

# ADVANCING PARTNERS & COMMUNITIES

EBOLA TRANSMISSION PREVENTION & SURVIVOR SERVICES, LIBERIA  
ENDLINE EBOLA SURVIVOR ASSESSMENT  
AUGUST 2018



## **Advancing Partners & Communities**

Advancing Partners & Communities (APC) is a five-year cooperative agreement funded by the U.S. Agency for International Development under Agreement No AID-OAA-A-12-00047, beginning October 1, 2012. APC is implemented by JSI Research & Training Institute, Inc., in collaboration with FHI 360. The project focuses on advancing and supporting community programs that seek to improve the overall health of communities and achieve other health-related impacts, especially in relationship to family planning. APC provides global leadership for community-based programming, executes and manages small- and medium-sized sub-awards, supports procurement reform by preparing awards for execution by USAID, and builds technical capacity of organizations to implement effective programs.

Cover photo: Participants in the project's mapping exercise in Sector 2, Montserrado County, Liberia. Photo credit: Sophie Roden, JSI.

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# ABBREVIATIONS AND ACRONYMS

APC	Advancing Partners & Communities
CDC	Centers for Disease Control and Prevention
ETP&SS	Ebola Transmission Prevention & Survivor Services
ETU	Ebola Treatment Unit
EVD	Ebola virus disease
JSI	JSI Research & Training Institute, Inc.
MOH	Ministry of Health
NESNL	National Ebola Survivors Network of Liberia
NGO	nongovernmental organization
NIH	National Institutes of Health
“Policy”	National Ebola Survivor Care and Support Policy
PREVAIL	Partnership for Research on Ebola Virus in Liberia
“Secretariat”	National Ebola Survivor Secretariat
“Survivor”	EVD survivor
WHO	World Health Organization

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# EXECUTIVE SUMMARY

## Introduction

The Ebola Transmission Prevention & Survivor Services (ETP&SS) program<sup>1</sup> was designed by the United States Agency for International Development (USAID) as a two-year (2016–2018) initiative aimed at supporting the implementation of selected components of the Liberian Ministry of Health’s (MOH) National Ebola Survivor Care and Support Policy, supporting the strengthening of clinical services available to survivors, reducing stigma and other barriers for survivors’ access to health care services, and reducing the risk of Ebola transmission from survivors to others.

Baseline and endline assessments were conducted with the survivor community to identify program targets, understand the broader context in which the program was operating, and assess program successes and changes over time in the survivor experience. These assessments focus on understanding survivors’ experiences when interacting with the Liberian health care system and their knowledge and perceptions of survivor representative bodies.

## Methodology

The assessments were conducted in the four ETP&SS program target counties (Montserrado, Margibi, Lofa, and Bong) using a mixed-methods format, with quantitative surveys of the survivor population (age 18 years and over) and qualitative interviews with key informants from the health sector and survivor organizations. The National Ebola Survivors Network of Liberia (NESNL) assisted in tracking and mobilizing the survivor community.

Data collection was conducted in February 2017 for the baseline and May 2018 for the endline assessment. Participants were selected through simple random samples drawn from existing survivor listings, stratified by administrative district and gender. In total, 649 survivors (297 males and 352 females) were surveyed.

Findings from the baseline assessment informed ETP&SS program design and provided evidence for the program indicators, including the need for strategies to increase engagement with clinical care services, refine referral pathways, reduce stigma, improve access to mental health services, and strengthen survivor advocacy bodies.

The results of the endline assessment provided information on if and how the survivor experience has changed over time. While direct attribution to program activities is not possible due to other, primarily non-EVD focused, public health programming conducted during the program’s timeline, assessment indicators were matched to program activities as closely as possible.

## Results

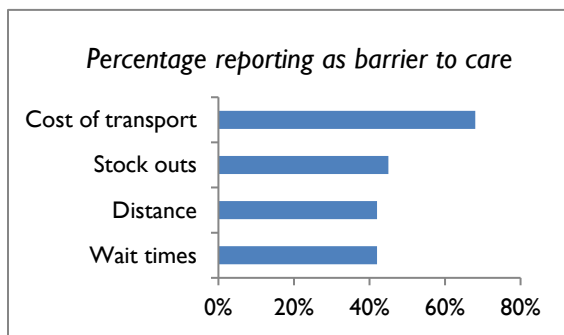
**Seeking health care:** The assessments confirmed that survivors have sought primary treatment from health facilities when they first get sick, with more than 90 percent of both baseline and endline respondents reporting that they had received treatment at a health facility within the past six months (92.3 and 91.7 percent, respectively). While initial attendance is high, one issue identified during the baseline assessment was poor attendance at referral appointments (referrals to a higher service level),

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<sup>1</sup> Funded through the Advancing Partners & Communities (APC) Project and managed by JSI Research & Training Institute, Inc.

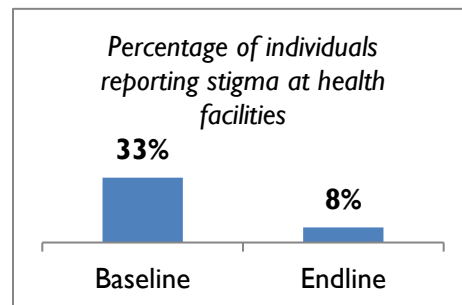
with only 60.3 percent of respondents reporting that they attended these appointments. To address this attrition trend, several program activities sought to promote engagement with higher level services when needed, including the roll-out of clinician trainings with specific content focused on referral protocols for survivors, with the aim of coordinating and strengthening the referral pathway for survivor patients. Between baseline and endline, there was a 35.7 percent increase (from 60.3 to 81.8 percent) in attendance at referral appointments.

**Barriers to care and stigma at health facilities:** In both the baseline and endline, the primary barriers to health care reported by respondents were transportation costs, medicine stock outs, distance to health facilities, and wait times. Cost of treatment was another major barrier, although this differed considerably between baseline and endline (44.6 and 19.3 percent, respectively, a 56.7 percent reduction). While not specific to the survivor population, these barriers can be insurmountable in the poorest countries in the world where transportation infrastructure and formal employment opportunities are extremely limited.



To increase access and decrease costs for survivors, the program provided free, comprehensive care for survivors at two faith-based hospitals, reimbursed transportation to all health facilities (primary, secondary, and to specialized care in survivors' home counties or Monrovia), supported public facilities with renovations, distributed essential equipment and medications, and coordinated survivor-specific specialty services<sup>2</sup> through sub-specialist rotations at selected county hospitals.

Several program activities concentrated on stigma reduction, including an EVD survivor clinical care guidelines training that reached 464 mid-level providers from 75 health facilities in 11 EVD-affected counties. Over the life of the program, there was a 76.4 percent reduction in experience of EVD-related stigma at health facilities, with 33.1 percent of baseline respondents claiming two or more occurrences of stigmatization by health facility staff in the past six months compared to 7.8 percent at endline. Similarly, the percentage of respondents reporting delaying or avoiding seeking care due to EVD-related stigma declined by 59.1 percent between baseline and endline (from 25.2 to 10.3 percent).



**Mental health support:** In the 12 months before each assessment, around half of respondents had received some form of mental health support or counseling. While this was a positive finding, there is clearly still room for improvement in connecting survivors with mental health care. This need is particularly salient in the context of two additional mental health specific assessments<sup>3</sup> that were conducted during the endline. One-fifth (20.1 percent) of respondents met the diagnostic criteria for depressive disorder and 14.8 percent met the score cut-point for generalized anxiety disorder, indicating a clear need for ongoing mental health services among the survivor population.

<sup>2</sup> Ophthalmology, rheumatology, and psychiatry.

<sup>3</sup> PHQ-9 and GAD-7. These assessments are meant as initial assessment tools; firm diagnosis of either depressive disorder or generalized anxiety disorder requires more intensive assessment by a mental health professional.



A major barrier to accessing mental health care in Liberia is the lack of trained mental health workers. In response to this, and in collaboration with the Phebe School of Nursing, the program supported two cohorts of a Post-Basic Mental Health Clinician training program. Thirty-eight nurses completed the six-month training program to date. These nurses are filling an immediate need for mental health services at both the primary and secondary levels of care.

## Conclusions

Our baseline assessment identified several barriers to survivor engagement with care, including stigma, cost of transportation, and distance to health facilities, resulting in delays in accessing care and high attrition rates between the primary and secondary-tertiary levels of care. The ETP&SS program sought to address these issues by increasing access to high-quality services for survivors through clinical trainings, referral system strengthening, facility renovations<sup>4</sup>, and other direct support to facilities providing care to survivors. While challenges still exist, over the life of the program, there was a significant decrease in experience of EVD-related stigma at facilities and a marked increase in attendance at referral appointments for more advanced care.

No	Indicator	Baseline % (n=433)	Endline % (n=213)
1	Percentage of individuals who believe they were treated respectfully by staff while seeking treatment at their local health facility on a regular basis	61.9 (n=259)	70.0 (n=147)
2	Percentage of individuals reporting two or more occurrences of being stigmatized by health care providers (limited to those who sought health care in the past 6 months)	33.1 (n=100)	7.8 (n=11)
3	Percentage of individuals aware of the existence of the National Ebola Survivors Network of Liberia (NESNL)	89.2 (n=386)	92.9 (n=198)
4	Percentage of individuals confident in the work of NESNL (limited to those with existing knowledge of NESNL)	83.4 (n=322)	61.4 (n=121)
5	Percentage of individuals aware of the existence of the Secretariat	28.9 (n=125)	37.5 (n=80)
6	Percentage of individuals confident in the work of the Secretariat (limited to those with existing knowledge of the Secretariat)	77.1 (n=91)	52.6 (n=41)
7	Percentage of male individuals reporting regular condom use with all sexual partners	26.9 (n=50)	12.8 (n=10)

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<sup>4</sup> A facility assessment was conducted at the beginning of the program to identify per-facility needs and develop tailored renovation plans.

# INTRODUCTION

## A. Background

The 2014–2015 Ebola virus disease (EVD) epidemic was the most widespread EVD outbreak in history; the epidemic devastated the West Africa sub-region, mainly Guinea, Liberia, and Sierra Leone. Liberia was one of the most affected countries, with a total of 10,678 confirmed EVD cases and more than 4,408 deaths. As a result of the crisis, there are an estimated 2,000–5,000 survivors in Liberia,<sup>5</sup> of whom 1,558 are registered with the MOH.

Although the outbreak has passed, Ebola survivors face ongoing challenges ranging from health complications to engagement with health care and employment. The health challenges appear to be a result of late complications from the disease. Preliminary findings of the Partnership for Research on Ebola Virus in Liberia (PREVAIL) III study in Liberia (2015), conducted by the U.S. National Institutes for Health (NIH) and the Liberian MOH and reported on the NIH website, revealed that 68 percent of Ebola survivors experienced neurologic problems, 60 percent eye difficulties, and 53 percent musculoskeletal problems.<sup>6</sup> The study further noted that 38 percent of 79 male survivors had Ebola detected in their semen at least once. Ebola survivors also experience psychological consequences of the disease, such as depression and suicide, which require specialized medical attention. These initial findings indicated that there was a need for programming in these clinical areas.

In response to the needs of the Ebola survivor population, the Liberian MOH, with assistance from the World Health Organization (WHO), U.S. Centers for Disease Control and Prevention (CDC), and other partners, rolled out the National Ebola Survivors Care and Support Policy (the Policy) in March 2016. The Policy focuses on using a “positive discrimination toward integration model” in which survivor clinics that were established are gradually integrated into primary and secondary health services within public facilities. The Policy also confirmed the role of the National EVD Survivor Secretariat (the Secretariat) as the body responsible for ensuring the implementation of the Policy and the role of the NESNL as a coordinating body for Ebola survivors.

In May 2016, the Advancing Partners & Communities (APC) project received funds from the Global Health Ebola Team of USAID/Washington for a program entitled Ebola Transmission Prevention & Survivor Services (ETP&SS); program implementation began in August 2016. ETP&SS was implemented by JSI Research & Training Institute, Inc. (JSI) in Liberia, Guinea, and Sierra Leone.

## B. Overview of ETP&SS in Liberia

The ETP&SS program was a two-year (2016–2018) initiative aimed at supporting the implementation of selected components of the MOH Policy, supporting the strengthening of clinical services available to survivors, reducing stigma and other barriers for survivors when accessing health care services, and

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<sup>5</sup> Ministry of Health [Liberia], ‘EVD Survivors Care and Support Policy’ (2016), Monrovia, Liberia, p2. Estimates varied between organizations, with the MOH estimating 1,558 based on their survivor registry, the CDC approximately 3,300, and the WHO 5,000.

<sup>6</sup> National Institutes for Health, ‘Ebola Survivor Study Yields Insights on Complications of Disease’ (23 February 2016). URL <<https://www.niaid.nih.gov/news-events/ebola-survivor-study-yields-insights-complications-disease>>.

reducing the risk of Ebola transmission from survivors to others. In Liberia, the program was implemented in the counties with the highest concentration of survivors: Montserrado, Lofa, Bong, and Margibi. The intended beneficiary population of the ETP&SS program in Liberia was EVD survivors, who were represented by their coordinating organizations, the NESNL, and the Secretariat.

The program has conducted capacity-building activities with selected facilities in the four target counties to improve the quality of general and specialty services for survivors. In addition, the program has provided training and mentoring in stigma reduction and survivor care protocols for health professionals in these counties. The program has played a formative role in the establishment of the Secretariat by seconding key staff to the MOH and providing capacity-building support to both the Secretariat and the NESNL.

## C. Research Questions

The baseline and endline assessments focused on understanding survivors' experiences with the Liberian health care system and their knowledge and perceptions of survivor representative bodies. Both assessments were developed in line with the ETP&SS performance monitoring plan and program objectives.

Primary research questions and indicators were developed and are outlined in Table I.

### Research Questions

- a) What are survivors' perceptions of health facility services and structures?
- b) What barriers do survivors face in their access to health services? Is stigma from health care providers one of the barriers to seeking and receiving health care?
- c) How aware are survivors of their representative bodies (the Secretariat and the Network)? What is their level of trust and confidence in these bodies to represent the interests of survivors?

Table I: ETP&SS Research Indicators

No	Indicator
1	Percentage of individuals who believe they were treated respectfully by staff whilst seeking treatment at their local health facility on a regular basis
2	Percentage of individuals reporting two or more occurrences of being stigmatized by health care providers (limited to those who have sought health care in the past 6 months)
3	Percentage of individuals aware of the existence of the National Ebola Survivors Network of Liberia (NESNL)
4	Percentage of individuals confident in the work of the NESNL (limited to those with existing knowledge of the NESNL)
5	Percentage of individuals aware of the existence of the Secretariat
6	Percentage of individuals confident in the work of the Secretariat (limited to those with existing knowledge of the Secretariat)
7	Percentage of male individuals reporting regular condom use with all sexual partners

## **D. Program Concept**

The ETP&SS program sought to leverage connections the NESNL has made within the survivor community to communicate information on program activities, and to build on the formative steps the MOH has made in developing the Ebola Survivors Care and Support Policy.

The program's conceptual framework aimed to improve health outcomes across the survivor population by ensuring that the public health system could deliver survivor services in a non-stigmatizing environment. The framework acknowledged the many barriers faced by both the general and survivor population in accessing health care in Liberia, including distances from facilities and cost of medicines. However, as the program's mandate was limited to building the capacity of survivor care services and implementation to two years, it was not possible for the program to provide longer-term solutions to these systemic issues.

Short-term solutions were enacted to encourage survivors to seek health care and to alert them to the specialty services developed by the program. The program provided short-term free health services at two private faith-based health facilities in Monrovia, and covered transportation costs for registered survivors who were referred by a health provider to receive care at one of these facilities.

# METHODOLOGY

The assessments adopted a mixed-method approach to develop a thorough understanding of the contextual factors affecting survivor engagement with health facilities and advocacy bodies. Both the quantitative and qualitative components of the assessments were conducted in the four program target counties of Montserrado, Margibi, Bong, and Lofa.

The quantitative component involved a 45-minute structured survey that was administered to a random selection of survivors on tablet computers in areas close to their homes. For the qualitative survey, 30–45 minute interviews were conducted with a purposive sample of key stakeholders, including county- and district-level health team members, health facility staff, and county-level NESNL leadership.

## Quantitative Survey

The size of the survivor population in Liberia is estimated to range from 2,000 to 5,000 individuals.<sup>7</sup> The exact number is unknown for two primary reasons: survivor information was not recorded at Ebola Treatment Units (ETUs) until a number of months into the outbreak, and many who were ill did not seek care at an ETU, instead receiving care in their community.

At the time of baseline sampling, the only survivor listing available was the MOH line listing capturing 1,558 survivors, which was based on information provided by ETUs and was last updated in early 2015. This listing was used as the sampling frame and was used to determine the assessment sample size both nationally and within counties and districts.

**The Assessment Population**

- Ebola survivors aged 18+
- Present in Lofa, Bong, Margibi, and Montserrado Counties
- Confirmed survivor status (baseline: ETU certificate or PREVAIL ID; endline: official survivor ID card)

As part of program activities, a mapping exercise was conducted across Liberia to create a more accurate listing of survivors in Liberia. In collaboration with the NESNL and Secretariat, survivors were tracked, verified through possession of a valid ETU certificate,<sup>8</sup> and provided with official ID cards. As this exercise had more stringent guidelines for verifying survivors than the original MOH list, the total number of survivors used for developing the sample was smaller (N=1,366 vs. N=876).

For both assessments, a stratified simple random sampling process was employed, with each district and gender representing a stratum. The sample size of each district was dependent on the proportion of the survivor population within that district. Within each stratum, a simple random sampling process was used to identify the Ebola survivors who were interviewed.

For baseline the total sample size was calculated based on the following assumptions:

- Design effect (deff) 2
- Confidence level (z) 90%

<sup>7</sup> Ministry of Health [Liberia], 'EVD Survivors Care and Support Policy' (2016), Monrovia, Liberia, p2. Estimates varied between organizations, with the MOH estimating 1,558 based on their survivor registry, the CDC approximately 3,300, and the WHO 5,000.

<sup>8</sup> Community or county stakeholders (e.g., County Health Teams) would occasionally provide additional verification.

- Non-response rate (r) 5%
- Margin of error ( $\epsilon$ ) 5%
- Population size 1,366

For endline, all assumptions were held the same except the total population was calculated at 876, and, based on baseline results, the design effect was eliminated (i.e., set to 1).

Applying these assumptions, the following sample sizes were calculated:

*Table 2: Quantitative Survey Sample Sizes, by County*

County	Baseline sampling frame	Baseline sample size	Endline sampling frame	Endline sample size
Montserrado	904	288	561	133
Margibi	216	69	150	35
Bong	113	36	62	24
Lofa	133	42	103	15
<b>TOTAL</b>	1,366	435 <sup>9</sup> (M=209, F=226)	876	207 <sup>10</sup> (M=90, F=123)

## Qualitative Interviews

The qualitative component of the assessment involved key informant interviews with stakeholders from the health facilities, government, and survivor community. A purposive sampling methodology was adopted to ensure that individuals with experience and awareness on survivor issues were interviewed. Recognizing that challenges faced by survivors and stakeholders vary between counties, individuals from each of the three stakeholder groups were identified within each county. Table 3 outlines the number of interviews conducted for both assessments.

*Table 3: Qualitative Survey Sample Sizes, by County and Stakeholder Group*

County	Ebola survivors	Health facilities	Government (county health team and district health team staff)
Montserrado	4	4	3
Bong	3	3	2
Margibi	2	3	1
Lofa	3	3	2
<b>Total</b>	<b>12</b>	<b>13</b>	<b>8</b>

<sup>9</sup> The total number of individuals surveyed during baseline was 433, as only 34 individuals were surveyed in Bong County due to challenges identifying participants to be surveyed.

<sup>10</sup> The total number of individuals surveyed during endline was 213.

## A. Tools

The research assessment employed two tools, a quantitative structured survey and a qualitative interview guide.

The quantitative structured survey was developed in consultation with JSI's Senior Evaluation Advisor and drew on the structure used by the APC/ETP&SS program in Sierra Leone.<sup>11</sup> The survey comprised seven topics: beneficiary information, health-seeking behavior and quality of care, barriers to accessing health care, engagement and awareness of advocacy bodies, stigma, and sexual behaviors. The tools were pre-tested in Liberia and adjustments to questions and response options were made based on feedback. The survey was administered in a private location with each respondent and took 30–45 minutes to complete. Based on lessons learned during the program, sections on mental health and satisfaction with healthcare services were added to the endline tool.

Three qualitative structured interview guides were developed, one for each of the three stakeholder groups. The tools focused on questions relating to the roles of the Secretariat and NESNL, health needs and barriers to care for survivors, and stigma. The tools include both key and probing questions as appropriate. The same tools were used for baseline and endline.

## B. Data Collection Process

### Quantitative Survey

Data collection for the quantitative survey was conducted between January 30 and February 10, 2017 for the baseline assessment and between May 16 and May 31, 2018 for the endline. Data was collected on tablets using the Ona application. To minimize the risk of survey participants providing false answers out of fear or embarrassment about their status as an Ebola survivor, all data collectors were EVD survivors themselves.

The data collectors were organized into four teams of 3–4 individuals. Each team was managed and supervised by a team lead who had extensive experience in data collection and team management but was not necessarily an EVD survivor. The data collection teams were trained (3 days for baseline; 5 days for endline) on the tools, data collection software, and research ethics and respondent confidentiality. All data collection team members signed contractual agreements that included clauses on confidentiality and impartiality.

Team leads were given lists of selected survey participants' names and contact details and coordinated with NESNL chapter and sector leads in each county to administer the survey. Due to the stigma associated with Ebola, interview location was based on participant preference, either at their home or place of work, or at a central location (e.g., main town) within a given district.

During endline, participants were required to show their official EVD survivor ID distributed during the mapping activity. During baseline, due to the lack of a listing of verified survivors, all participants were required to show an official ETU certificate or the NIH/PREVAİL ID card.<sup>12</sup> When participants could not

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<sup>11</sup> References to materials drawn upon during the development of the survey are noted in the tool included in Annex II.

<sup>12</sup> PREVAİL is a joint Liberia-US clinical research partnership that began operations in Liberia in 2015. PREVAİL is leading a number of studies including the Ebola Natural History Study, a 5-year clinical research study that is investigating the long-term medical impact of Ebola on

present evidence of their survivor status, social verification was sought by confirmation from an elected representative of the NESNL. If the representative did not know the person, two or more individuals from the participant’s community were asked to confirm that the participant was a survivor.<sup>13</sup> Where community feedback on the participant’s status was contradictory or unclear, the participant was disqualified from the survey. Only two participants were disqualified from the survey due to a lack of clarity on their status.

The survey forms were submitted by the data collection team to the Ona online server. The Ona server was password protected, with access limited to the APC Monitoring and Evaluation Advisor. All data downloaded from the server were stored on secure, password-protected devices.

## Qualitative Interviews

APC staff conducted the qualitative interviews. During baseline, all interviews were recorded and transcribed, unless the interviewee did not consent to recording. During endline, interviewers recorded the dominant themes discussed. Thematic analysis was used for both baseline and endline. Access to recordings, transcripts, and/or notes was limited to APC’s monitoring and evaluation team.

## C. Analysis

Results from the quantitative and qualitative pieces were analyzed individually and compared.

Baseline survey data was analyzed using Microsoft Excel 2013 and R 2016 (version 3.3.2). Endline data was analyzed using Microsoft Excel 2010 and Stata 13.

Composite indicators were created for the following variables:

Indicator	Cronbach’s alpha
Confidence in the NESNL	0.80
Confidence in the Secretariat	0.80
Patient satisfaction	0.83
Barriers to care	0.65
Stigma	0.81

All composite indicators were verified for internal reliability using Cronbach’s alpha tests. Significance of demographic factors on indicators was verified using chi-squared tests and factorial ANOVA tests where appropriate. The qualitative data was analyzed using thematic analysis, including the generation of themes and sub-themes.

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survivors and their close contacts. Further information on the research studies being conducted by PREVAIL can be found at <https://clinicaltrials.gov>.

<sup>13</sup> The research makes a clear distinction between survivors and affected persons. Individuals who cared for an individual suffering from Ebola but did not come down with the disease were excluded from this study.



## D. Limitations

There are several limitations to the quantitative survey, with a majority stemming from the survivor listings.

First, there is a risk of selection bias within the sampling framework as those surveyed were limited to individuals who had registered their name with the NESNL for baseline or during the mapping activity for endline. Individuals who have faced the greatest discrimination or who feel most ashamed about their status are less likely to disclose their status. Additionally, individuals who did not agree with the work being done by the NESNL or APC are less likely to have registered.

Participant bias may also have occurred, as certain survivors who were engaged in full-time employment may have been unable to participate.<sup>14</sup> Additionally, those who did not have a favorable relationship with the NESNL, the Secretariat, or APC were more likely to refuse to participate.

Some survey participants in Margibi and Bong Counties were in remote communities that could not be reached (e.g., access to one particular participant would have required a four-hour walk through rough terrain, each way). This led to selection of more accessible survivors, creating a bias in the assessment, compounded by the fact that survivors in the most remote communities are likely to face the greatest challenges accessing health care and the least likely to be aware of or involved with survivor representative/coordination bodies.

An additional limitation is that the sample size is dramatically reduced for certain indicators and results, particularly where complex skip logic was applied, making indicators less reliable. Throughout the report it is noted where sample sizes are reduced. Sample size figures for the key indicators can be found in Appendix II.

Further bias may have occurred through the tool structure. The tool limits questions on the quality of health care to those that have recently sought it. Individuals who are highly unsatisfied with health facilities are unlikely to have sought health care recently, resulting in the sample being biased to those who have a greater satisfaction level with facilities. The tool included questions to determine why an individual chose not to go to the health facility for treatment.

## E. Ethical Approval

Both assessments were approved by the JSI Ethical Review Board as well as the National Research Ethics Board of Liberia.

The assessment did not record the name of any survivor who participated in the survey and participant listings were shredded upon the completion of data collection to ensure confidentiality. Informed consent was obtained from each respondent prior to beginning any survey or interview. Participants signed consent forms or, when not possible, data collectors signed to confirm observation of informed consent for each survey.

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<sup>14</sup> If necessary, and when possible, interviews were conducted during work breaks or after work hours.

# RESULTS

## A. Survey Demographics<sup>15</sup>

In total, the quantitative survey was conducted with 642<sup>16</sup> EVD survivors, of whom 46 percent were male and 54 percent were female. As sampling was stratified by both administrative district (county) and gender, the sample population is believed to be reflective of the survivor population on these two factors. As outlined in the sampling methodology, more than half the individuals interviewed were from Montserrado County, where a majority of the survivor population in Liberia is located.

Composite data, meant to convey total survey population sociodemographic characteristics, is reported for variables where there was no statistically significant difference between baseline and endline variables. Test statistics are detailed for variables with statistically significant difference where appropriate. An alpha level of 05 was used for all statistical tests.

### Age

The survey shows that the adult survivor population in Liberia is young, with approximately half of all respondents between 18 and 34 years of age (49.7 percent) and more than 75 percent of adult survivors being under 45.

### Religious background

A majority of survivors interviewed identified as Christian (78.5 percent), with the remaining respondents all identifying as being of Muslim faith. This distribution was reflected across the counties, except Lofa County, where 52.9 percent of the survey population identified as Muslim. This distribution has a greater percentage of individuals identifying as Muslim than found within the religious demographics among the general Liberian population.<sup>17</sup>

### Education levels

The overall education level of survivor respondents was higher than that of the average population in Liberia, with more than half of all respondents surveyed having a high school certificate qualification or higher (58.2 percent).<sup>18</sup> A large proportion had little-to-no schooling (25.4 percent)<sup>19</sup>, while 7.9 percent of respondents had a university qualification.<sup>20</sup> The education levels vary considerably for survivors

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<sup>15</sup> More detailed data on respondent's demographics can be found in Annex I.

<sup>16</sup> Combined baseline and endline samples.

<sup>17</sup> Liberia Institute of Statistics and Geo-Information Services (LISGIS), Ministry of Health and Social Welfare [Liberia], National AIDS Control Program [Liberia], and ICF International, 'Liberia Demographic and Health Survey, 2013' (2014), Monrovia, Liberia, p34.

<sup>18</sup> According to the Liberia Demographic and Health Survey 2013 (above n9, p36–37) only 10.3% of Liberian women and 28.3% of men have completed secondary school or more. 33.2% of women and 12.9% of men have no schooling at all.

<sup>19</sup> According to the 2014 Household Income and Expenditure Survey, 37.7 percent of Liberians have no formal education. Liberia Institute of Statistics and Geo-Information Services (LISGIS), 'Household Income and Expenditure Survey 2014: Statistical Abstract' (March 2016), Monrovia, Liberia, p34.

<sup>20</sup> According to the 2014 Household Income and Expenditure Survey (above n11, p35), 8.1 percent of Liberians are reported to have a university qualification.

outside Montserrado. While not a statistically significant difference, during baseline Lofa County had the lowest education levels and during endline Bong County had the lowest. Note that the education measurements used in this survey only asked respondents to identify the highest level of education they had attained; it did not consider the quality of education received nor did it assess literacy or numeracy levels.

#### *Health worker status*

Fifty-one respondents (7.9 percent) identified themselves as having served as professional health workers during the Ebola outbreak. Because of the small sample size, indicators and results were not disaggregated by health worker status.

#### *Head of household*

Respondents were asked if they considered themselves to be the head of the household. There was a statistically significant difference between baseline and endline ( $X^2 = 9.82, p=.002$ ), with 80.1 percent reporting as the head of household during baseline and only 69.01 percent during endline. It is not clear how this may affect the analysis between the two assessments, particularly considering that related demographics (e.g., income source and income-generating skills) did not vary significantly between baseline and endline.

#### *Income and skills*

Questions on respondent's income sources and income generating skills were included to help better understand member circumstances. There was a statistically significant difference between income source between baseline and endline ( $X^2=23.26, p<.001$ ). In baseline, only 8.1 percent of respondents reported being formally employed compared to 13.6 percent of endline respondents. Similarly, 16.2 percent of baseline respondents reported being daily laborers compared to 7.5 percent of endline respondents. Roughly half of respondents reported being in petty trade, with little difference between baseline and endline (51.5 percent and 48.8 percent, respectively).

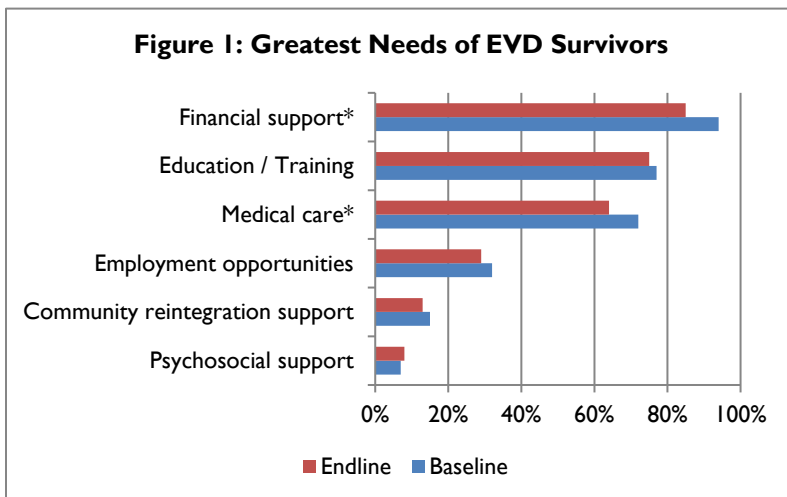
There was also a statistically significant difference between the two assessments of respondents reporting having income-generating skills ( $X^2=6.48, p=.01$ ), with 48.0 percent of baseline respondents reporting having skills compared to 58.7 percent of endline respondents. Just over half (51.6 percent) of the total survey population reported having no income generating skills. Types of skills did not vary significantly, with the primary skills being soap making, professional (e.g., accounting or nursing), and hairdressing. Less common skills included carpentry, masonry, tailoring, electrical, mechanical, and driving.

### Greatest needs

Respondents were asked to identify their three greatest needs (unranked) from a list of seven options. As outlined in Figure 1, financial support was the most common need reported by respondents, followed by education/training and medical care.

While there was not a large amount of variance between baseline and endline data overall, there were statistically significant differences for two particular needs (starred in

Figure 1): financial support (baseline=94.0 percent, endline=85.5 percent,  $X^2=12.97$ ,  $p<.001$ ); and medical care (baseline=72.1 percent, endline=63.9 percent,  $X^2=4.52$ ,  $p=.03$ ).



The proportion of respondents listing medical care as a great need varied by county ( $X^2=17.81$ ,  $p<.001$ ), being highest in Lofa (83.8 percent) and lowest in Margibi (56.2 percent).

The proportion of respondents listing psychosocial support as a great need did not vary significantly between baseline and endline. Interestingly, however, it did vary by income source ( $X^2=13.40$ ,  $p=.02$ ), with 24.4 percent of individuals getting income through formal employment identifying psychosocial support as a major need, much higher than the overall average of 7.0 percent. For a detailed breakdown of greatest need response see Annex I.

## B. Health-Seeking Behavior and Barriers to Care

As outlined in the background section above, it is often reported that survivors fail to seek health care due to fears of stigma or poor treatment. This assessment aimed at understanding the veracity of these reports and learning more about the primary barriers to care.

### Health-Seeking Behavior

Respondents were asked if they had experienced a health problem in the past six months, and if so, if they sought care at a health facility. In both baseline and endline, more than 90 percent of respondents reported seeking treatment at a health facility (92.9 and 92.2 percent, respectively). This suggests that survivors are willing and able to seek treatment at facilities, at least at the initial onset of a health problem. Of those who did not seek treatment at a health facility, many sought treatment at a pharmacy (60.0 percent).

Data from the baseline qualitative interviews illuminated survivor's health-seeking behavior, with reports that survivors often attend a facility when they first get sick but fail to attend follow-up appointments or follow through with referrals. Survey data demonstrates that a majority of individuals who sought treatment at a facility were required to return for follow up treatment two or more times, although with little variation between baseline and endline (82.4 and 82.3 percent, respectively).

### **Strengthened Referral Pathways**

During baseline, only 60 percent of survivors who were referred for advanced care acted on the referral. This increased by 36 percent over the course of the program, to 82 percent.

The program conducted a number of activities to strengthen referral systems and increase access to more advanced care, including clinical training modules on referral pathways for mid-level health clinicians; survivor mapping to strengthen survivor mobilization and follow-up; technical assistance and administrative support to survivor advocacy bodies (the NESNL and Secretariat); provision of free, comprehensive care and transportation

reimbursement; and rotations by EVD sequelae-related sub-specialists at program target facilities.

The assessments sought to examine information on the referral process for survivors, but between the two assessments only 80 (18.1 percent) respondents reported being referred by a provider. Given this small sample, there are limitations on the reliability of the referral information. Baseline results showed that only 60.3 percent of survivors reported attending referral appointments. During endline we found that this had increased by 35.7 percent, with 81.8 percent of respondents reporting having attended referral appointments.

For those who did not attend the referral facility, the primary barriers were cost of transport and expected cost of treatment.<sup>21</sup> These findings were supported by qualitative data. Family obligations were also commonly listed as a reason for being unable to attend.

Survivors primarily sought care at hospitals, with 66.4 percent of baseline respondents reporting having sought care at a hospital in the last six months and 72.4 percent of endline respondents reporting the same.

**“Most of them [survivors] do not return for follow up because of the distances they travel to come to the health facility.”**

—Health facility staff member

Respondents who had visited a formal health facility in the last six months were asked to indicate type of facility. Of note, respondents could indicate visiting multiple types of facilities (e.g., visiting both a clinic and a hospital within the six-month period). The primary facility type at which survivors sought treatment was hospitals, with little variation between the assessments. Overall, 66.4 percent of respondents reported having attended a hospital in the last six months. However, this was not consistent across counties during baseline (endline data had no significant variation by county). In Lofa, baseline respondents were more likely to visit a clinic (60.7 percent) compared to a hospital (35.7 percent), compared to Montserrado, where, likely due to the greater availability of hospitals, respondents were much more likely to visit a hospital (63.1 percent) than a clinic (33.9 percent).

Respondents were asked if they attend the nearest health facility to them. Overall, 40.3 percent reported seeking care at further away facilities. There was no significant difference between assessments, but facility choice did significantly vary by county ( $X^2=58.13$ ,  $p<.001$ ), age ( $X^2=11.09$ ,  $p=.05$ ), and income source ( $X^2=14.19$ ,  $p=.01$ ). Respondents in Lofa were more likely to attend the nearest facility (91.2 percent reporting doing so) than those in Montserrado (50.12 percent), likely due to the scarcity of facilities in Lofa. Respondents between ages 18 and 24 were the most likely to attend the closest health facility (68.2 percent) compared to 55 to 64 year olds (48.9 percent). Daily laborers were less likely to travel (64.0 percent attending nearest facility) compared to those with formal

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<sup>21</sup> Cost of transportation, while not statistically significant, did reduce between baseline and endline. As part of the program, all survivors were entitled to and receiving transport reimbursement for medical visits.

employment (39.1 percent). These data suggest that availability of alternative facilities, formal work (and likely greater income), and age may all factor into health-seeking behaviors.

Common reasons provided for traveling further for health care were quality of service, services being free at other facilities, being familiar with health facility staff, and access to survivor-specific care. The key informant interviews offered additional insight, as some informants suggested they prefer to attend facilities that have a PREVAIL or Men's Health Screening Program<sup>22</sup> site attached to it. This is likely due to the fact that both programs pay a stipend to patients who visit the facilities and have staff with more intensive training on and experience working with EVD survivors.<sup>23</sup>

## Barriers to Health Care

Respondents were asked to rank their top three challenges to accessing care ("Hardest challenge," "Second hardest challenge," and "Third hardest challenge"). For both assessments, the primary barriers were transport costs and the distance to health facilities.<sup>24</sup> These barriers were also consistent with qualitative data. Other major barriers identified in the quantitative and qualitative data included the cost of treatment and long wait times at facilities.

However, these results varied across counties, with all barriers except distance to the health facility and staff treatment showing statistically significant variation between counties. For example, 43.8 percent of Bong County respondents listed cost of transportation as the hardest challenge compared to only 27.1 percent in Montserrado ( $\chi^2=42.14, p<.001$ ). This is likely because the distances required to travel to seek health care and the costs incurred from the travel are greater for individuals outside Monrovia and as a result is a larger barrier to accessing health care.

**"Just recently a survivor nearly died because he was very ill, but thanks...to free care provided to him at ELWA hospital he is now well and planning his wedding."**

—EVD survivor

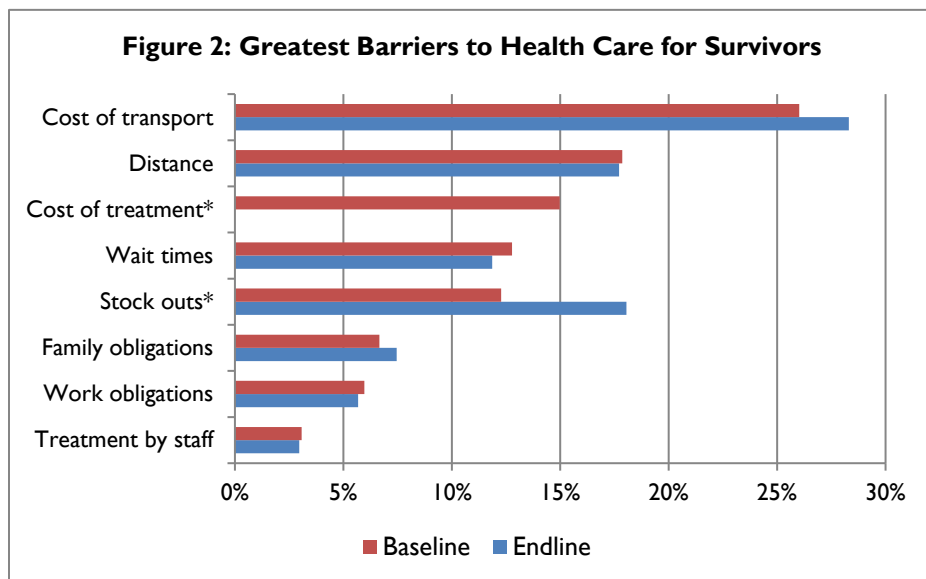
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<sup>22</sup> The Liberia Men's Health Screening Program was established in Liberia in 2015. It is a program that combines semen testing with counselling for survivors to promote safer sex practices. For further information, see <http://www.cdc.gov/globalhealth/countries/liberia>.

<sup>23</sup> Participants in the PREVAIL study are required to attend a PREVAIL center every six months for medical testing. The participants are provided a financial incentive for attending these visits. They are also paid to return to the center to collect their test results. Additionally, the PREVAIL centers offer amenities to survivors when they seek care at the health facility next to the PREVAIL center, such as cold water, air conditioning, places to sit, etc.

<sup>24</sup> Figure 2 represents the results from a combined score developed by weighting the results from primary, secondary, and tertiary barriers.

Only two of the barriers had statistically significant differences between baseline and endline: cost of treatment ( $X^2=40.95$ ,  $p<.001$ ) and medicine stock outs ( $X^2=10.86$ ,  $p=.01$ ). These findings were supported by qualitative data. Cost of treatment was reported as a barrier to care by 44.6 percent of baseline respondents, with 16.6 percent listing it as the primary barrier to care. At endline, this was reduced to 19.3 percent, with only 9.4 percent reporting it as the primary barrier.



Conversely, stock outs were a more prominent barrier at endline than baseline (50.3 and 42.3 percent, respectively, reporting as a barrier). This difference was more pronounced for those listing it as the primary barrier, showing a 47.4 percent increase between baseline and endline (16.0 and 9.5 percent, respectively). As EVD-focused funding has been reduced, there are fewer programs focusing specifically on care for the survivor population. In addition, Liberia faces many challenges to maintaining a robust supply chain, resulting in regular stock outs across all types of facilities and for all patients. Shortly after the endline was completed, the program distributed medications reserved for use by EVD survivors to the target health facilities, with the goal of alleviating some of the burden of this barrier.

Only 9.8 percent of individuals listed staff behavior as a barrier to accessing health care, with little change between baseline and endline. While this matches self-reported experience of stigma at health facilities for endline respondents (7.8 percent), it is markedly different from baseline reports of stigma (33.1 percent). Stigma was also a frequent theme identified through the qualitative survivor interviews. A more detailed discussion on stigma at health facilities can be found in the following section.

Importantly, gender barriers such as a lack of a female doctor or getting a husband or partner's permission were not considered a barrier by many women across all the counties. However, family obligations were reported by many women to be a barrier, especially in Lofa County, where 25.7 percent of female respondents listed it as the greatest barrier to care.

Table 4: Barriers to Health Care, by Assessment

	Baseline (%)	Endline (%)
Cost of transport	26.0	28.3
Distance	17.9	17.7
Cost of treatment*	15.0	7.5
Wait time	12.8	11.9
Stock outs*	12.2	18.1
Family obligations	6.7	7.5

Work obligations	6.0	5.7
Health staff behavior	3.1	3.0
Lack of female doctor	0.2	0.2
Male permission	0.2	0.3

\* Statistically significant at  $p < .01$

## Stigma

The survivor community has consistently reported that they face stigma at the facilities where they seek health care. The data confirms that the presence of stigma varies on a facility by facility level.

To address the issue of stigma among the EVD survivor population, the program developed a three-day modular training for mid-level health workers based off the MOH's *Ebola Survivors Clinical Care Guidance* handbook. The modules covered clinical care as well as stigma reduction education and practices. This training was conducted with 464 mid-level health workers (e.g., Registered Nurses and Physician Assistants) from 11 EVD affected counties. The program also worked with County Health Teams (CHTs) and program target facilities to develop memoranda of understanding in which the CHTs and target facilities formally committed to providing survivor health care and medications procured for survivors for a period of 12 months following the program end date.

To more clearly understand the stigma levels faced by survivors, program assessments examined how often facility staff were aware of a survivor's status and if survivors felt they had experienced different types of stigma (e.g., receiving worse care than non-survivors).

There was little variation between baseline and endline in disclosure of survivor status to health facility staff. Overall, the vast majority (81.7 percent) of survivors surveyed confirmed that the last time they sought health care the health worker was aware of their status. Most survivors freely disclosed their survivor status (85.4 percent) or the clinician had treated them when they had Ebola (10.8 percent). Few survivors reported that their status was disclosed without their permission (3.7 percent).

Survivors were asked if they had experienced various types of stigma due to their EVD survivor status: refusal of care, staff appearing nervous or uncomfortable, staff openly gossiping about their status, longer wait times than non-survivors, and worse care than non-survivors.

There was a significant reduction in self-reported experience of stigma between the baseline and endline assessments ( $X^2=36.45, p<.001$ ). For baseline respondents who had sought health care in the past six months, 33.11 percent claimed they faced two or more occurrences of stigmatization by health facility staff. This was reduced by 76.4 percent, to 7.8 percent of respondents, at endline. The proportion of respondents who stated they faced two or more cases of stigma did not vary considerably by gender, educational level, or age group.

However, there was significant variation across counties ( $X^2=8.19, p=.04$ ), with stigma levels being considerably lower in Montserrado County (20.5 percent) compared to Margibi (29.5 percent) and Bong (35.4 percent). This is surprising given that the primary facilities used by respondents in Margibi and Bong had staff who themselves are survivors.

**“Everyone is treated equally at the facilities. Over the past time there was lot of stigma in facilities, but with the help of JSI and other partners we don’t see such things taking place.”**

- EVD survivor



Table 5: Types of Stigma, by Assessment

Type of stigma	Baseline (%)	Endline (%)	Test statistic
The doctor/nurse refused to treat you or refused to do relevant tests	10.6	4.2	$X^2=7.50$ , $p=.01$
You had to wait longer for the doctor/nurse to treat you than other patients	36.0	16.0	$X^2=27.69$ , $p<.001$
The doctor/nurse appeared nervous or uncomfortable treating you	22.6	7.5	$X^2=22.46$ , $p<.001$
The doctor/nurse gossiped about your survivor status	18.7	5.6	$X^2=19.79$ , $p<.001$
You received less care/attention than other patients	28.6	10.8	$X^2=25.85$ , $p<.001$
Have you ever avoided or delayed seeking health care treatment because you were afraid of the doctor/nurses attitudes towards you as an Ebola Survivor	25.2	10.3	$X^2=19.46$ , $p<.001$

Reduction in experience of stigma translated to a reduction of stigma on health-seeking behavior. At baseline, 25.2 percent of respondents reported avoiding or delaying seeking health services because, as survivors, they feared stigma from facility staff. This was reduced to 10.3 percent at endline.

## Mental Health Care

The program collaborated with the Phebe School of Nursing Rural Training Institute (Phebe) to implement the Post-Basic Mental Health Clinician Training Program for two cohorts of students comprised of mid-level health workers (i.e., Registered Nurses, Physician Assistants, and Registered Midwives). The aim of this program was to train, graduate, and certify into practice Mental Health Clinicians, recognizing the limited availability of mental health services for both the EVD survivor population and the general population. In total, the program graduated 38 trainees.

Two psychiatrists recruited from Nigeria and Uganda coordinated the nurse training program and also provided clinical psychiatric care to both survivors and the general population at select program target health facilities.<sup>25</sup>

To understand the mental health needs and experiences of survivors, the assessments asked participants if they had received some form of mental health support or counselling for their Ebola experience in the prior year. There was a statistically significant difference between the assessments ( $X^2=9.64$ ,  $p<.001$ ), with 60.3 percent of baseline respondents having received counselling compared to 47.4 percent of endline respondents. The reduced use of counselling services may be due to the

### **Where are survivors seeking mental health support?**

The most common providers of mental health care were APC-supported health facilities (e.g., JFK Medical Center and Duport Road Medical Center). Other providers included home-based care and PREVAIL sites.

<sup>25</sup> Phebe Hospital, Redemption Hospital, and Tellewoyan Hospital

endline being conducted longer after the epidemic, with survivors feeling reduced need for counselling on their experiences. There was no variation in the proportion of individuals who have received mental health support by gender or education level.

Findings did vary between counties ( $X^2=18.55, p<.001$ ): 75 percent of respondents in Margibi had received support, 66.2 percent in Lofa, 62.5 percent in Bong, and 50.1 percent in Montserrado. A potential explanation for this county-level variation is where survivors sought care. The most common location where survivors received mental health support was through APC-supported health facilities.

The need for mental health care is particularly salient in the context of two mental health assessments conducted during the endline, the Patient Health Questionnaire 9-question (PHQ-9) and the Generalized Anxiety Disorder 7-question (GAD-7).<sup>26</sup> Internal reliability was good for both the PHQ-9 and GAD-7, with Cronbach's alphas of 0.83 and 0.81, respectively.

One-fifth (20.2 percent) of respondents met the diagnostic criteria for depressive disorder, including 7.07 percent for major depressive disorder (MDD). The PHQ-9 asks respondents if they've experienced various depression diagnostic criteria in the last two weeks. Nearly half (47.0 percent) of respondents reported that they had little interest or pleasure in doing things; 42.6 percent reported feeling down, depressed, or hopeless; 57.7 percent reported feeling tired or having little energy; and 40.8 percent said they felt like a failure or had let themselves or their families down. Of concern, 15.9 percent of respondents said they had had thoughts that they would be better off dead or of harming themselves in some way in the last two weeks.

In robust univariable linear regression, PHQ-9 scores, where a higher score indicates greater experience of depressive symptomology, were positively associated with the GAD-7 anxiety score ( $beta=0.86, p<.001$ ). Depression score was also positively associated with both experience of stigma ( $beta=4.46, p<.001$ ) and avoiding care due to fear of stigma ( $beta=2.71, p=.03$ ). Scores were negatively associated with positive perceptions of care: satisfactory quality of care ( $beta=-2.12, p=.03$ ) and adequate access to care ( $beta=-2.48, p=.01$ ); meaning that a higher depression score was related to poorer perceptions of quality of and access to care, suggesting that depression may be related to negative perceptions of care. Depression score was not significantly associated with age, gender, education, or having sought counseling in the last year.

Additionally, 14.8 percent met the score cut-point (score of 10 or greater) for generalized anxiety disorder (GAD). Similar to the PHQ-9, the GAD-7 asks about experience of GAD-related symptoms in the prior two weeks. The majority (50.7 percent) of respondents said they worried too much about different things; 42.4 percent reported not being able to stop or control worrying; and 37.4 percent feeling nervous, anxious, or on edge.

Similar to the PHQ-9, in robust univariable linear regression GAD-7 scores, where a higher score indicates greater experience of anxiety symptomology, were positively associated with both experience of stigma ( $beta=1.98, p=.02$ ) and avoiding care due to fear of stigma ( $beta=1.59, p=.04$ ). Anxiety score was also negatively associated with positive perceptions of satisfactory quality of care ( $beta=-1.68, p=.04$ ) and adequate access to care ( $beta=-2.62, p<.001$ ). Anxiety score was not significantly associated with age, gender, education, or having sought counselling in the last year.

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<sup>26</sup> These assessments are meant as initial assessment tools; firm diagnosis of either depressive disorder or generalized anxiety disorder requires more intensive assessment by a mental health professional.

Participants who met the criteria for either depression or anxiety, and anyone who reported thoughts of suicide or self-harm, were connected by the enumerator to a mental health focal person in their county to arrange counselling.

## **C. Engagement with Representative Bodies**

The ETP&SS program provided technical assistance, capacity-building, administrative, and logistical support for both the NESNL and Secretariat.

Building the capacity of the nascent NESNL was a critical component of the ETP&SS program's strategy to build resilience and self-reliance, helping them establish themselves as a strong, sustainable local nongovernmental organization (NGO). To achieve this goal, APC worked with the NESNL in a myriad of ways—by significantly assisting them to formalize their network into a formal NGO; supporting their local and national elections; supporting the development of their constitution and bylaws; and funding the NESNL's National Convention in early 2018 where they validated their constitution and by-laws. The program supported the development of their strategic plan, and provided direct support for their national office and the operation of that office. Furthermore, ETP&SS provided logistics support with vehicles, vehicle maintenance and fuel to assist with their engagement in referrals, survivor mapping, and outreach activities. To build capacity, the program provided training in resource mobilization and advocacy, and also supported the NESNL's ability to share information and learn from other national survivor organizations and international research organizations through regional meetings and workshops.

The ETP&SS program supported the MOH's transition from emergency-period survivor activities, i.e., leadership from the Incident Management System (IMS)/Emergency Operations Center (EOC) during the epidemic/immediate post-epidemic period to leadership from MOH Health Services under the general supervision of the Chief Medical Officer. The Secretariat successfully mediated this transition over a period of approximately 17 months of operation. The ETP&SS program supported the recruitment and official formation of the Secretariat, facilitated a self-led organizational capacity assessment, assisted with the development of the Secretariat's action plan, provided direct support for the operation of that office, and provided direct support for Secretariat members to participate in trips to Sierra Leone and Guinea; the trips focused on resource mobilization and advocacy, experience sharing with key stakeholders and representative bodies serving survivors in Guinea and Sierra Leone.

The Secretariat's key role was to prioritize implementation of the EVD Survivor Care and Support Policy while the MOH was adjusting to the administration transition. The Secretariat functioned as the key point office and served as a liaison between the lay survivor population, the NESNL leadership at county and national levels, MOH, and ETP&SS program management.

The NESNL was established in February 2015 by a group of EVD survivors committed to addressing EVD survivor needs and advocating for survivors and affected populations. The Network actively participated in information sharing, resource mobilization, clinical care coordination, survivor mapping, and stigma reduction activities related to survivor care and coordination.

The Secretariat was formed with support from ETP&SS in January 2017 with the mandate to prioritize implementation of the EVD Survivor Care and Support Policy while the MOH adjusted to the presidential administration transition. The Secretariat consisted of four officers seconded to the MOH; they worked to translate the National Survivor Care and Support Policy into action, and to coordinate

survivor outreach, mobilization, facilitation, and follow-up. The Secretariat functioned as the key liaison between the lay survivor population, the NESNL leadership at county and national levels, MOH at county and central levels, and ETP&SS program management.

The baseline and endline assessments aimed to understand the level of awareness and engagement that survivors had with these two representative bodies: NESNL, a body of EVD survivors serving as elected representatives for the survivor community, and the Secretariat, a group of four technical specialists seconded to the MOH to coordinate survivor care activities.

## The National Ebola Survivors Network of Liberia

Survey participants were identified through listings provided by the NESNL, which was also engaged in the data collection process. As such, there is expected bias towards greater knowledge and positive opinion of the NESNL.

Between baseline and endline there was a slight increase in knowledge of the NESNL, from 89.2 percent to 93.0 percent. The minor increase may be explained by the high baseline level of knowledge.

During baseline, there were statistically significant differences in knowledge of the NESNL by gender, age, and education. Baseline awareness levels were significantly higher among males than females, with 93.2 percent of males being aware of the NESNL compared to 85.5 percent of females. Awareness levels were positively associated with education level, with 73.4 percent of respondents with no education reporting awareness compared to 93.2 percent of respondents with high school education and 100% of university graduates.

During endline, no significant variation was found based on gender, age, and education, suggesting that outreach efforts had reached the groups most in need of information.

In both baseline and endline, variation was found between counties. While in baseline the highest awareness was in Margibi (94.2 percent) and lowest in Lofa (78.6 percent), during endline the highest was in Montserrado (96.4 percent) and lowest in Bong (64.3 percent). With county-level NESNL chapters taking much of the leadership in the outreach process, this suggests that some county chapters may have been more successful than others in promoting awareness.

Despite high levels of awareness among the survivor population, understanding of the role and purpose of the NESNL and its activities was comparatively low in both assessments, with 73.02 percent of baseline respondents and 54.0 percent of endline respondents having a correct understanding of the NESNL's role and responsibilities.

Respondents who were aware of the NESNL were asked a series of questions to measure their confidence in the NESNL and its representatives, such as if they were happy with the work of the NESNL. A composite score was developed from these results, which showed that 83.4 percent of baseline respondents and 61.4 percent of endline respondents were confident in the work of the NESNL ( $X^2=19.28$ ,  $p<.001$ ). This confidence level varied significantly by county, with Lofa County respondents being the most confident through both assessments (baseline=97.0 percent, endline=80.0 percent), while Margibi had the lowest confidence at baseline (72.3 percent) and Bong at endline (33.3 percent). This variation may reflect the strong chapter leadership and regularity of NESNL meetings in Lofa County. The confidence levels did not vary significantly by gender, educational level, or age.

## The National Secretariat of Ebola Survivors

Because the Secretariat was a newly formed body at baseline, it was not expected that many respondents would be aware of its activities or role, particularly respondents outside Monrovia. This was confirmed at endline, as only 28.9 percent of baseline respondents were aware of the Secretariat. There was a statistically significant increase at endline, with 37.6 percent of respondents reporting awareness of the Secretariat ( $X^2=4.98$ ,  $p=.03$ ).

Between the two assessments, males were more likely to be aware (36.6 percent) than women (27.6 percent). Surprisingly, baseline awareness was greatest in Lofa County, with 40.5 percent of respondents reporting knowledge on the secretariat, compared to 28.2 percent in Montserrado County, and 24.6 percent in Margibi County. At endline, Bong had the highest awareness (57.1 percent) followed by Lofa (53.9 percent). As above, it is likely that this high level of awareness in Lofa County reflects the regularity of meetings and the effectiveness of the Lofa chapter's information dissemination.

Inverse to awareness, knowledge of the activities of the Secretariat (limited to those who reported awareness) decreased significantly between baseline and endline, from 66.4 percent to 39.6 percent ( $X^2=11.54$ ,  $p<.001$ ).

Respondents who reported being aware were asked a series of questions aimed at measuring their confidence in the Secretariat, which were then developed into a composite indicator. Similar to the NESNL, confidence in the Secretariat decreased significantly between baseline and endline, from 77.1 percent to 53.3 percent ( $X^2=12.14$ ,  $p<.001$ ). This confidence score did not vary significantly by gender, educational level, or age of respondents in either assessment.

## D. Program Research Indicators and Results

Table 6: Research Indicators and Results

No	Indicator	Baseline (n=433)	Endline (n=213)	Test statistic
1	Percentage of individuals who believe they were treated respectfully by staff while seeking treatment at their local health facility on a regular basis	61.9 (n=259)	70.0 (n=147)	$X^2=2.99$ , $p=.09$
2	Percentage of individuals reporting two or more occurrences of being stigmatized by health care providers (limited to those who sought health care in the past 6 months)	33.1 (n=100)	7.8 (n=11)	$X^2=32.80$ , $p<.001$
3	Percentage of individuals aware of the existence of the National Ebola Survivors Network of Liberia (NESNL)	89.2 (n=386)	92.9 (n=198)	$X^2=2.39$ , $p=.12$
4	Percentage of individuals confident in the work of NESNL (limited to those with existing knowledge of NESNL)	83.4 (n=322)	61.4 (n=121)	$X^2=34.6$ , $p<.001$
5	Percentage of individuals aware of the existence of the Secretariat	28.9 (n=125)	37.5 (n=80)	$X^2=4.98$ , $p=.03$
6	Percentage of individuals confident in the work of the Secretariat (limited to those with existing knowledge of the Secretariat)	77.1 (n=91)	52.6 (n=41)	$X^2=12.14$ , $p<.001$
		(n=50)	(n=10)	

# CONCLUSIONS AND PROGRAMMATIC IMPLICATIONS

The baseline results outlined in this report give broad insight to the demographics of the survivor population in Liberia, a vulnerable and understudied group. Findings from the baseline assessment informed ETP&SS program design and provided evidence for the program indicators, including the need for strategies to increase engagement with clinical care services, refine referral pathways, reduce stigma, improve access to mental health services, and strengthen survivor advocacy bodies.

The results of the endline assessment provided information on if and how the survivor experience has changed over time. While direct attribution to program activities is not possible due to other, primarily non-EVD focused public health programming conducted during the program's timeline, assessment indicators were matched to program activities as closely as possible.

## Health-Seeking Behaviors

The endline results indicate the importance of understanding the continuum of care for survivors. They clearly demonstrate that a majority of survivors go to a health facility when they first get sick, and that there has been a significant increase in likelihood to attend referral appointments for more advanced care. It is clear, however, that continued work is necessary to retain survivors through the continuum of care. Survivor advocacy bodies should continue to facilitate patient referrals, including follow-up after a patient's initial visit to a facility. As an autonomous, legally incorporated advocacy body, the NESNL has a key role to play in mobilizing and encouraging survivors to attend follow-up appointments and referral facilities.

The results demonstrate that the primary barriers to health care for survivors are the same as those faced by the general population, including proximity to health facilities and stock outs. Although some stigma continues at certain health facilities, there was a significant decrease in both the experience of stigma and its impact on health-seeking behavior. Future activities should focus on expanding the geographic scope of health system strengthening activities, such as clinical training and infrastructure development.

## Advocacy Bodies

While awareness of the NESNL increased, there was very limited knowledge of their primary functions and limited confidence in their work, although this differed between counties. The data confirm that the NESNL is well known within its population base at both the county chapter and national leadership levels; however, members need education on its role and mandate to set reasonable expectations within the broader survivor community.

Lessons learned from counties with higher awareness and confidence (e.g., Lofa with regular meetings and coordination with the County Health Teams and health facilities) should be used to inform counties that have struggled to maintain positive perceptions within the survivor community. The NESNL should

urge county chapters to hold regular meetings and actively inform its membership of the NESNL's role and planned activities. The chapter leadership should develop stronger coordination ties with County and District Health Teams and health facilities to improve survivor health outcomes.

## Mental Health

The endline results demonstrate that mental health issues are prevalent among the survivor population and should be a focus of future public health programming. The association between mental health and perceptions of and willingness to engage in care suggests that response to mental health among the survivor population may be complicated, but could also positively affect health-seeking behaviors.

Greater focus should be put on mental health conditions among the survivor population, including better understanding of the effects of EVD survivorship on mental health. Liberian institutions such as the Phebe Rural Training Institute, which received support from APC/ETP&SS to implement two cohorts of a six-month modular training program for Mental Health Clinicians, should lead these efforts going forward.

# ANNEX I: Survivor Survey Demographics

The demographics of the survey participants provide insight into the current characteristics of the survivor population in Liberia. Survivors' experiences and background vary greatly by the county where they reside. Data below are disaggregated by county except where no variation is observed. Note that the geographic breakdown of the survey participants reflects the sampling methodology adopted for the survey. This methodology was based on existing information about survivors' location. See full report for more information.

Figure 3: Participant Age

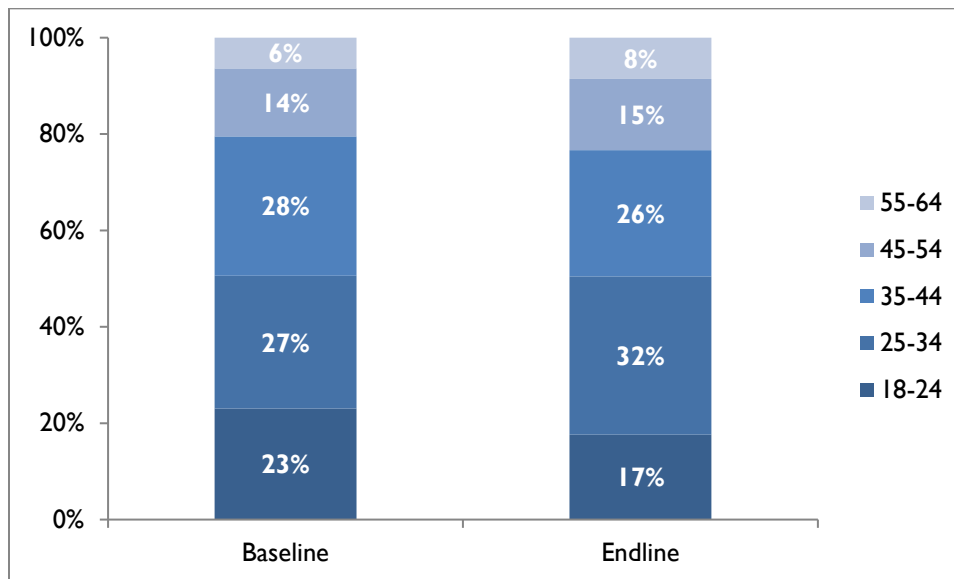


Figure 4: Participant Education

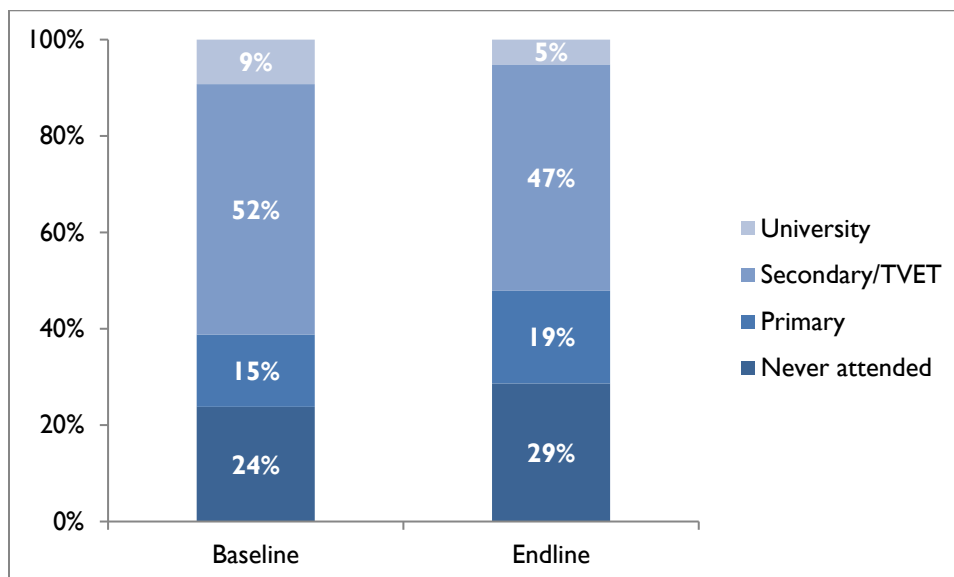




Figure 5: Participant Income Source

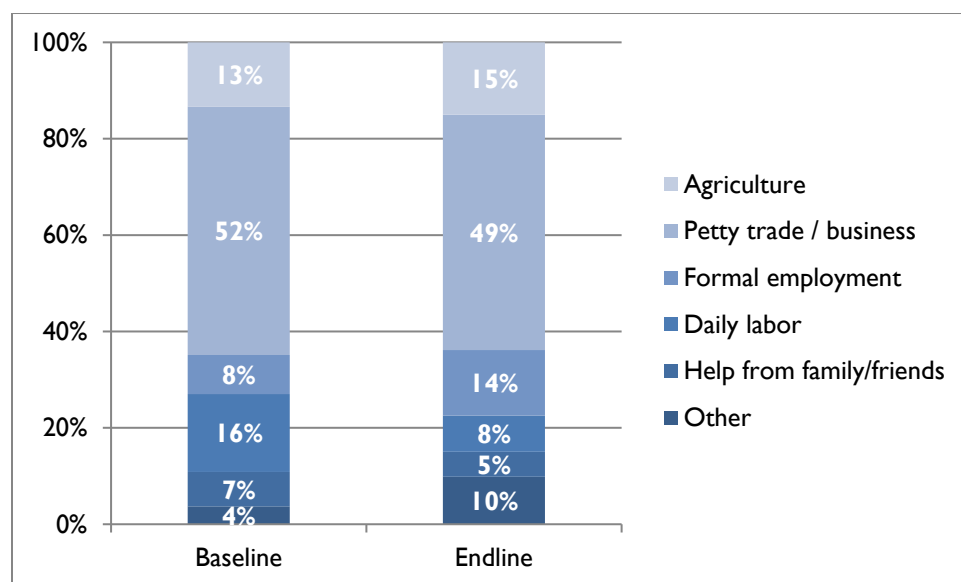


Table 7: Participant Demographics

Indicator	Percentage or med (IQR)		Test statistic (assessment comparison)
	Baseline (n=433)	Endline (n=213)	
Gender			$X^2=1.49, p=.22$
Male	47.3	42.3	
Female	52.7	57.8	
Age			$X^2=4.88, p=.43$
18-24	22.6	17.4	
25-34	27.0	32.4	
35-44	28.4	25.8	
45-54	13.9	14.6	
55-65	6.2	8.5	
65+	1.9	1.4	
Education			$X^2=8.94, p=.11$
None/Kindergarten	23.8	28.6	
Primary	15.0	19.3	
Secondary/TVET	52.0	46.9	
University	9.2	5.2	
Religion			$X^2=0.19, p=.66$
Christian	79.0	77.5	
Muslim	21.0	22.5	

Head of household (yes)*	80.1	69.0	$X^2=9.82, p=.002$
Health worker during Ebola outbreak (yes)	8.1	7.5	$X^2=0.05, p=.80$
Children (biological or non-biological)	4 (2-6)	4 (2-7)	ANOVA(F(1,646),=1.51, p=.22)
Income source*			$X^2=13.70, p=.02$
Agriculture	13.4	15.5	
Petty trade	51.5	53.1	
Daily labor	16.2	8.0	
Outside support	7.2	5.2	
Formal employment	8.1	14.1	
Other	3.7	4.2	
Income-generating skills (any, yes)*	48.0	58.7	$X^2=6.48, p=.01$

\* Statistically significant at  $p<.05$

# ANNEX II: Quantitative and Qualitative Tools

## A. Quantitative Survey Tool

PART A: BENEFICIARY INFORMATION			
NO	QUESTION	RESPONSE	SKIP
A1	Partipant ID Number		
A2	Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female	
A3	County	<input type="checkbox"/> Bong <input type="checkbox"/> Lofa. <input type="checkbox"/> Margibi <input type="checkbox"/> Montserrado	
A4	District		
A5	What is the name of the community you live in?	_____	
A6	Approximately how many people live in this community?	_____	
A7	What is the name of the closest health facility to you?	_____	
A8	Where do you go for health treatment?	_____	
A9	[Enumerator only] Did the respondent listed the same health facility for both questions above?	<input type="checkbox"/> Yes <input type="checkbox"/> No	If 1, skip to A11
A10	Why do you go to _____ [say name of health facility previously mentioned]?	_____	
<i>Beneficiary general information</i>			
	What is your gender	<input type="checkbox"/> Male <input type="checkbox"/> Female	
A11	What is your age group?	<input type="checkbox"/> 18–24 years old <input type="checkbox"/> 25–34 years old <input type="checkbox"/> 35–44 years old <input type="checkbox"/> 45–54 years old <input type="checkbox"/> 55–64 years old <input type="checkbox"/> 65 years or higher	
A12	Are you Christian or Muslim?	<input type="checkbox"/> Christian <input type="checkbox"/> Muslim	
A13	Are you the head of your household?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
A14	Were you a trained health worker during the Ebola outbreak? (e.g., doctor or nurse)	<input type="checkbox"/> Yes <input type="checkbox"/> No	
A15	What is the highest level of schooling you have completed?	<input type="checkbox"/> Kindergarten <input type="checkbox"/> Primary school (grades 1–6) <input type="checkbox"/> High school (grades 7–12) <input type="checkbox"/> TVET <input type="checkbox"/> University <input type="checkbox"/> Never attended school	

A16	How many children do you take care of?	_____ (number)	
A17	What are your three greatest needs right now? (Select only three)	<input type="checkbox"/> Psychosocial support <input type="checkbox"/> Medical care <input type="checkbox"/> Financial support <input type="checkbox"/> Education/training <input type="checkbox"/> Employment opportunities <input type="checkbox"/> Community reintegration support <input type="checkbox"/> Other _____	
A18	What is your main source of income for the household?	<input type="checkbox"/> Agriculture /farming/livestock <input type="checkbox"/> Petty trade/business <input type="checkbox"/> Daily laborer <input type="checkbox"/> Help from family/friends <input type="checkbox"/> Formal employment <input type="checkbox"/> Other _____	
A19	Apart from your main source of income, what else do you do to get money?	_____	
A20	Do you have any income-generating skills/trade?	<input type="checkbox"/> Yes <input type="checkbox"/> No	If 2 selected, skip to Part B
A21	What type of skills/trade? (Please select all that apply)	<input type="checkbox"/> Carpentry <input type="checkbox"/> Masonry <input type="checkbox"/> Mechanic <input type="checkbox"/> Pastry <input type="checkbox"/> Soap making <input type="checkbox"/> Hair dressing <input type="checkbox"/> Tailoring <input type="checkbox"/> Electrician/technician. <input type="checkbox"/> Professional skills (accounting, nursing, social work etc.) <input type="checkbox"/> Other _____	

<b>PART B: Health-Seeking Behavior and Quality of Health Care</b>			
<b>NO</b>	<b>QUESTION</b>	<b>RESPONSE</b>	<b>SKIP</b>
B1	Have you had any health problems in the past 6 months?	<input type="checkbox"/> Yes <input type="checkbox"/> No	If 2 selected, skip to B9
B2	When you had this problem, did you go to a clinic or health facility to get treatment?	<input type="checkbox"/> Yes <input type="checkbox"/> No	If 1 selected, skip to B4
B3	If you did not go to a health facility where did you go to get treatment for your health problem?	<input type="checkbox"/> Community health worker/gCHV <input type="checkbox"/> Trained traditional midwife <input type="checkbox"/> Pharmacy <input type="checkbox"/> Country doctor <input type="checkbox"/> Pastor/imam <input type="checkbox"/> Community leader <input type="checkbox"/> Drug sellers/black baggers <input type="checkbox"/> Other _____ <input type="checkbox"/> Nowhere	Skip to B9
B4	What type of facility did you visit?	<input type="checkbox"/> Clinic	

	(Select all facilities visited)	<input type="checkbox"/> Health centre <input type="checkbox"/> Hospital	
B5	How many times did you go to the clinic or facility to solve this health problem?	<input type="checkbox"/> Once <input type="checkbox"/> Twice <input type="checkbox"/> Three times <input type="checkbox"/> Four times or more <input type="checkbox"/> Don't know	
B6	Did the facility refer you to a bigger or different facility to get better treatment?	<input type="checkbox"/> Yes <input type="checkbox"/> No	If 2 selected, skip to B9
Eval1	Do you feel you should have been referred?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
B7	Were you able to go to the referral facility to get the treatment?	<input type="checkbox"/> Yes <input type="checkbox"/> No	If 1 selected, skip to B9
B8	Please explain why not.  (Select all that apply)	<input type="checkbox"/> Transport costs/distance <input type="checkbox"/> Cost of treatment at referral facility <input type="checkbox"/> Fear <input type="checkbox"/> Employment obligations <input type="checkbox"/> Family obligations <input type="checkbox"/> Other _____ <input type="checkbox"/> No response	
Eval2	Was the quality of healthcare that you received satisfactory?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Eval3	Do you feel that your access to healthcare for this problem was adequate?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Eval4	In the past two years (since the end of the Ebola time), do you feel that care for this problem has:	<input type="checkbox"/> Got much better <input type="checkbox"/> Got a little better <input type="checkbox"/> Stayed the same <input type="checkbox"/> Got a little worse <input type="checkbox"/> Got much worse <input type="checkbox"/> Don't know	
<i>For the next set of questions, I will ask how often something occurred during your most recent visit to a health facility/clinic. The responses are limited to "every time, some times, one one time or never".</i>			
B9	How often did the medical staff talk to you nicely and treat you well?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once. <input type="checkbox"/> Never <input type="checkbox"/> No response	
B10	How often did the medical staff listen carefully to what you had to say?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
B11	How often did the medical staff explain to you clearly about the problem you were having or the tests they were doing?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
B12	How often did the medical staff answer the questions you were asking?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once	

		<input type="checkbox"/> Never <input type="checkbox"/> No response	
B13	How often is there a good place to sit when you are waiting to be seen by the doctor/nurse?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
B14	How often does the doctor/nurse hurry too much when providing treatment?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
B15	How often do you have to wait a long time before you get to see the doctor/nurse?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
B16	How often does the staff member finds a private place to talk so other people can't hear?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
B17	How often does the doctor send you to another (bigger) facility if they cannot help you with the health problem?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
B18	In the past year, have you received any mental health support or counselling on your Ebola experience?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response	If 2 or 99 selected, skip to Part C.
B19	Where did you receive this support or counseling?	<hr/> <hr/>	

PART C: Barriers to Accessing Health Care		
NO	QUESTION AND RESPONSE	
C1	<p>Among the list of challenges I am going to read, please rank the three things that make it the hardest for you to go to the health facility?</p> <p>(Enter numbers 1 to 3 in 3 boxes. 1 is the hardest, 2 the second hardest and 3 the third hardest)</p>	<input type="checkbox"/> Long distance to the facility <input type="checkbox"/> Cost of transportation to the facility <input type="checkbox"/> Finding someone to care for the children <input type="checkbox"/> Getting time off work/someone to mind your business <input type="checkbox"/> (Women only) your boyfriend/husband allowing you to go <input type="checkbox"/> Long wait periods/ticket system at health facility <input type="checkbox"/> Shortage of medication/equipment at facility <input type="checkbox"/> The way the health staff treat you <input type="checkbox"/> The cost of services/tests at the facility <input type="checkbox"/> (Women only) lack of a female doctor at the facility <input type="checkbox"/> No major challenges <input type="checkbox"/> Other _____ <input type="checkbox"/> No response

## PART D: Engagement and Awareness of Advocacy Bodies

(Note: Adapted from J. Grunig et al, 'Guidelines for Measuring Relationships in Public Relations', Institute for Public Relations, 1999)

NO	QUESTION	RESPONSE	SKIP
D1	Do you know of any group which represents survivor interests? <i>Probe: Any group of people which meet to talk about survivor issues and that tries to make the government and other organizations help Ebola survivors?</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No	If 2 selected, skip to D3
D2	What is the name of the group(s) you know of?	_____	
D3	Have you heard of a group called the National Ebola Survivors Network?	<input type="checkbox"/> Yes <input type="checkbox"/> No	If 2 selected, skip to D10
D4	From your knowledge, what do they do?/ what is their role? <i>Correct understanding: The Network is responsible for advocating and assisting with the well-being of Ebola survivors. It links survivors to services where possible.</i>	<input type="checkbox"/> Correct understanding <input type="checkbox"/> Partial understanding <input type="checkbox"/> Incorrect understanding <input type="checkbox"/> Don't know <input type="checkbox"/> No response	
D5	Are you a member of the National Ebola Survivors Network?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<i>For the following questions please respond on whether you "agree I, neither agree or disagree, or disagree"</i>		
D6	<i>(Integrity)</i> Whenever the survivor network makes an important decision, I know it will be concerned about people like me	<input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> No response	
D7	<i>(Dependability)</i> I think it is important to watch the survivor network closely so I can be confident that they are doing a good job	<input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> No response	
D8	<i>(Competence)</i> I feel very confident about the survivor network's ability to get better support for people like me	<input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> No response	
D9	<i>(Satisfaction)</i> I am happy with the work that the survivor network is doing	<input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> No response	
D10	If the person did not have the correct understanding, explain the correct understanding of the Survivor Network.  Now you know what they do, would you be willing to join this network?	<input type="checkbox"/> Yes <input type="checkbox"/> No	

D11	Have you heard of a group within the Ministry of Health called the National Ebola Survivors Secretariat?	<input type="checkbox"/> Yes <input type="checkbox"/> No	If 2 selected, skip to D17
D12	From your knowledge, what does it do? What is its role? <i>Correct understanding: The Secretariat is responsible for coordinating all activities relating to Ebola survivors in line with the Ministry of Health. They are also responsible for implementing aspects of the Survivor Care and Support Policy.</i>	<input type="checkbox"/> Correct understanding <input type="checkbox"/> Partial understanding <input type="checkbox"/> Incorrect understanding <input type="checkbox"/> Don't know <input type="checkbox"/> No response	
	<i>For the following questions please respond on whether you "agree, neither agree or disagree, or disagree"</i>		
D13	<i>(Integrity)</i> Whenever the secretariat makes an important decision, I know it will be concerned about people like me	<input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> No response	
D14	<i>(Dependability)</i> I think it is important to watch the secretariat closely so I can be confident that they are doing a good job	<input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> No response	
D15	<i>(Competence)</i> I feel very confident about the secretariat's ability to get better support for people like me	<input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> No response	
D16	<i>(Satisfaction)</i> I am happy with the work that the secretariat is doing	<input type="checkbox"/> Agree <input type="checkbox"/> Neither agree nor disagree <input type="checkbox"/> Disagree <input type="checkbox"/> No response	
D17	If person did not have the correct understanding, explain the correct understanding of the Secretariat.  <i>Correct understanding: The Secretariat is responsible for coordinating all activities relating to Ebola survivors in line with the Ministry of Health. They are also responsible for implementing aspects of the Survivor Care and Support Policy</i>		



**PART E: Stigma**

(Note: Adapted from Stangl A., et al, 'Measuring HIV Stigma: Results of a field test in Tanzania', The Synergy Project, 2005)

NO	QUESTION	RESPONSE	SKIP
E1	The last time you went for medical advice or treatment, did the health staff know you were an Ebola survivor?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> No response	
E2	If yes, how did they know?	<input type="checkbox"/> I told them <input type="checkbox"/> Someone else told them with my consent <input type="checkbox"/> Someone else told them without my consent <input type="checkbox"/> They treated me when I had Ebola <input type="checkbox"/> Don't know <input type="checkbox"/> No response	
	<i>In the past 12 months, has any of the following things happen to you at a health facility because you were an Ebola survivor?</i>		
E3	The doctor/nurse refused to treat you or refused to do relevant tests	<input type="checkbox"/> Yes <input type="checkbox"/> No	
E4	You had to wait longer for the doctor/nurse to treat you than other patients	<input type="checkbox"/> Yes <input type="checkbox"/> No	
E5	The doctor/nurse appeared nervous or uncomfortable treating you	<input type="checkbox"/> Yes <input type="checkbox"/> No	
E6	The doctor/nurse gossiped about your survivor status	<input type="checkbox"/> Yes <input type="checkbox"/> No	
E7	You received less care/attention than other patients	<input type="checkbox"/> Yes <input type="checkbox"/> No	
E8	Have you ever avoided or delayed seeking health treatment because you were afraid of the doctor/nurses attitudes towards you as an Ebola survivor	<input type="checkbox"/> Yes <input type="checkbox"/> No	

**PART F: SEXUAL BEHAVIOR**

NO	QUESTION	RESPONSE	SKIP
	<i>For Women only: Now I am going to ask you some questions about man business. You can feel free to tell me anything.</i>		
F1	Were you in a relationship before you had Ebola?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<i>If no, skip to F3</i>
F2	Are you still in the same relationship now?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<i>If yes, skip to F4</i>
F3	Are you in a new relationship now?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<i>If no, skip to F7</i>
F4	Are you married? (Ask if still in relationship from before or in a new relationship now)	<input type="checkbox"/> Yes <input type="checkbox"/> No	

F5	In the last 12 months, have you done man/woman business with your husband/boyfriend?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response	
F6	When you do man/women business with your husband/boyfriend, how often do you use a condom?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
F7	In the last 12 months, have you done man/woman business with a man who is not your husband or boyfriend?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response	
F8	When you do man/women business with a man outside your partners, how often do you use a condom?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
F9	Since you had Ebola, have you had any child born to you?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response	
F10	How many children have you given given birth to, since you had Ebola?	_____ number	
	<i>For Men Only: Now I am going to ask you some questions about woman business. You can feel free to tell me anything.</i>		
F11	Were you in a relationship before you had Ebola?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<i>If no, skip to F13</i>
F12	Are you still in the same relationship now?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<i>If yes, skip to F14</i>
F13	Are you in a new relationship now?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<i>If no, skip to F18</i>
F14	Are you married? (Ask if still in relationship from before or in a new relationship now)	<input type="checkbox"/> Yes <input type="checkbox"/> No	
F15	In the last 12 months, have you done man/woman business with your wife/girlfriend?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response	
F16	When you do man/women business with your wife/girlfriend, how often do you use a condom?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
F17	In the last 12 months, have you done man/woman business with a woman who is not your wife or your girlfriend?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response	
F18	When you do man/women business with a woman outside your partners, how often do you use a condom?	<input type="checkbox"/> Every time <input type="checkbox"/> Sometimes <input type="checkbox"/> Once <input type="checkbox"/> Never <input type="checkbox"/> No response	
F19	Since the Ebola business finished, have you had your semen tested for Ebola?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response	<i>If 2 or 99 selected, skip to G17</i>

F20	When was the last time you had your semen tested for Ebola?	<input type="checkbox"/> One month ago <input type="checkbox"/> Two months ago <input type="checkbox"/> More than two months ago <input type="checkbox"/> Don't know <input type="checkbox"/> No response	
F21	Do you know the results of your last semen test?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response	
F22	Have you received any counselling or advice since your semen tests?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response	
	<i>Thank you very much for your time today. I want to remind you that your responses will remain confidential and safe. Do you have any questions for me?</i>		

<b>PART F: Mental Health</b>			
<b>NO</b>	<b>QUESTION</b>	<b>RESPONSE</b>	<b>SKIP</b>
	<p><i>"Read aloud: I now want to ask you some questions about depression. I will read a list of symptoms, and I want you to tell me how often you have experienced each symptom in the last two weeks.</i></p> <p><b>IF YOU DO NOT FEEL COMFORTABLE ANSWERING THESE QUESTIONS, PLEASE LET ME KNOW AND WE CAN SKIP ANY OR ALL OF THEM"</b></p>		
G1	Little interest or pleasure in doing things	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G2	Feeling down, depressed, or hopeless	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G3	Trouble falling or staying asleep, or sleeping too much	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G4	Feeling tired or having little energy	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G5	Poor appetite or overeating	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G6	Feeling bad about yourself — or that you are a failure or have let yourself or your family down	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	

G7	Trouble concentrating on things, such as reading the newspaper or watching television	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G8	Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G9	Thoughts that you would be better off dead or of hurting yourself in some way	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G10	How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	<input type="checkbox"/> Not at all difficult <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Very difficult <input type="checkbox"/> Extremely difficult	<i>Skip if G1+G2+...G9 =0</i>
	<p>"Read aloud: I now want to ask you some questions about anxiety. I will read a list of symptoms, and I want you to tell me how often you have experienced each symptom in the last two weeks.</p> <p>IF YOU DO NOT FEEL COMFORTABLE ANSWERING THESE QUESTIONS, PLEASE LET ME KNOW AND WE CAN SKIP ANY OR ALL OF THEM"</p>		
G11	Feeling nervous, anxious or on edge	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G12	Not being able to stop or control worrying	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G13	Worrying too much about different things	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G14	Trouble relaxing	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G15	Being so restless that it is hard to sit still	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G16	Becoming easily annoyed or irritable	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days <input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G17	Feeling afraid as if something awful might happen	<input type="checkbox"/> Not at all <input type="checkbox"/> Several days	

		<input type="checkbox"/> More than half the days <input type="checkbox"/> Nearly every day	
G18	How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	<input type="checkbox"/> Not at all difficult <input type="checkbox"/> Somewhat difficult <input type="checkbox"/> Very difficult <input type="checkbox"/> Extremely difficult	<i>Skip if</i> <i>G11+G12+...G17</i> <i>=0</i>

## B. Qualitative Key Informant Interview Tool

### Network Representatives Interview Guide

*Hello, I am from JSI and we are conducting research on the challenges Ebola survivors face in accessing health care and the quality of health care they receive. Given you are an elected representative within the Ebola Survivors Network, I would like to ask you some questions on these topics. This will take approximately 30 minutes.*

#### Network and Secretariat:

1. Please explain to me what is the role of the Ebola Survivors Network?
  - *Probe:* What are the main things they do?
  - *Probe:* How do you see the Network supporting improved health care services for Ebola survivors in this county?
2. Please explain to me your understanding of the National Secretariat?
  - *Probe:* What is their main job?
  - *Probe:* How do you see the Secretariat supporting improved health care services for Ebola survivors in this county?
3. When Ebola survivors are having a problem or challenge (any type of challenge) where do they go for help?
  - *Probe:* Are they getting the help they need from these places? If no, why not?
  - *Probe:* What other places could they be going to for help?

#### Health needs and barriers to access:

1. What would you say are the biggest day to day challenges of Ebola survivors in this county?
  - *Probe:* Are health concerns/health problems impacting the day to day lives of Ebola survivors?
  - *Probe:* If so, what are the health concerns?
  - *Probe:* How do these challenges impact the survivor's day to day life?
  - *Probe:* What are the primary needs for Ebola survivors? (Economic, Psychosocial, Health)
2. Do you feel that Ebola survivors in your county are going to the health facility when they are having health problems?
  1. *Probe:* If not, why not?
    - What makes it challenging for them to go to the health facility?
    - What do you think can be done to encourage Ebola survivors to be going to the facilities for treatment?
  2. *Probe:* If yes, why do you think they are actively seeking treatment?
    - Why is it easy for them to go get treatment?
    - What makes them comfortable to go get treatment?

#### Stigma faced by Ebola survivors:

1. Have you ever been to the main health facility in your county? If yes, when was the last time you were there?
2. How do you think the main health facility in your county manages the health needs of Ebola survivors?
  - *Probe:* Is the facility able to provide the services Ebola survivors need?

- What types of services are they able to provide?
  - What services are they unable to provide?
  - What do they do if they do not have the ability to provide treatment or care for a specific issue?
3. How do health workers treat patients in their main health facility in your county (all patients, regardless of survivor status)?
- *Probe:* Have you ever observed a health worker treating a survivor patient differently for non-survivor patients?
  - *Probe:* How did they treat the survivor differently?
  - *Probe:* Please give an example of what you observed
  - *Probe:* What effect, if any, did this have on the Ebola survivor? Did they feel more or less welcome at the health facility because of this treatment?

### Health Facility Staff Interview Guide

*Hello, I am from JSI and we are conducting research on the challenges Ebola survivors face in accessing health care and the quality of health care they receive. Given you are medical professional that treats Ebola survivors I would like to ask you some questions on these topics. This will take approximately 30 minutes.*

#### Health needs and barriers to access:

1. Do you have Ebola survivors accessing services at this facility?
  - *Probe:* Tell us about the characteristics of the survivors that visit this health facility: men, women, children, disabled, HIV positive etc.
2. What are the main services access by survivors at this health facility?
  - *Probe:* What are some of the main health problems they face?
  - *Probe:* Are you able to provide treatment for these services? What do you do if you are not able to provide treatment?
  - *Probe:* What challenges do you face when you are treating survivors?
3. Have you ever worked with or engaged with Survivor Network representatives or with MoH Survivor Representatives?
  - *Probe:* If so, who? How did you engage with them?

### Psychosocial Focal Points (County/District Health Team) Interview Guide

*Hello, I am from JSI and we are conducting research on the challenges Ebola survivors face in accessing health care and the quality of health care they receive. Given you are the psychosocial representative for your County Health Team and you work closely with Ebola survivors, I would like to ask you some questions on these topics. This will take approximately 30 minutes.*

#### County Health Team engagement with Survivors

1. Please tell me a bit about how the county health team works with Ebola survivors?
  - *Probe:* How do you support Ebola survivors? What services do you provide?
  - *Probe:* Do you engage with the Survivors Network? If so, how do you engage with them?
2. What are the biggest challenges Ebola survivors face in your county?
  - *Probe:* What are their greatest needs?
  - *Probe:* What should be provided to help support Ebola survivors?
  - *Probe:* How are you supporting these needs?

Health needs and barriers to access:

1. What are some of the biggest health problems you see survivors facing?
  - *Probe:* How do these challenges impact the survivor's day to day life?
2. Do you feel that Ebola survivors in your county are going to the health facility when they are having health problems?
  - *Probe:* If not, why not?
    - What makes it challenging for them to go to the health facility?
    - What do you think can be done to encourage Ebola survivors to be going to the facilities for treatment?
  - *Probe:* If yes, why do you think they are actively seeking treatment?
    - Why is it easy for them to go get treatment?
    - What makes them comfortable to go get treatment?
3. Do you feel the health facilities in your county are able to provide sufficient treatment for survivors?
  - *Probe:* If not, why not?
    - Has the county health team tried to resolve these challenges? What has been done?









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