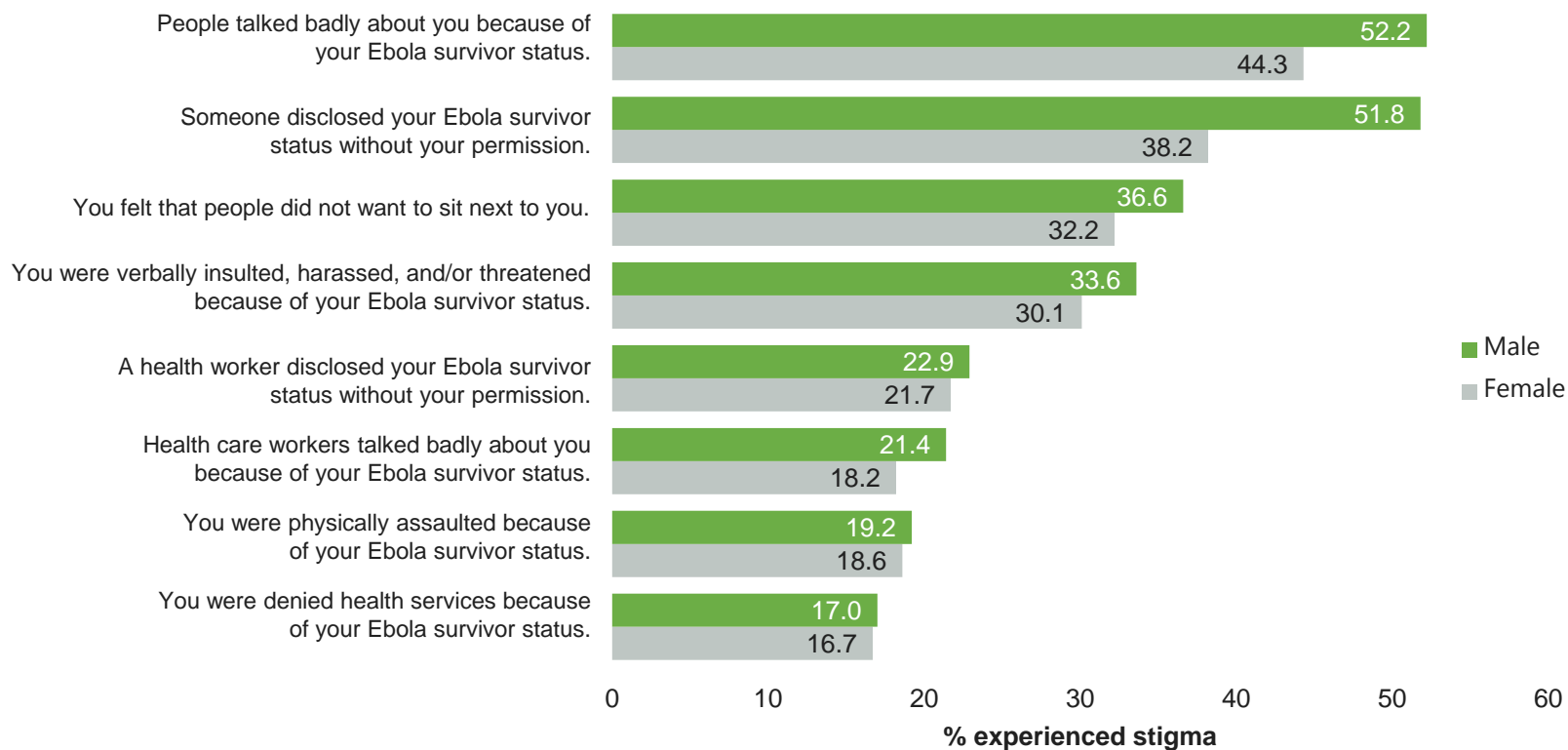
23.9%
of EVD survivors
experienced some
degree of stigma
during interactions
with a health worker



55.5%
of EVD survivors
experienced some
degree of stigma

Stigma

A full breakdown of the various types of stigma experienced by EVD survivors is depicted in the figure below.



Stigma

Many SAs, DHMT members, and SLAES reported that in recent months they had not heard EVD survivor complaints of experiencing stigma at health facilities. A few mentioned that previously, stigmatization from facility staff did occur, but campaign efforts from the MOHS and CPES greatly improved treatment toward survivors.



Instances of stigmatization from communities were reported by some respondents. One PHU staff member indicated that whenever he encountered EVD survivors who were “being humiliated in their communities” or marginalized “from other activities that the community will be engaging in” during his outreach services, he talked to the community to reduce discrimination against the survivors.

Two SAs reported that they felt stigma had decreased over time due to interventions from organizations, chiefs, and police. Despite the success with reducing stigma, it was reported that care was still taken to ensure a safe environment for EVD survivors.

“It is only at first that they were stigmatizing them but since they sent letter to them from the Ministry of Health that everything ended and they are not stigmatizing survivor there again. [...] Stigma had stopped for a very long time. ... Since the Ministry of Health sent letters to PHUs, that is the time stigma ended and it never came up again...”

–Survivor advocate

“When I am with my client in the communities and there is a problem between my client and the people in the community, I make sure to address the problem so that my client will be safe from all harm at the hands of the community people.[...].Before, the stigma that survivors were going through was great ... it has reduced although it has not being stopped totally because we have survivors who are still being stigmatized in our communities indirectly.”

–Survivor advocate

Psychosocial Support

	Western Area		All Districts		
	Male	Female	Male	Female	Total
	%	%	%	%	%
1-2 times	16	12.6	9.4	9.8	9.6
3+ times	20.2	26.4	27.8	42.7	35.7
Many times	63.8	60.9	62.8	47.4	54.6

n = 707

98.3% of EVD survivors surveyed indicated that they had received some form of psychosocial support/counselling on Ebola prior to the implementation of CPES; of those the majority received both individual counselling and psychological first aid.


96.6% of EVD survivors indicated that they received individual counselling either at home or at a health facility.

The majority of EVD survivors who reported receiving individual counselling indicated that **they received this counselling many times**, with only 9.6% of respondents receiving individual counselling only 1–2 times.

High levels of psychosocial support (97.6%) were also observed among both male and female EVD survivors, the majority of whom (69.1%) reported receiving psychological first aid many times.

The majority of those interviewed believed that there was a clear need for counselling to help EVD survivors cope with the trauma of losing family members to Ebola and to manage the stresses of ill health and poverty.

The need for counselling was perceived by some respondents to be greater than the need for medicines.

A woman with dark skin and braided hair, wearing a light blue V-neck shirt, stands with her arms crossed in front of a fence made of vertical bamboo poles. She is smiling at the camera. The background shows some green foliage and a bright, slightly overcast sky.

“If our people are well and they have sound minds, they will be able to live well . But remember that our people have gone through very traumatic situations... some ,when they come to the facilities, they really don’t need drugs but [rather] psychosocial therapy. That is just what a good number of them need.”

–DHMT representative

Psychosocial Support

The majority of these EVD survivors (67.4%) reported interacting with their SA many times within the last month. Only 9.4% reported interacting with their SA 1-2 times in the last month.

SAs were reported to serve a variety of roles in support of EVD survivors. The two most common reasons for interacting with SAs were that the survivor needed counselling or assistance to go to a health facility (79.1% and 79.7% respectively). About a quarter said they needed the SA to help them access care at higher-level facilities. SAs also helped to settle disputes between EVD survivors and their community, family, etc.

*A major source of support for EVD survivors was their SA. **Almost all respondents reported being happy with their SA (98.1%)** and saw their SA at least once in the past month (97.8%).*

	Western Area		All Districts		Total
	Male	Female	Male	Female	
	%	%	%	%	%
Assistance with going to a health facility	84.7	86.2	77.1	80.9	79.1
Need additional care at higher level facility	21.4	9.6	29.3	21.7	25.3
Needed counseling	83.7	100	79.9	79.4	79.7
Help settling disputes	0.00	7.4	18.4	22.7	20.7

n=741

Psychosocial Support

Qualitative data found that SAs had a positive relationship with EVD survivors. There appeared to be a high level of interaction between the two, with SAs reporting that they provided counselling, home visits, accompaniment to the health facilities, and support when conflicts within the community or family emerged.

SAs greatly empathized with the pain of their clients. The SLAES motto, 'who feels it, knows it,' was mentioned from time to time, highlighting a deep internalization of the concept and the presence of solidarity among survivors and SAs.

"...we know the pain of Ebola, we know the suffering and pain we went through, we were all taken as a family, therefore as a survivor we know all the problem we faced together ... and the good about it is that all survivors have their advocate's number, which they are allow to call even in the middle of the night, so they just need to make the call and ambulance will be sent to take them to the hospital."

—Survivor advocate

**TRAINING
ROOM 2**

PSYCHOSOCIAL

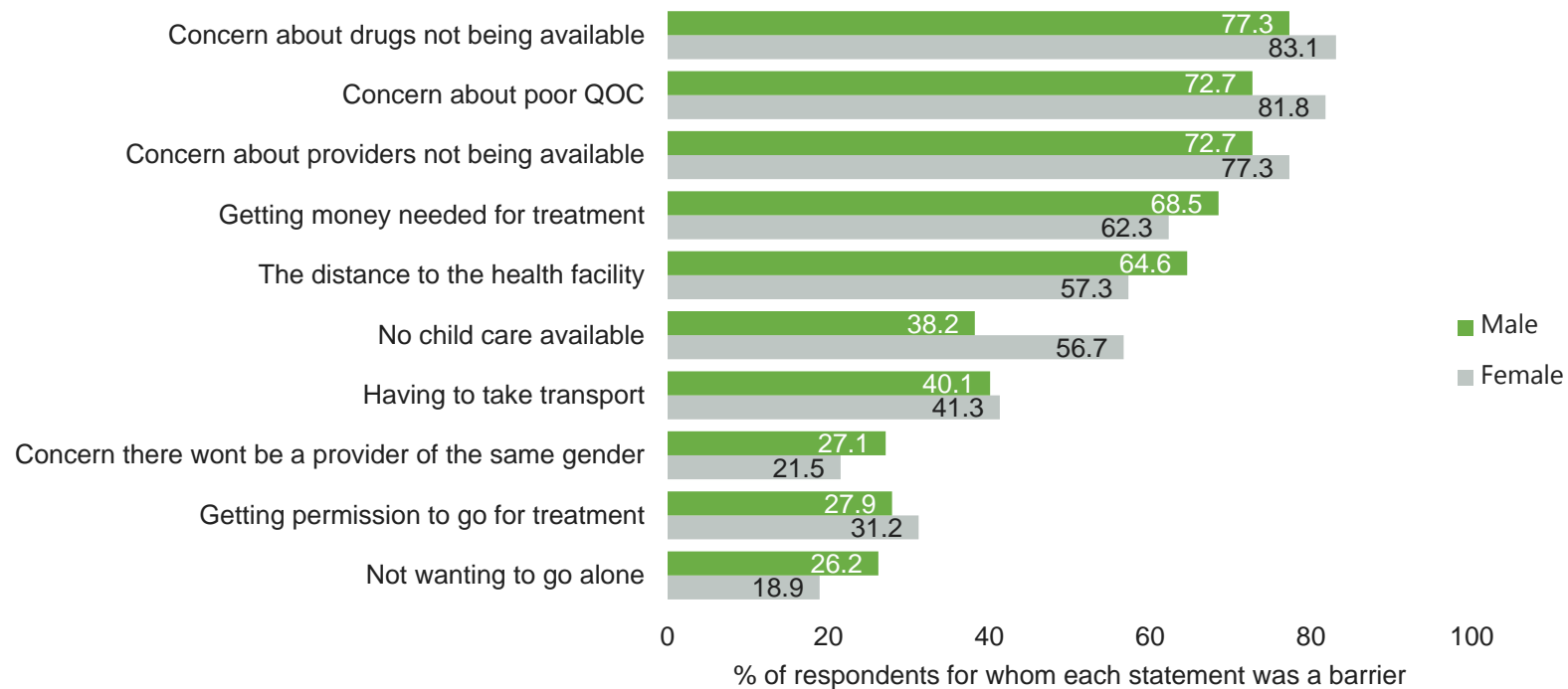
TRAINING

"Well, I am a survivor, I know the problem of survivors, I know our inner feelings, therefore any kind of problem survivors complain I see myself in the picture, and I am trying my ability and power to do all I can to do to help my colleagues... if I see a survivor being stigmatized I feel offended, and I will take up that case to see that their problem is being solved."

—Survivor advocate

Barriers to Accessing Care

EVD Survivors faced many barriers to accessing care for EVD-related health problems. The **biggest barrier was concern over the necessary drugs not being available at the facility (80.3%)**. Below is the proportion of EVD survivors who encountered each barrier to access care at the health facility.



Barriers to Accessing Care

Child care was a particular concern for women. Concerns were consistent across all age groups. with the exception of worries related to the distance EVD survivors needed to travel to reach the facility, which was more often reported as a problem for EVD survivors ages 18–39 than those 40 years and older. Below is a breakdown of barriers to accessing health care faced by survivors across age groups.

	All Districts						
	Age 18-28 yrs		Age 29-39 yrs		Age 40+ yrs		Total
	Female	Male	Female	Male	Female	Male	
	%	%	%	%	%	%	
Concern about drugs not being available	77.5	69.1	82.6	83.5	90.2	77.8	
Concern about poor QOC	75.4	67.7	80.7	75.5	90.7	74.4	77.5
Concern about providers not being available	72.8	65.5	74.7	80.1	85.5	70.8	75.1
Getting money needed for treatment	65.7	68.1	57.8	75.1	63.2	60.1	65.3
The distance to the health facility	52.9	64.9	66.2	58.8	37.8	29.0	60.8
No child care available	44.9	20.8	60.0	46.6	66.5	44.2	48.0
Having to take transport	38.1	32.2	50.5	39.4	35.0	49.6	40.7
Concern there wont be a provider of the same gender	28.3	34.2	28.4	21.9	37.8	29.0	29.6
Getting permission to go for treatment	26.1	19.8	13.5	30.7	24.5	30.2	24.2
Not wanting to go alone	20.1	28.1	13.6	21.7	23.2	30.2	22.4

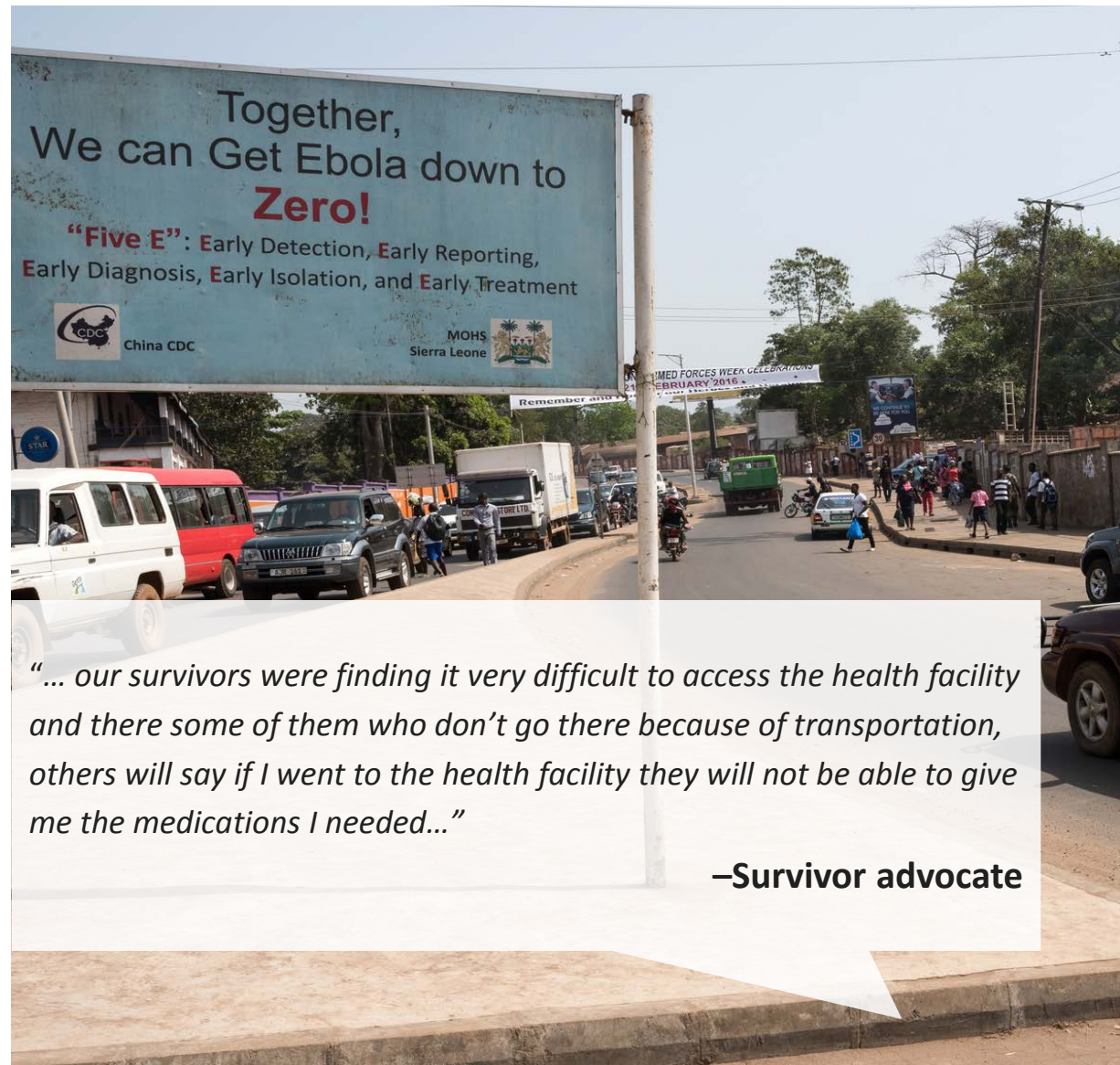
n=758

Barriers to Accessing Care

Main barriers mentioned in the qualitative interviews were **transportation** and **long distances** to health facilities.

Some respondents specifically mentioned that despite its mandate, CPES did not cover transportation fares to the PHUs, leaving clients unable to attend.

It was also mentioned that the constant lack of medicine at facilities deterred them from visiting because they assumed that drugs would be stocked out.



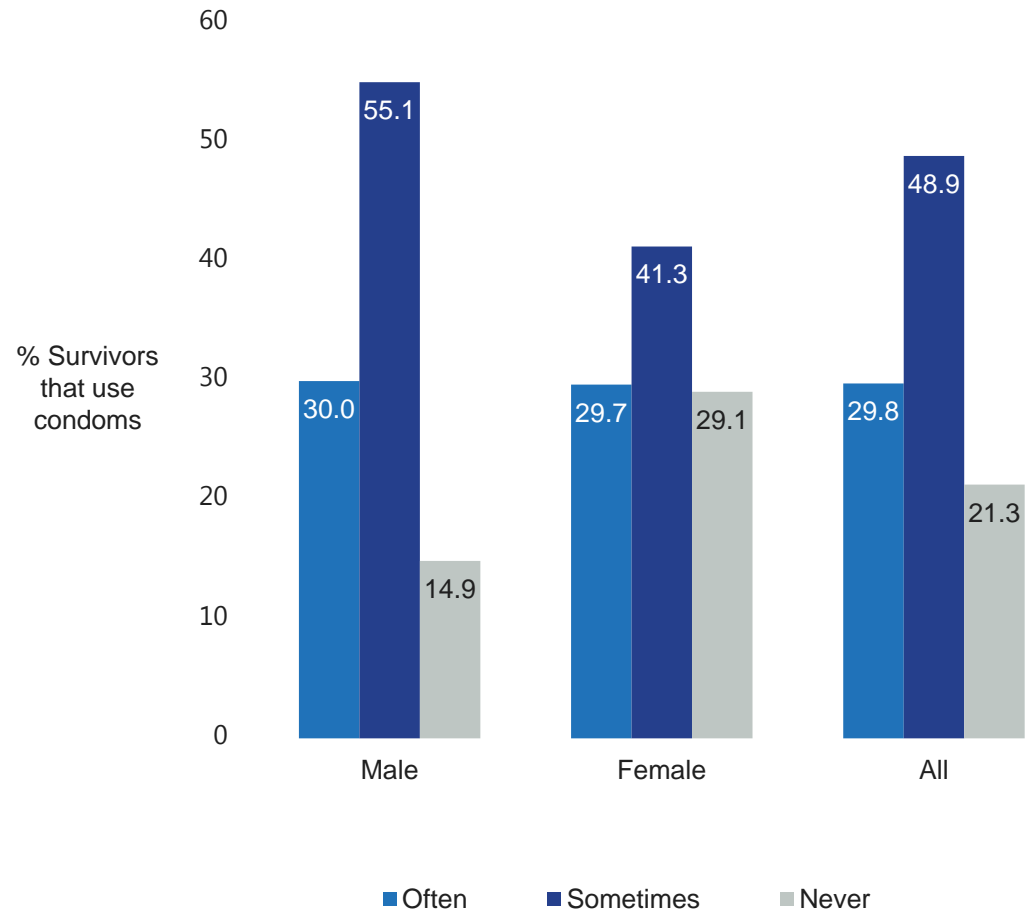
"... our survivors were finding it very difficult to access the health facility and there some of them who don't go there because of transportation, others will say if I went to the health facility they will not be able to give me the medications I needed..."

—Survivor advocate

Sexual Behavior

78.9% of EVD survivors reported having sex within the past year. However, only **46.0% of these survivors reported using a condom the last time they had sex**, with 38.1% of females and 50.2% of men reporting condom use.

For frequency of condom use, most respondents (48.9%) indicated that they sometimes used condoms; 29.8% reported using condoms often; and 21.3% indicated that they never use condoms.



Viral Persistence

Male EVD survivors were asked a series of questions about testing for Ebola viral persistence. The **majority⁶ (79.6%) reported that they had participated in semen testing** for Ebola viral persistence (EVP) at least once.

Of those who indicated participating in testing, **87% reported receiving pre/post testing counselling** on EVP, and **83.2% reported receiving the results** for their last viral persistence test.

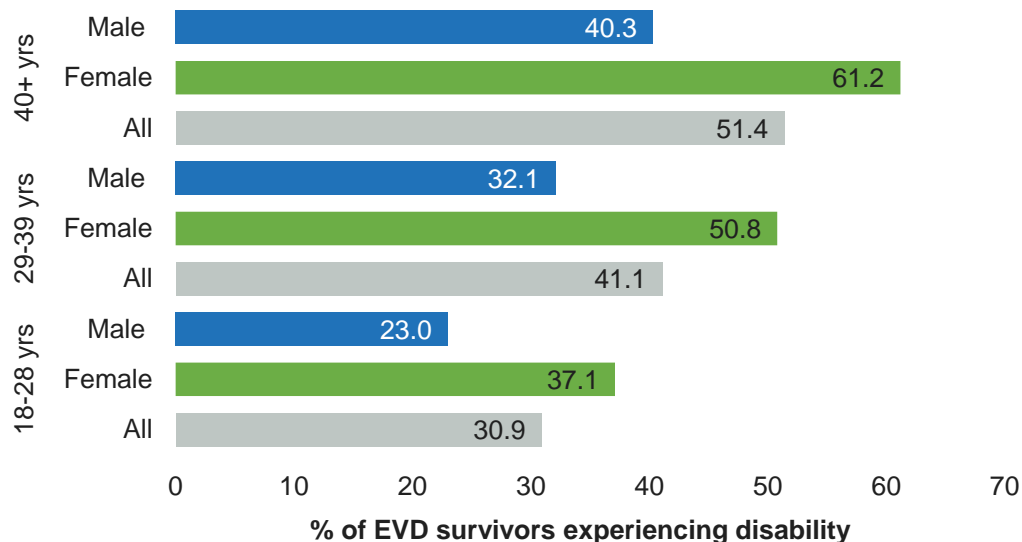
⁶Information related to EVP testing for this program is of interest for males age 15 years and older. For the purposes of the baseline survey we only interviewed respondents age 18 and above due to sensitivities related to the inclusion of minors in the study sample. However, despite not including younger males in the study sample, results from this baseline survey related to EVP are also applicable to the 15+ age group targeted as part of this program.

Health & Livelihood Needs

Looking at the breakdown of specific tasks that EVD survivors found most difficult (defined as having 'severe or extreme difficulty') following their illness, five stood out:

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

Based on an analysis of the WHO Disability Assessment Schedule (DAS) (short), 40.7% of survivors experienced some level of disability. Women seemed to have higher rates of disability than men across all districts. Not surprisingly, higher rates of disability were observed with increasing age of EVD survivors.



Health & Livelihood Needs

Qualitative data found that farmers were particularly affected by Ebola because of the body and joint pain that prevented them from working in the fields.

Because Ebola resulted in the loss of key caretakers, reduced efficiency at work, lowered income, and loss of housing, the majority of respondents voiced the need for livelihood assistance in the qualitative interviews. In particular, skills-building efforts for adults and financial support to continue the education of children whose parents did not survive Ebola were viewed as critical for improving the lives of survivors.

“Some of them are farming [as a source of income]; planting potato leaves, cassava leaves, but they will definitely tell you that they are not effective in doing that since they became survivors because they are feeling so much pain all over their bodies...”

–Survivor advocate

7 | Limitations



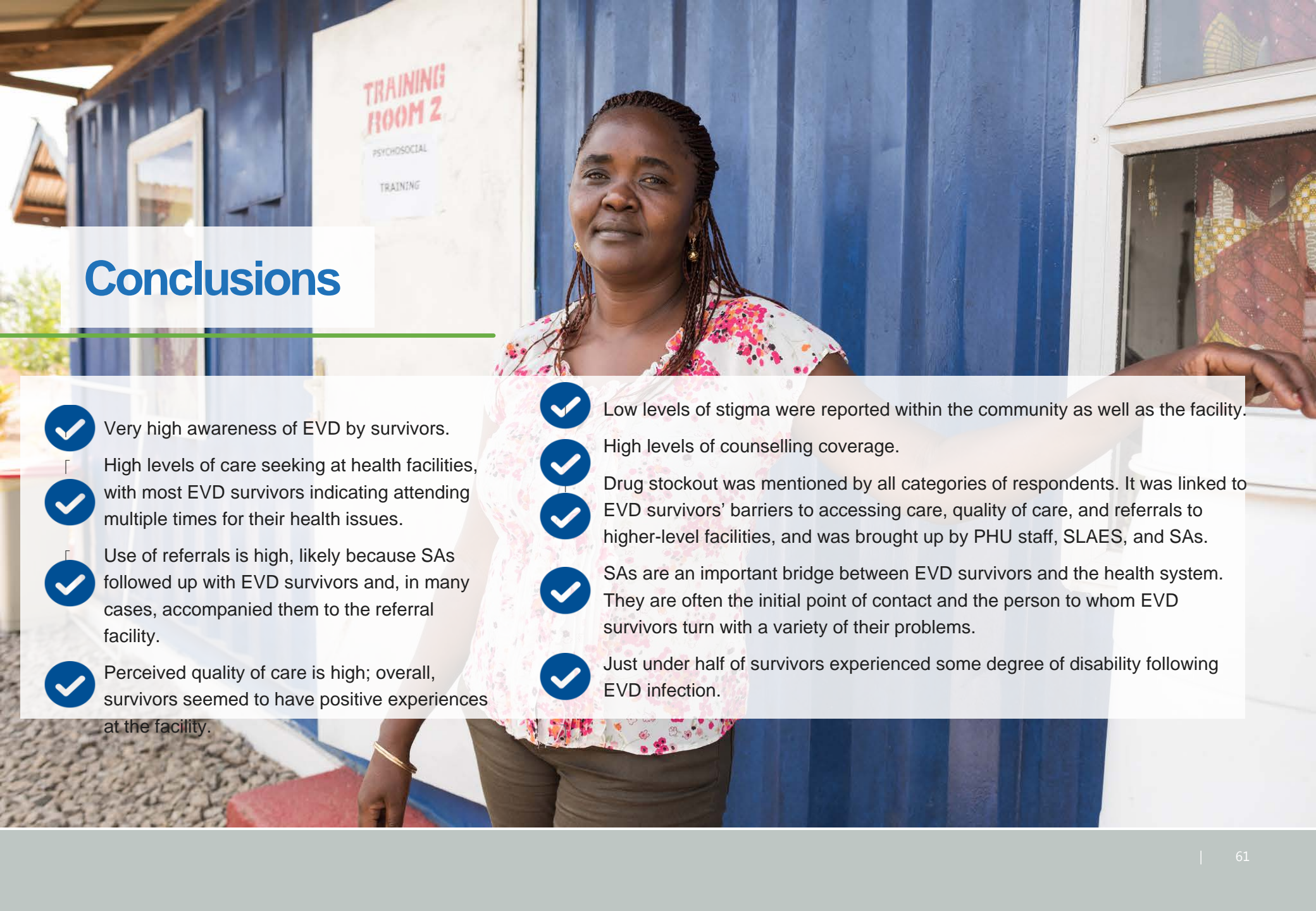
Limitations

- LQAS used small sample sizes in each district, so results are not representative for each individual district.
- Many survey responses were based on survivor perception rather than direct observation. This was particularly true for quality of care and stigma, which are based on survivor perceptions because direct observation would have been complicated and resource-intensive.
- Potential problems with question interpretation (particularly those related to counselling).
- Some questions posed to survivors during the survey asked about experiences that occurred in the last year, which had the potential for recall bias in their responses.

8

Conclusions

Conclusions

- 
- ✓ Very high awareness of EVD by survivors.
 - ✓ High levels of care seeking at health facilities, with most EVD survivors indicating attending multiple times for their health issues.
 - ✓ Use of referrals is high, likely because SAs followed up with EVD survivors and, in many cases, accompanied them to the referral facility.
 - ✓ Perceived quality of care is high; overall, survivors seemed to have positive experiences at the facility.
 - ✓ Low levels of stigma were reported within the community as well as the facility.
 - ✓ High levels of counselling coverage.
 - ✓ Drug stockout was mentioned by all categories of respondents. It was linked to EVD survivors' barriers to accessing care, quality of care, and referrals to higher-level facilities, and was brought up by PHU staff, SLAES, and SAs.
 - ✓ SAs are an important bridge between EVD survivors and the health system. They are often the initial point of contact and the person to whom EVD survivors turn with a variety of their problems.
 - ✓ Just under half of survivors experienced some degree of disability following EVD infection.



Comprehensive Program for Ebola Survivors Baseline Report Annexes



Contents

Annex A: Quantitative Data Collections Tool	3
CPES Baseline and Endline Survey Questionnaire	3
Annex B – Qualitative Data Collection Tools	18
CPES Baseline and End line Qualitative Data Collection Guide:Survivor Advocates	18
CPES Baseline and End line Qualitative Data Collection Guide:PHU Health Staff	20
CPES Baseline and End line Qualitative Data Collection Guide: SLAES	24
CPES Baseline and End line Qualitative Data Collection Guide: DHMT	26

Annex A: Quantitative Data Collections Tool

CPES Baseline and Endline 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.	PART 1: Knowledge and Awareness on Ebola: Now, I would like to ask you some questions about what you know about some things related to your health	Response		
		Yes (1)	No (0)	Don't know (99)
K1	Have you ever heard of a disease called EBOLA? <i>[If No or Don't know, skip to Part 2]</i>	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.	PART 2 (Retrospective): Health Services Received :	Response
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	Now, I would like to ask you some questions about health services that you may have received after your discharge, but before this program began (that is – before the rains started last year).			
		Yes (1)	No (0)	Don't know (99)
HS1	Did you have any health problems? [If Yes, go to HS2 else skip to Part 3]	1	0	
HS2	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 Other (specify) _____ <input type="checkbox"/> Don't know/ Can't remember			
HS3a	When you had these health problems, where di d you seek care? <input type="checkbox"/> Health facility [Set the skip pattern for HS5a] <input type="checkbox"/> Somewhere outside the health facility, including pharmacy, traditional healers, religious or community leaders, or others [Set the skip pattern for HS4] <input type="checkbox"/> I did not seek care [Set the skip pattern for HS3b]			
HS3b	If you did not seek care at a health facility, please explain why not _____			

	[Answer and move to Part 3]			
HS4	<p>For the location outside the health facility, where did you go to get treatment for your health problem?</p> <p>1 Community Health Worker</p> <p>2 Pharmacy</p> <p>3 Country doctor/traditional healer</p> <p>4 Pastor/Imam</p> <p>5 Community leader</p> <p>Other (specify) _____</p> <p>6 Nowhere</p>			
HS5a	<p>For any of the health problems in question HS2, what type of health facility did you go to? [Multiple selection]</p> <p>1 PHU</p> <p>2 District hospital</p> <p>3 Hospital in Freetown</p> <p>4 Other</p> <p>99 Don't know</p>			
HS5b	<p>How many times did you go to treat the health problem(s)?</p> <p>1 Once</p> <p>2 Two times</p> <p>3 More than two times</p> <p>99 Don't know</p>			
HS5c	<p>Were you referred to a higher level facility to get better treatment?</p> <p>[If No or Don't know, go to Part 3]</p>	1	0	99
HS5d	<p>Were you able to go to the referral facility to get the treatment?</p> <p>[If No or Don't know, go to HS5e, else go to Part 3]</p>	1	0	99
HS5e	<p>Please explain why not (select all that apply)</p> <p>1. Getting permission (from relative, spouse etc.) to go for treatment</p> <p>2. Getting money needed for treatment</p> <p>3. The distance to the health facility</p>			

	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			
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No.	PART 3 (Current): Health Services Received : Now, I would like to ask you some questions about health services that you may have received in the last 3 months – (since the rains ended)	Response		
		Yes (1)	No (0)	Don't know (99)
HS1_3mo	Have you had any health problems in the last 3 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 Other (specify) _____ <input type="checkbox"/> Don't know			
HS3a_3mo	When you had these health problems, where did 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 Part 4]	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			

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

No.	PART 4: Quality of Health Care: These questions relate to the care you received before the programme started – same time period as the previous questions – after your discharge but before the program started (last rainy season) How strongly do you agree or disagree with each of the following statements?	Response					Has it improved? Yes/No/ Don't know
		Strongly Disagree (1)	Disagree (2)	Uncertain (3)	Agree (4)	Strongly agree (5)	
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?						
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No.	PART 5: Stigma Scale: The next questions are about your personal observations and experiences on the support you receive from the community as a survivor. I will read issues and you answer yes or no. Again, these refer to the time before the rains last year.	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	Your 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?			
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No.	PART 6: Psycho-social Support & Counselling 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 time from when you were discharged to when this program started – when last rainy season started - 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	<p>In the last 3 months, how often have you interacted with your Survivor Advocate? [if NONE, move on to Part 7]</p> <p>1. None 2. 1-2 3. 3+ 4. Many 99. Don't Know</p>			
CPES6	<p>What was the reason for interacting with the Survivor Advocate? [select all that apply]</p> <p>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)</p>			
CPES7	Did you physically meet with the survivor advocate?			

No.	Part 7: Barriers to Access: Many different factors can prevent people from getting medical advice or treatment for themselves. The next questions are about your experiences in the past 6 months. When you are sick and wanted to get medical advice or treatment, is each of the following a big problem or not?	Response
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		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.	PART 8: Sex and Sexual behaviour: The next questions ask about sexual behaviour. There is no right or wrong answer. Your response will not be linked to you in any way or shared with anyone, including your partner, family, or others.	Response			
		Yes (1)	No (0)	Don't Know (99)	
SB1	In the past 12 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?	Record number of days ____				
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	Record number of days ____				

	condition?	
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?	<i>Record number of days</i> _____

This completes the questionnaire. Thank you.

Annex B – Qualitative Data Collection Tools

CPES Baseline and End line Qualitative Data Collection Guide: Survivor Advocates

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 (Village/Town & Place): _____

Type of respondent (Please circle one) Survivor Advocate DHMT SLAES PHU Staff

IF DHMT, current Designation: _____

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.

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

CPES Baseline and End line Qualitative Data Collection Guide: PHU Health Staff (who have treated survivors)

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.

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?
- 8. Overall, what changes (if any) would you like to see in the near future to improve the health situation of survivors? Why?**
- 9. 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

CPES Baseline and End line Qualitative Data Collection Guide: SLAES

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.

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. 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

CPES Baseline and End line Qualitative Data Collection Guide: DHMT

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 (village/town & place): _____

Type of respondent (Please circle one) Survivor Advocate DHMT SLAES PHU Staff

IF DHMT, current Designation: _____

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.

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. 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