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BASELINE EBOLA SURVIVOR ASSESSMENT
FEBRUARY, 2017

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Advancing Partners & Communities

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Photo Credit: Pia Kochhar, JSI R&T.

Photo Caption: Dr. Romeo Orone, Ebola Survivor Clinic, ELWA Hospital.

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ACRONYMS

APC	Advancing Partners and Communities
CDC	Centers for Disease Control and Prevention
ETP&SS	Ebola Transmission, Prevention and Survivor Services
ETU	Ebola Treatment Unit
EVD	Ebola Virus Disease
GHET	Global Health Ebola Team (USAID)
IPC	Infection Prevention and Control
JSI R&T	John Snow Research and Training Institute, Inc.
MHSP	Liberia Men's Health Screening Program
MOH	Ministry of Health
Network	National Ebola Survivors Network of Liberia
NIH	National Institutes for Health
PREVAIL	Partnership for Research on Ebola Virus in Liberia
Secretariat	National Ebola Survivor Secretariat
Survivor	Use of the word survivor implies EVD survivor throughout
WHO	World Health Organization

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EXECUTIVE SUMMARY

Introduction

The Ebola Transmission Prevention & Survivor Services (ETP&SS) program is a two year (2016-2018) initiative aimed at supporting the implementation of selected components of the Ministry of Health's Ebola Survivors Care and Support National Policy, supporting the strengthening of clinical services available to survivors, reducing stigma and other barriers for survivors when accessing health care services, and reducing the risk of Ebola transmission from survivors to others.

Given the ETP&SS programs objectives and beneficiary population, a baseline assessment was conducted with the survivor community to identify program targets and to understand the broader context within which the program is operating. The assessment is focused on understanding survivors' experiences when interacting with the Liberian health care system and their knowledge and perceptions of survivor representative bodies. The assessment was developed in line with the ETP&SS performance monitoring plan and program objectives.

Methodology

The assessment was conducted in the four ETP&SS program counties; Montserrado, Margibi, Lofa and Bong. The assessment took a mixed methods form, with a quantitative survey of the survivor population (aged 18 years and over) and qualitative interviews with key informants from the health sector and survivor representative bodies. The assessment was conducted with the assistance of the National Ebola Survivors Network of Liberia (the Network).

The sampling strategy adopted for the survey was a stratified simple random sampling process, with survey participants pre-selected from an existing survivor listings. A total of 433 survivors (205 male and 228 female) were surveyed. The key informants were identified through discussions with health facilities and county and district health teams. Appropriate data security procedures and participant confidentiality practices were adopted throughout the data collection process. The survey indicators were tested for their accuracy and validity.

Results

Seeking health care: The assessment confirms that survivors are seeking primary treatment from health facilities when they first get sick, with over 90% of respondents reporting they sought treatment for their health problems at a health facility in the past six months. However, the data suggests there is a drop in facility attendance rates once a survivor is required to attend follow up appointments or when a referral is made, with only 60.34% of survivors who were referred attending the referral facility.[1]

Barriers to care and stigma at health facilities: The primary barriers to health care reported by respondents were transport costs and the distance to health facilities. Other major barriers included the cost of treatment, primarily the cost of pharmaceuticals, and wait times at facilities. Stigma was not listed as a major barrier to care, despite 33.11% of respondents claiming they faced two or more occurrences of stigmatization by health facility staff in the past 6 months. 25.17% of respondents did acknowledge

[1] Note, that given the small sample size on referral data (only 58 respondents) there are limitations to the reliability of data on referrals.

that the presence of stigma at health facilities led them to avoid or delay seeking care. Interestingly, low stigma levels were correlated with an active County Network Chapter.

Data from the qualitative interviews suggested that stigma rates may be overstated due to misunderstandings in the survivor population about the current MOH policy on survivor care, with many survivors expecting to be treated as priority cases over other health patients.

Mental health support: A majority of respondents have received some form of mental health support or counselling on their Ebola experience in the past year (60.05%). However, data from qualitative interviews confirms that although many survivors have sought mental health care, there is an ongoing need for additional mental health services.

Engagement with representative bodies: There was a high level of awareness and confidence in the Network, however not all participants could accurately identify the Networks role or primary duties. Fewer individuals were aware of the National Ebola Survivors Secretariat (the Secretariat) and those that were aware had little understanding on role of primary duties of the Secretariat.

Table 1: Research indicators and results

No.	Indicator	Result
1	% of individuals that believe they were treated respectfully by staff whilst seeking treatment at their local health facility on a regular basis	61.93% (n=410)
2	% 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)	33.11% (n=302)
3	% of individuals aware of the existence of the Network	89.15% (n=433)
4	% of individuals confident in the work of the Network (limited to those with existing knowledge of the Network)	83.42% (n=386)
5	% of individuals aware of the existence of the Secretariat	28.87% (n=433)
6	% of individuals confident in the work of the Secretariat (limited to those with existing knowledge of the Secretariat)	72.80% (n=125)
7	% of male individuals reporting regular condom use with all sexual partners	26.88% (n=186)

Conclusions and Programmatic Implications

The results of the assessment will feed in to the ETP&SS program design and provide evidence for the program indicators. The results also identify many areas where the Network and the Secretariat have key roles to play, including stigma reduction, education on the MOH Ebola Survivor Care and Support Policy, sexual health education and improvement in referral pathways for survivors.

INTRODUCTION

A. Background

In 2014-2015 the devastating Ebola Virus Disease outbreak occurred across the West African region. Liberia was one of the worst affected, with a total of 10,675 confirmed EVD cases and over 4,408 deaths. As a result of the crisis, there are estimated to be over 5,000 Ebola survivors in Liberia, of which 1,558 are registered with the Ministry of Health (MOH).

Although the outbreak has passed, Ebola survivors continue to face ongoing challenges ranging from health complications to employment and community integration problems. The health challenges faced from Ebola survivors appear to be a result of "late complications" from the disease. Preliminary findings of the PREVAIL III study in Liberia (2015) conducted by the U.S. National Institutes for Health (NIH) and the Ministry of Health (MOH) and reported on the NIH website, revealed that 68% of Ebola survivors experienced neurologic problems, 60% eye difficulties, and 53% experienced musculoskeletal problems.[2] The study further noted that 38% 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.

A significant challenge for survivors is the ability to access the needed routine and specialized medical care to treat these health complications. Healthcare providers often lack the knowledge and experience treating complications of Ebola, and may be reluctant to offer services due to concerns about the possible risk of transmission via body fluids. Pregnant women have reported being turned away due to health providers' fear and specialty services that are required – such as neurology, psychiatry/mental health, and ophthalmology – are largely absent in Liberia.

In response to the needs of the Ebola survivor population, the Liberian Ministry of Health, with assistance from WHO, Centers for Disease Control and Prevention (CDC), and other partners, developed the Ebola Survivors Care and Support National Policy (the Policy). The Policy focuses on using a "positive discrimination towards 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 National Survivors Network (the Network) as a coordinating body for Ebola survivors.

In May 2016, the Advancing Partners & Communities (APC) Project received funds from the Global Health Ebola Team (GHET) of USAID/Washington for a program entitled "Ebola Transmission Prevention and Survivor Services" (ETP&SS). ETP&SS is being implemented by John Snow Research and Training Institute, Inc. (JSI R&T) in Liberia, Guinea and Sierra Leone.

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[2] 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>.

B. Overview of ETP&SS in Liberia

The ETP&SS program is 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 reducing the risk of Ebola transmission from survivors to others. In Liberia, the program is being implemented in the four counties with the highest concentration of Ebola survivors; Montserrado, Lofa, Bong and Margibi. The intended beneficiary population of the ETP&SS program in Liberia is EVD survivors, who will be represented by their coordinating organizations, the National Ebola Survivor Network (Network) and the newly established National Ebola Survivor Secretariat (Secretariat).

The program is conducting capacity building activities with selected facilities in the four target counties to improve the quality of general and specialty services for survivors. In addition to this, the program is providing training and mentoring in stigma reduction and survivor care protocols for health professionals within these counties. To complement these activities, the program is playing a formative role in the establishment of the Secretariat, by seconding key staff and providing capacity building support, and is providing capacity building support to the Network.

C. Research Questions

Given the ETP&SS programs objectives and beneficiary population, a baseline assessment was conducted with the survivor community to identify program targets and to understand the broader context within which the program is operating. The assessment is focused on understanding survivors' experiences when interacting with the Liberian health care system and their knowledge and perceptions of survivor representative bodies. The assessment was developed in line with the ETP&SS performance monitoring plan and program objectives.

Primary research questions and indicators were developed. The research indicators are outlined in Table 1.

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?

d) How often are sexual health precautions being taken?

Table 2: ETP&SS Research Indicators

No.	Indicator
1	% of individuals that believe they were treated respectfully by staff whilst seeking treatment at their local health facility on a regular basis
2	% 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	% of individuals aware of the existence of the Network
4	% of individuals confident in the work of the Network (limited to those with existing knowledge of the Network)
5	% of individuals aware of the existence of the Secretariat
6	% of individuals confident in the work of the Secretariat (limited to those with existing knowledge of the Secretariat)
7	% of male individuals reporting regular condom use with all sexual partners

D. Program Concept

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

The program's conceptual framework aims to improve health outcomes across the survivor population by ensuring that the government health system has the skills and equipment needed to deliver survivor services and that these services are delivered in a non-stigmatizing environment.

The framework acknowledges the many barriers currently faced by both the general and survivor population in accessing health care in Liberia, including distances from health facilities and the cost of medicines. However, as the program's mandate is limited to building the capacity of survivor care services and the program's implementation period is limited to two years, it is not possible for the program to provide longer term solutions to these systemic issues.

To encourage survivors to seek health care and to alert them to the specialty services developed by the program, short term solutions to two major healthcare barriers have been put in place. The program will provide short term free health services at two private health facilities in Monrovia, and will cover transportation costs (on a case-by-case basis) for survivors who have been referred by a health provider to receive care at one of these facilities.

The survivor assessment will help further inform and develop the program concept by providing information on the level of stigma faced by survivors, the level of awareness and trust in the Network, and by identifying any additional barriers to care that exist.

METHODOLOGY

The assessment adopts a mixed methods approach with the aim of developing a thorough understanding of the contextual factors affecting survivor engagement with health facilities whilst also collecting indicator data. Both the quantitative and qualitative components of the assessment were conducted in the four program counties: Montserrado, Margibi, Bong and Lofa.

The quantitative component involved a thirty-minute structured survey that was administered to a random selection of survivors on tablet computers in areas close to their homes. The qualitative component involved a thirty to forty-five-minute key informant interview with key stakeholders. Key stakeholders included county and district level health team members, health facility staff and Network leadership at the county level.

A. Sampling

Quantitative Survey

The size of the survivor population in Liberia is estimated to range from 2000 to 5000 individuals.[3] The exact population size is unknown for two primary reasons: survivor information was not recorded at Ebola Treatment Units (ETUs) until a number of months in to the outbreak and many who were ill did not seek care at an ETU, instead receiving care in their community. The Liberian Ministry of Health has a line listing of 1,558 survivors, of which 1,114 are aged 18 years or over. This listing has not been updated since early 2015 and is limited to survivor information provided by ETU's.

At the time of sampling the MOH's line listing was the only listing of survivors available to JSI R&T. This listing 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 County

Survivor status confirmed through either an ETU certificate, PREVAIL ID card or community based/social identification.

A stratified simple random sampling process was employed, with each district 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 that were interviewed.

[3] Ministry of Health [Liberia], 'EVD Survivors Care and Support National Policy' (2016), Monrovia, Liberia, p2.

The total sample size was calculated based on the following assumptions:

- Design effect (deff) 2
- Confidence level (z) 90%
- Non-response rate (r) 5%
- Margin of error (ε) 5%
- Population size 1,366

Applying these assumptions, along with the assumption that 50% of the respondents report being confident in the work of the National Ebola Survivor Network, a sample size of 435 individuals was obtained. Proportions of males and females interviewed were adjusted to reflect the gender balance of the survivor population. A total of 226 females and 209 males were targeted for the survey. Table 2 outlines the sample size for each county as compared to the reported population size.

Table 3: Sample size of quantitative survey by county

County	Reported Population Size	Sample Size
Montserrado	904	288
Margibi	216	69
Bong	113	36
Lofa	133	42
TOTAL	1366	435[4]

At the time of data collection, an updated list of survivors was shared by the Network. The random selection of survivors that were to be interviewed was done off the more recent listings shared by the Network. All survivors to be interviewed were pre-selected prior to data collection by the JSI R&T Monitoring and Evaluation Advisor.

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 that were conducted.

Table 4: Sample size of qualitative interviews by county and stakeholder group

County	Ebola Survivors	Health Facilities	Government (County Health Team and District Health Team staff)
Montserrado	3	3	2
Bong	2	2	1
Margibi	1	2	0
Lofa	2	2	1
Total	**8**	**9**	**4**

[4] The total number of individuals surveyed was 433, as only 34 individuals were surveyed in Bong County due to challenges identifying participants to be surveyed.

B. 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 R&T's Senior Evaluation Advisor and drawing on the structure used by JSI R&T in Sierra Leone.[5] The survey was comprised of six 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 tool was pre-tested prior to use and adjustments to questions and response options were made based on feedback received during the pre-test. The survey was administered in a private location with each respondent and took approximately 30 minutes long.

Three separate qualitative interview guides were developed, one for each of the three stakeholder groups. The tools focused on questions relating to the following topics: the role of the Secretariat and Network, health needs of survivors and barriers to access for survivors, stigma faced by Ebola survivors. The tools include both key questions and probing questions where appropriate.

C. Data Collection Process

Quantitative Survey

Data collection for the quantitative survey was conducted between 30th January and 10th February 2017. 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 the data collectors were Ebola 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 an Ebola survivor. The data collection teams were trained for two days on the tools and Ona software prior to data collection. All data collection team members signed contractual agreements which included clauses on confidentiality and impartiality.

Team leads were provided with lists of the selected survey participant's names and contact details. The team leads then coordinated with the Network Chapter and Sector leads in each county to administer the survey. Survey participants were first contacted by the Network and advised that they had been selected to participate in the survey. These participants then came to a central location within the county for the survey to be administered. Where necessary, the teams also went from house to house to interview survey participants that were unable to come to the central location. All participants were required to show documentation confirming their identify and status as a survivor. Participants confirmed their status as a survivor by showing their ETU certificate or PREVAIL ID card.[6] Where

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[5] References to materials drawn upon during the development of the survey are noted in the tool included in Annex II.

[6] PREVAIL is a joint Liberia-US clinical research partnership that began operations in Liberia in 2015. PREVAIL 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 survivors and their close contacts. Further information on the research studies being conducted by PREVAIL can be found at https://clinicaltrials.gov.

participants could not show evidence of their survivor status, social verification of their status was conducted.

Social verification of a survivors status was done in the following manner: An elected representative of the Network was required to confirm the individual's status as a survivor, if the representative did not know the person, two or more individuals from the participant's community was asked to confirm if the participant was a survivor.[7] 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 survivor 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 JSI R&T Monitoring and Evaluation Advisor and the JSI R&T Montserrado Monitoring and Evaluation Officer. All data downloaded from the server was stored on secure, password protected devices.

Qualitative Interviews

Data collection for the qualitative interviews occurred between 1st February and 28th February. Data collection was conducted by JSI R&T's four Monitoring and Evaluation Officers. All interviews were recorded and transcribed, unless consent for recording was not provided by the interview participant. Access to recordings and transcripts were limited to JSI R&T's Monitoring and Evaluation Team and all information was stored on secure, password protected devices.

D. Analysis

Results from the quantitative and qualitative pieces were analyzed individually, and afterwards results across the two pieces were compared.

Prior to quantitative analysis the baseline survey data was cleaned and reviewed. The data was analyzed using Microsoft Excel 2013and R 2016 (version 3.3.2)[8]. Composite indicators were created for the following variables:

- Confidence in Network
- Confidence in Secretariat
- Patient satisfaction with health facilities
- Barriers to care

All composite indicators were verified for their accuracy and validity using principal component analysis and Cronbach's alpha tests. Significance of demographic factors on indicators was verified using chi-squared tests, Pearson correlation coefficients and factorial ANOVA tests where appropriate. The qualitative data was analyzed using systematic coding techniques, including the generation of themes and sub-themes.

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[7] The research makes a clear distinction between survivors and affected persons. Individuals who had cared for an individual suffering from Ebola, but had not come down with the disease themselves were not considered as part of this study.

[8] R Core Team, 'R: A language and environment for statistical computing', (2016), R Foundation for Statistical Computing, Vienna, Austria. URL <https://www.R-project.org>. The *PLYR pkg* was also used during analysis: Hadley Wickham, 'The Split-Apply-Combine Strategy for Data Analysis' (2011), Journal of Statistical Software, 40(1), 1-29. URL <http://www.jstatsoft.org/v40/i01/>.

E. Limitations

There are several limitations to the quantitative survey, with a majority stemming from the challenges of not having an accurate listing of survivors.

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 Network. Individuals who have faced the greatest discrimination or who feel most ashamed about their status are unlikely to have given their contact details to the Network. Additionally, individuals who do not agree with the work being done by the Network are unlikely to have their name registered. Despite this risk, there is limited means of ethically identifying survivors except through the support of the Network, and as such this risk is unavoidable.

Selection bias may also have occurred during the data collection process, where certain survivors that were engaged in full time employment could not participate in the survey due to work obligations. Attempts were made to address this by the data collection team travelling to work places to do the surveys, however not all survivors could be engaged in this manner.

In Margibi and Bong Counties some survey participants were based in communities that could not be reached due to their remote location. This led to selection of other more accessible survivors to survey. This creates a bias in the assessment as the survivors in the most remote locations were not included. The survivors in the most remote communities are likely to be the ones that face the greatest challenges accessing health care and are least likely to be engaged or aware of 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. This makes the 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 health care. Individuals who are very unsatisfied with health facilities are unlikely to have sought health care from them recently, resulting in the sample being biased to those who already have a greater satisfaction level with facilities than those that do not. To address this risk, questions were included in the tool to determine why an individual chose not go to the health facility for treatment.

F. Ethical Approval

The baseline survey was approved by the JSI R&T Ethical Review Board as well as the Liberia Institutional Review Board (IRB).

The assessment did not record the name of any survivor that participated in the survey and the survey participant listings were shredded upon the completion of data collection to ensure confidentiality of survivor's status. Informed consent was obtained from each respondent prior to beginning any survey or interview. Data collectors for the survey signed to confirm observation of informed consent for each survey.

RESULTS

A. Survey Demographics[9]

The survey was conducted with 433 individuals, of which 47% were male and 53% were female. This is reflective of the assumed gender distribution of the survivor population in Liberia. 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.

It is not possible to conduct tests to determine whether the survey population is representative of the survivor population in Liberia as there is no existing data on the demographics of survivors. The demographics data from this assessment provides the first snap shot on the adult survivor population in Liberia. It is important to note that this assessment did not collect information from survivors aged under 18 years old.

Age: The survey shows that the adult survivor population in Liberia is very young, with approximately half of all respondents being aged between 18 to 34 years old (49.65%) and over 75% of adult survivors being under the age of 44.

Religious background: A majority of survivors interviewed identified as Christian (78.98%), with the remaining respondents all identifying as being of Muslim faith. This distribution was reflected across the counties, except for Lofa County where 52.38% of the survey population identified as Muslim. This distribution has a greater percentage of individuals identifying as Muslim than is found within the religious demographics among the general Liberian population.[10]

Education level: The overall education levels 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 (61.20%).[11] A large proportion had little to no schooling (23.79% - no schooling or only kindergarten)[12], whilst 10% of respondents had a university qualification.[13] The education levels vary considerably for survivors outside of Montserrado, with Lofa County having the lowest education levels among the survivor population. 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 take in to account the quality of education received nor did it verify literacy levels.

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[9] Further analysis of respondent's demographics can be found in Annex I.

[10] 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.

[11] 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 having no schooling at all and 12.9% of men having no school at all.

[12] According to the 2014 Household Income and Expenditure Survey 37.7% 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.

[13] According to the 2014 Household Income and Expenditure Survey (above n11, p35), 8.1% of Liberians are reported to have a university qualification.

Health worker status: 8.08% of survivors interviewed identified themselves as professional health workers (38 individuals in total). Given this small sample size indicators and results were not disaggregated by health worker status.

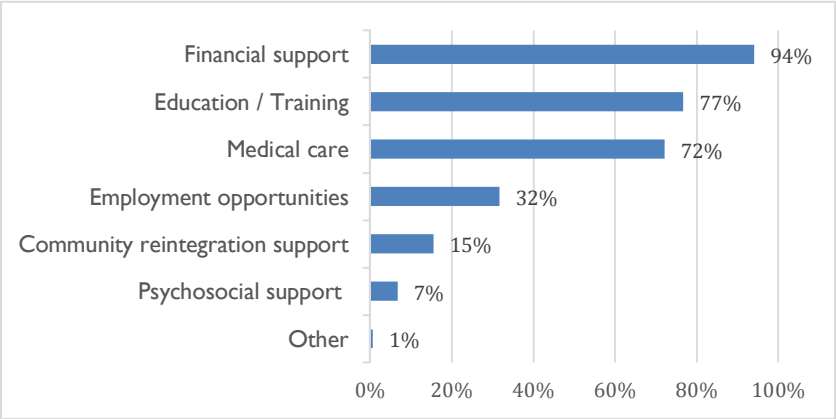
Income and skills outcomes:

For the Network to better understand the income and skills background of its members, additional questions were included on respondent's income sources and income generating skills. Half of surveyed survivors reported that petty trade was their main source of income (51.50%). Only 8.08% of survivors reported their main income source as being formal employment. 16.17% reported their main income source coming from daily contract work, whilst 13.39% reported their primary income source coming from agriculture, farming or livestock. 7.16% reported being primarily dependent on family and friends for support.

Just over half of the survivor population surveyed reported having no income generating skills (51.96%). Of the 208 individuals, that reported having income generating skills, the primarily skills listed were soap making, professional skills (eg. accounting, nursing), catering and hair dressing. Other skills reported included carpentry, masonry, tailoring, electrical, mechanical and driving skills.

Greatest needs:

Figure 1: Greatest needs of the survivor population in Liberia



Respondents were asked to identify their three greatest needs from a list of seven options. As outlined in Figure 1, 94% of all respondent listed financial support as a major need, followed by 77% of respondents listing education or training as a major need.

The proportion of respondents listing medical care as a great need varied by county. In Montserrado and Lofa, 77.78% and 80.95% of respondents listed medical care as a great need, whilst in Margibi and Bong, only 50.72% and 55.88% listed it as a great need. It also varied somewhat by gender with 75.88% of women listing it as a great need, compared to 67.80% of men.

The proportion of respondents listing psychosocial support as a great need varied across the counties. In Montserrado County 9.03% listed it as a great need, whilst in Bong County it was not listed as a need by any individual. For Margibi and Lofa, the proportion listing it as a great need was 1.45% and 4.76% respectively. A greater proportion of female respondents listed psychosocial support as a great need (7.89%), compared to male respondents (5.37%). Interestingly, 20.00% of individuals getting income through formal employment identified psychosocial support as a major need, which is significantly higher than the average of 6% across all other income source groups. 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 are failing to seek health care due to fears of stigma or poor treatment. This assessment aimed to understand the veracity of these reports and find out more about the primary barriers to care.

Health seeking behavior

Respondents were asked to report on whether they had experienced a health problem in the past 6 months, and if so, if they sought care at a health facility. From the respondents who experienced health problems in the past six months, over 90% reported seeking treatment for their health problems at a health facility. This suggests that survivors are seeking treatment at facilities, at least at the initial onset of their health problems. The results demonstrated that of the 7% who did not seek health treatment at a health facility, manty of them sought treatment at a pharmacy (54.17%).

Data from the qualitative interviews shed more light on survivor's health seeking behavior, with reports that survivors often attended a facility when they first get sick, however they failed to attend follow up appointments or follow through when referrals are made. Survey data demonstrates that a majority of individuals that sought treatment at a facility were required to go back for follow up treatment at least two or more times (82.12%). Additional information on whether survivors attended these follow up visits was not captured in the survey, so it is not possible to conclude on whether attendance levels remain as high for follow up visits.

Limited follow through of referral pathways

Only 60.34% of survivors who were referred for advanced care sought care at the referral facility.

The primary barrier for those that did not attend the referral facility was cost of transport and expected cost of treatment.

The assessment sought to examine information on the referral process for survivors, however only 58 (13.39%) respondents reported being referred by a provider. Given this small sample, there are limitations on the reliability of the information on referrals. Despite this, the results confirm that there is much lower rate of survivors that attend appointments once referred to an alternative facility, with only 60.34% of survivors who were referred attending the referral facility. For those that were unable to attend the referral facility, the primary barrier was the cost of transport as well as the expected cost of treatment at the referral center. Family obligations were also commonly listed as a reason for being unable to attend the referral facility. This is consistent with data from the key informant interviews where the process of referrals was considered to be a major barrier to care. One key informant stated that a major challenge for survivors was "referrals and the difficulty they face in transporting themselves to access required health services if they have to seek advanced care."

The primary facility type that survivors are seeking treatment at is hospitals (53.75%). The key informant interviews outlined that survivors do not always attend the facility closest to them, as they prefer to attend facilities which have a PREVAIL or Men's Health Screening Program[14] site attached to it. This is

[14] The Liberia Men's Health Screening Program (MHSP) 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 on the MHSP see http://www.cdc.gov/globalhealth/countries/liberia. For further information on PREVAIL, see above n8.

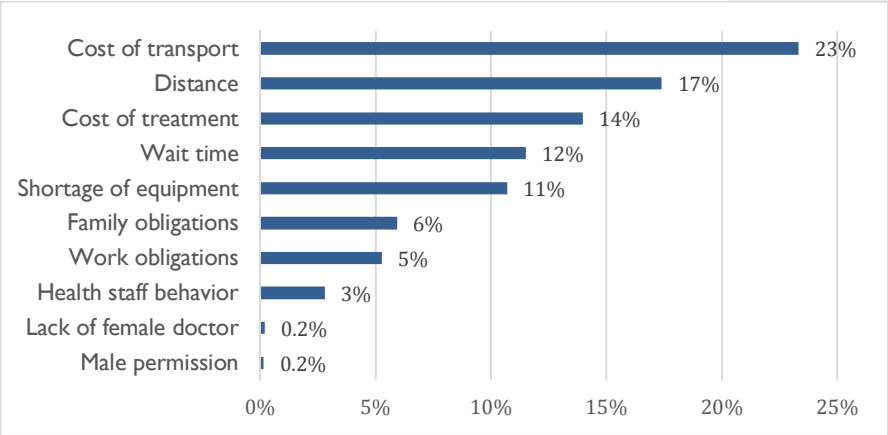
likely due to the fact that both PREVAIL and Men's Health program incentivize their visits to the facilities.[15] However, this is not consistent across all the counties. In Lofa County a greater proportion of the population chose to visit clinics (40.48% of Lofa respondents), whilst in Bong County an equal proportion of survivors chose to visit a hospital or a clinic.

Barriers to health care

The primary barriers to health care reported by respondents were transport costs and the distance to health facilities.[16] These primary barriers were consistent across all counties and were consistent with qualitative data.

Other major barriers identified in both the quantitative and qualitative data included the cost of treatment, primarily the cost of pharmaceuticals, and long wait times at facilities. However, these results vary across counties. For example, 18.40% of Montserrado County respondents listed the cost of treatment as their greatest barrier, compared to 2.4% of Lofa County respondents and 8.8% of Bong County respondents. This is most likely because the distances required to travel to seek health care and the costs incurred from the travel are greater for individuals outside of Monrovia and as a result are the primary barrier to health care.

Figure 2: Greatest barriers to health care for survivors



Interestingly, in the survey only a few individuals reported that staff behavior was a major barrier to accessing health care. However, the issue of stigma was a common barrier to care raised during the qualitative 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 partners 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, this was most evident in Lofa County, where 19.05% of respondents listed it as their greatest barrier to healthcare.

[15] Participants who are enrolled in the PREVAIL study are required to attend a PREVAIL center every 6 months for medical testing. The participants are provided with a financial incentive for attending these visits. They are also incentivized to return to the PREVAIL center shortly after their visit 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.

[16] Figure 2 represents the results from a combined barrier score developed by weighting the results from primary barrier, secondary barrier and tertiary barriers.

Table 5: Barriers to health care by county

	Montserrado	Margibi	Bong	Lofa
Cost of transport	20.3%	33.3%	34.8%	18.3%
Distance	17.4%	15.2%	23.0%	16.3%
Cost of treatment	15.5%	15.7%	8.8%	5.2%
Wait time	12.7%	8.7%	6.4%	11.9%
Shortage of equipment	9.9%	11.6%	9.8%	15.5%
Family obligations	4.6%	5.8%	7.4%	13.9%
Work obligations	6.3%	3.4%	1.5%	4.4%
Health staff behavior	3.0%	2.4%	0.5%	4.0%
Lack of female doctor	0.3%	0.0%	0.0%	0.0%
Male permission	0.2%	0.0%	0.0%	0.0%

Mental health care

A majority of respondents have received some form of mental health support or counselling on their Ebola experience in the past year (60.05%). This figure varies on a county level with approximately 70% of respondents in Lofa, Bong and Margibi receiving some form of counselling compared to only 54.51% in Montserrado County.

There is no variation in the proportion of individuals who have received mental health support between men and women or by education level. The data did outline that the most common location where survivors received mental health support was in their home or community. However this figure varied by gender with 31.88% of females receiving mental health care in their home or community, compared to 18.85% of men.

Data from qualitative interviews confirms that although many survivors have received mental health care, there is an ongoing need for additional mental health services.

Where are survivors seeking mental health support?

The most common providers of mental health care in Bong and Margibi County were PREVAIL and the health facilities attached to a PREVAIL center (C.H. Rennie and Phebe Hospital).

In Lofa County, survivors primarily received mental health support from the NGOs operating support programs such as Samaritans Purse and BRAC.

There were no primarily providers of mental health support in Montserrado with survivors seeking care either at their local health facility or being visited at their house by a mental health worker.

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 more clearly understand the stigma levels faced by survivors the assessment examined how often facility staff were aware of a survivor's status and the level of stigma the survivors believe they experienced.

Approximately 80% of survivors surveyed confirmed that the last time they sought health care the health worker was aware of their status, with most survivors (81.63%) freely disclosing their status to

the health worker. Few survivors reported that their status was disclosed to health staff without their permission (4.08%).

From individuals that have sought health care in the past 6 months, 33.11% claimed they faced two or more occurrences of stigmatization by health facility staff. 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, with stigma levels being considerably lower in Lofa County (only 21.43%) compared to Margibi (43.31%) and Bong County (51.85%). This is surprising given that the primary facilities used by respondents in Margibi County and Bong County were ones with a presence of survivors as health facility staff.

Facility staff confirmed that stigma still exists at certain facilities, with one health facility staff member stating "fear still lingers within the health workers here as they fear being infected with the EVD virus".

> *"Most of the time survivors don't come to the facility because they feel people will discriminate them from other patients"*
>
> - Health facility staff member

Of major concern, is that 25.17% of respondents reported avoiding or delaying seeking health due to fear of health staff's attitudes towards them as an Ebola survivor. It is interesting to note that in the county where the County Chapter of the Network appears more active and accepted, stigma levels and fear is lower, with only 16.67% of Lofa County respondents reporting avoiding or delaying seeking health care, compared to 32.35% of respondents in Bong County.

Survivor expectations of facilities

Despite the evidence of ongoing stigma towards survivors, the data outlines that survivor's expectations of health facilities are often inconsistent with existing/current government policies. The assessment demonstrated that there exists an expectation among certain survivors that survivors should be given preferential treatment at facilities. Survivor County leadership confirmed this by stating that a barrier to survivors seeking care was that "survivors were not being prioritized at health facilities". The expectation to be prioritized due a survivor's status is not consistent with government policy, which specifies that "EVD survivors' clinical care shall be freely accessible and integrated within the existing healthcare services in accordance with the National Health Policy and National Health Plan".[17]

Health facility and county health team staff confirmed this, reporting that some survivors perceive they are being 'stigmatized' if they are not given priority treatment at a facility. As one key informant stated: "Over time they [survivors] have developed the habit of demanding special treatment and rights especially for health care. They want to be treated as the first priority at all health facilities. Survivors should be empowered to do things for themselves instead of being given priority at all costs/levels." Whether this expectation is leading to an increased perception of stigmatization is not clear. As one facility staff member said: "Some survivors are very difficult to deal with but we try out best to get them treated regardless of their status".

> *"Over time they [survivors] have developed the habit of demanding special treatment and rights especially for health care. They want to be treated as the first priority at all health facilities. Survivors should be empowered to do things for themselves instead of being given priority at all costs/levels."*
>
> - Key informant

To better understand the factors that affect survivor's health

[17] EVD Survivors Care and Support National Policy, above n2, p9.

seeking behavior and their experience at health facilities a composite indicator was developed measuring respondent's perceptions of staff behavior towards them. The indicator results suggest that most survivors perceive they are treated respectfully by health facility staff members, with 62.93% of respondents confirming that they are treated respectfully by health facility staff on a regular basis. These results varied significantly on a county basis, with 67.67% of survivors in Montserrado reporting they were treated respectfully, compared to 58.82% in Bong County and only 44.12% in Margibi County.

C. Engagement with Representative Bodies

The assessment aimed to understand the level of awareness and engagement survivors had with their two representative bodies: the National Ebola Survivors Network of Liberia, a body of EVD survivors serving as elected representatives for the survivor community, and the National Ebola Survivor 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 Network; the Network was engaged in the data collection process. Given this, it was expected that survivor's awareness levels about the Network and its activities would be quite high. This was confirmed with 89.15% of respondents confirming they were aware of the Network. Awareness levels were significantly higher among males than females, with 93.17% of males being aware of the Network compared to 85.53% of females. Variation was also found between counties, with awareness levels highest in Margibi (94.20%) and Montserrado County (90.28%), and lowest in Bong County (78.57%). Awareness levels also varied significantly by educational background and age groups, with those most educated being more aware (between 90.77% for those with primary level schooling up to 100% for those with university level attainment), and those with no schooling being least aware (74.76%).

Despite these high levels of awareness among the survivor population, understanding of what the role and purpose of the Network is and its activities is comparatively low. Only 64.51% of individuals who reported being aware of the Network could accurately identify what the Networks role was and what activities it did.

Respondents who were aware of the Network were asked a series of questions to measure their level of confidence in the Network and its representatives. A composite score was developed from these results. The results show that 83.42% of individuals are confident in the Network. This confidence level varies significantly by county, with Lofa County respondents being the most confident (96.97%) and Margibi County respondents the least confident (72.31%). This variation may be reflective of the strong chapter leadership and the regularity of Network meetings in Lofa County. The confidence level does not vary significantly by gender, educational level or age.

Despite high levels of awareness of the Network among the survivor population, data from the interviews suggest that there is a low level of engagement between the Network and the County and District Health Teams and the health facilities. The only exception to this are in Lofa County where it was reported that the Network Chapter leadership is working proactively with the County Health Team and health facilities and Bong County where the leadership is working proactively with the County Health Team.

The National Secretariat of Ebola Survivors

Given the Secretariat is a newly formed body it was not expected that many respondents would be aware of their activities or role, particularly for respondents outside of Monrovia. This was confirmed with only 28.87% of respondents aware of the Secretariat. This awareness varied significantly by gender, county and education level. Males were more likely to be aware (34.63%) than women (23.68%). Surprisingly, awareness was greatest in Lofa County with 40.48% of respondents reporting knowledge on the secretariat, compared to 28.15% in Montserrado County and 24.64% in Margibi County. As above, it is most likely that this high level of awareness in Lofa County is reflective of the regularity of meetings and the effectiveness of the Lofa Chapter leadership in disseminating information.

Among the limited population that were aware of the Secretariat, only 55.20% of respondents could accurately identify the role and purpose of the Secretariat, with 16.80% of respondents stating that they had no knowledge on what the purpose of the Secretariat was.

Respondents who reported being aware of the Secretariat were asked a series of questions aimed at measuring their confidence in the Secretariat. The results of these were developed in to a composite indicator on Secretariat confidence. The indicator confirms that 72.80% of respondents who are aware of the Secretariat also have confidence in the work of the secretariat. This confidence score does not vary significantly by gender, educational level or age of respondents. However, it does vary by county, with only 47.06% of respondents from Margibi confirming confidence, compared to 74.07% of Montserrado respondents and 88.24% of Lofa respondents.

Results from the qualitative data also confirm that awareness levels are very low at the health facility and county health team level.

D. Sexual Health Behavior

Liberia was most recently declared Ebola-free in June 2016. However, as indicated by several of the most recent clusters of cases in Liberia the disease can re-emerge in a country after it has been declared Ebola-free. Evidence suggests that these cases may be linked to the transmission of the disease from Ebola survivors, as the virus has been found in the eyes, breast milk, spinal columns, semen and other bodily fluids of survivors. It is not currently known how long the disease will persist in the body.

This assessment sought to identify the proportion of survivors that are engaging in safe sexual practices. Both male and female respondents were asked about their use of protection during sexual intercourse. Sample sizes for this section of the assessment was small as responses were disaggregated by gender and limited to those who admitted to having sexual intercourse in the past 12 months.

Among women, of the 73% who reported they had had sexual intercourse with their partner[18]in the past 12 months, only 16.27% reported using a condom every time they had sexual intercourse, and 54.82% reporting never using a condom. Condom use was considerably higher among women who had sexual intercourse with someone who was not a partner. Of the 12% of women who reported they had had having sexual intercourse with a non-partner, 48.15% reported using a condom every time, and 29.63% reported to never using a condom.

[18] Partner is defined as someone a person was in a longer term relationship with such as a husband or wife, or boyfriend or girlfriend.

Among men, the results are quite different. 90% of men reported having had sexual intercourse with a partner in the past 12 months, and 28.80% stated they used a condom every time. A much lower proportion of men reported never using a condom with their partner (29.89%). The proportion of men who reported having had sexual intercourse with a non-partner was significantly higher (42%). Condom use with non-partners was similar to that of women, with 57.47% of men reporting they used a condom with a non-partner every time, and only 14.94% reported never using a condom with a non-partner.

CONCLUSIONS AND PROGRAMMATIC IMPLICATIONS

The results outlined in this report were collected to feed in to the ETP&SS program design and provide evidence for the program indicators. The results also give a broader insight in to the demographics of the survivor population. Key conclusions and recommendations for program implementation are outlined below.

Health Seeking Behaviors

The results bring to light the complexities around measuring whether survivors are seeking health care at a health facility. They clearly demonstrate that a majority of survivors are going to a health facility when they first get sick, however, it is less clear whether they are attending follow up visits and it is likely that many are not following through the referral pathways after being referred.

Recommendation: A focus area for the ETP&SS program should be working with the Network to ensure there is follow up after a patient's initial visit to a facility. The Network has a key role to play in mobilizing and encouraging survivors to attend follow up appointments and referral facilities. Additionally, the challenges surrounding referrals highlighted in this report should be taken into consideration when developing referral pathways for survivors.

The results demonstrate that the primary barriers to health care for survivors are the same as those faced by the general population. Stigma continues to remain an issue at certain health facilities; however, it is not a key factor deterring survivors from seeking health care. Additionally, the data suggests that there is a need for education among the survivor population about what to expect at facilities and what the current government policy is regarding incorporating survivor care in to general population care.

Recommendation: The ETP&SS program should continue its efforts on educating health workers about treating Ebola survivors to reduce the level of fear and stigma within health workers. Accompanying this, the Secretariat should engage the survivor community in an education campaign to encourage survivors to seek health care whilst also setting reasonable expectations about how survivors will receive health care at government health facilities. Educating survivors on the government's survivor policy would also be beneficial.

Advocacy Bodies

The positive results from Lofa County suggest that where the Network's County Chapters are holding regularly monthly meetings and coordinating productively with county health teams and health facilities, outcomes regarding stigma and health seeking behavior are improved. This confirms the key role the Network can play in improving positive outcomes for the survivor community.

The data confirms that the Network is well known within its population base at both the county chapter and national leadership levels, however, there is a need to educate its members on what its role and

mandate will be to set reasonable expectations within the broader survivor community. Additionally, the data highlights that there are key coordination gaps between the Network and most of the relevant county health teams and health facilities. Building and strengthening these relationships will likely improve outcomes for the broader survivor population.

Recommendation: The National Network leadership should mobilize its county Chapters to hold regular meetings and actively inform its membership of the Network's role and planned activities. The Chapter leadership should develop coordination ties with county and district health teams and health facilities to improve survivor health outcomes.

The results demonstrate that now the Secretariat has been established, it will need to actively educate the survivor population about its existence and the role it will play in managing survivor health issues. It will also need to develop close coordination ties with county health teams, health facilities and Network Chapter leadership.

Recommendation: The Secretariat should incorporate awareness visits and disseminate information about its role and purpose to the survivor community during its monthly coordination meetings with county leadership.

Sexual Health Behavior

The results demonstrate that there continues to be a substantial proportion of male survivors that do not regularly use condoms during sex. This poses severe risks for Liberia and its efforts to prevent the re-occurrence of Ebola.

Recommendation: The ETP&SS program should work with the Network and Secretariat to promote healthy sexual health behaviors among male survivors and improve access to condoms for the male and female survivor population.

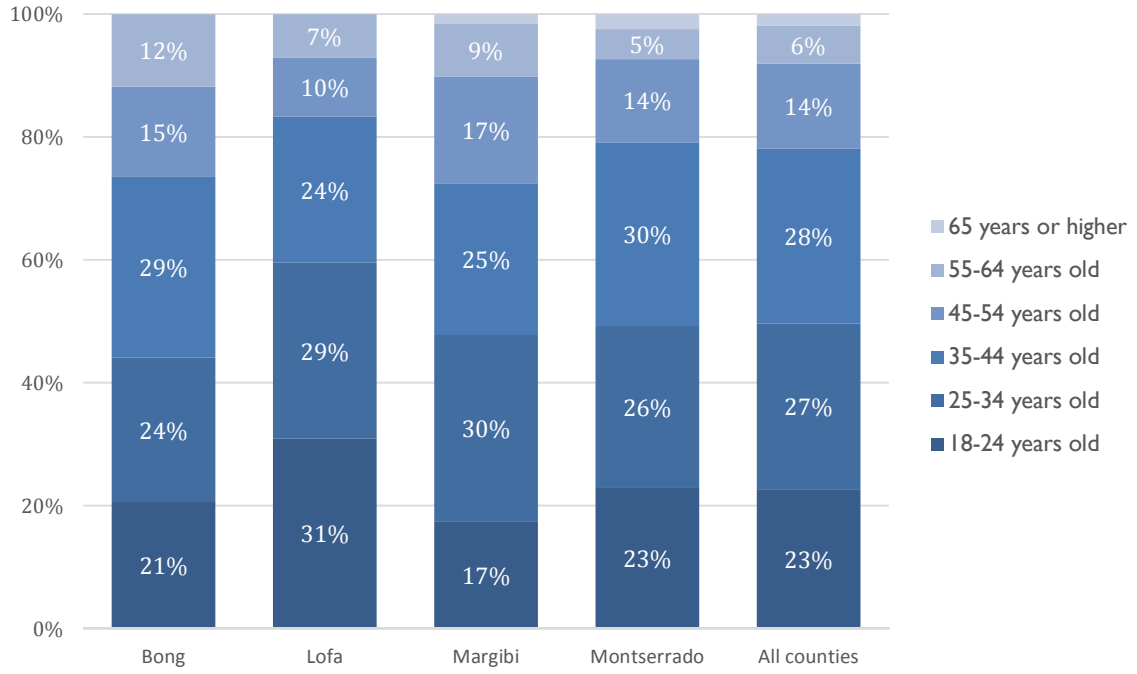
ANNEX I: Survivor survey demographics

The demographics of the survey participants provide an insight in to the current characteristics of the survivor population in Liberia. Survivor's experiences and background vary greatly by the county where they reside. Data below will be disaggregated by county except where no variation is observed. It is important to note that the geographic breakdown of the survey participants reflects the sampling methodology adopted for the survey. This methodology was based off existing information about survivor's location, please see full report for more information.

Age breakdown

Liberia is known for the large proportion of young people which make up its population. This is no different in the survivor population with 50% of respondents aged 34 or under. Lofa County has the highest level of young respondents (34 years old and under). However, it must be noted that the background of survey respondents is likely to have oversampled young people as they are the most active and were willing to move to a survey location. Figure 3 demonstrates the age background of survivors surveyed disaggregated to a county level.

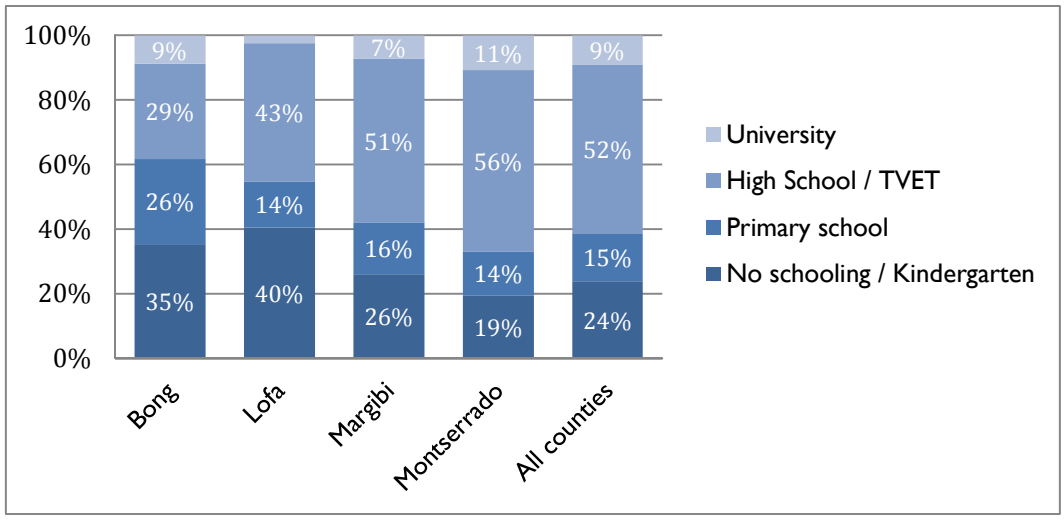
Figure 3: Current age of survey respondents by county



Educational Profile

The educational profile of respondents varies significantly by county, with Bong and Lofa County having the lowest levels of education among their survivor populations. Figure 4 demonstrates the educational profile of survivor respondents by county and overall.

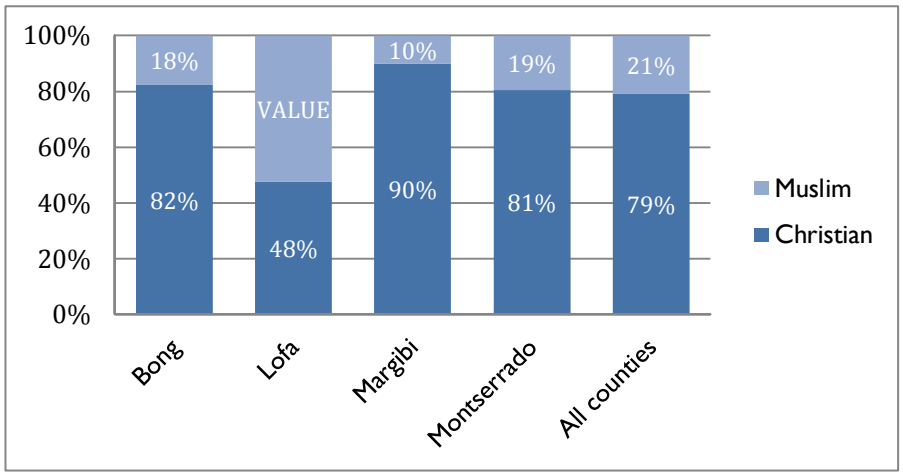
Figure 4: Highest level of educational attainment of survey respondents by county



Religious Affiliation

In Liberia, religious backgrounds and tribes are closely linked. This is reflected in the religious affiliations of survivors, with Lofa County, home to the Mandingo tribe, having the greatest proportion of Muslim respondents.

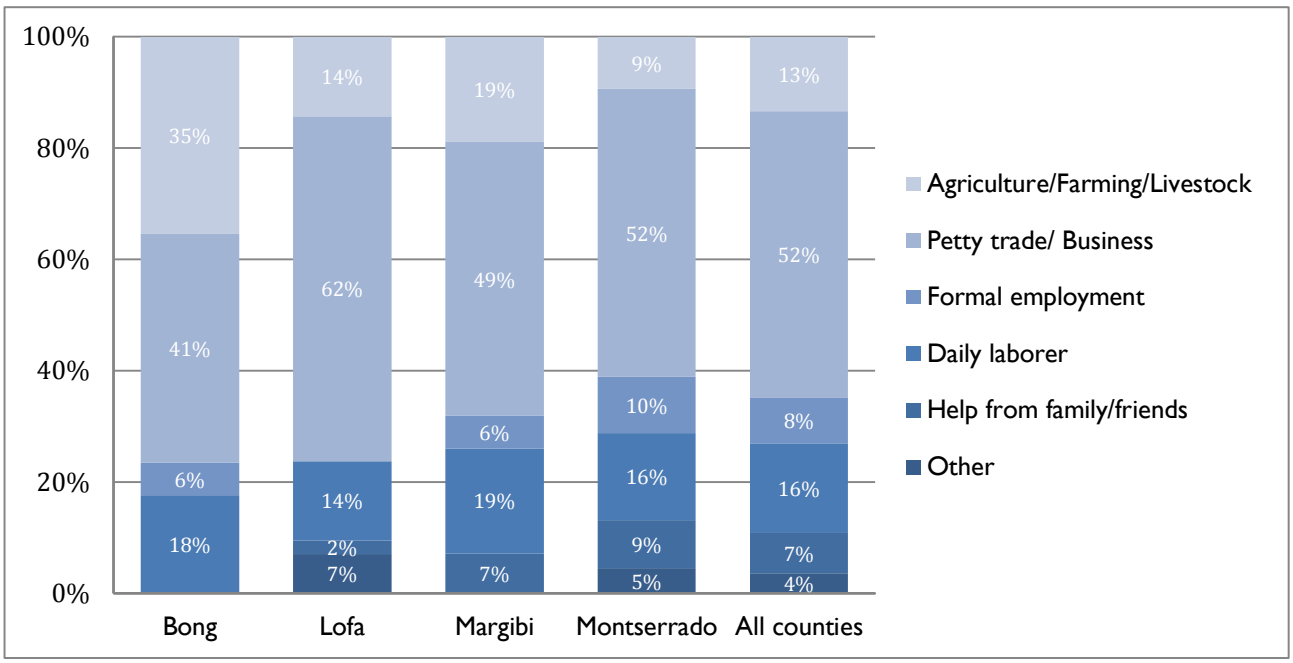
Figure 5: Religious affiliation of survey respondents by county



Income Source

The primary income source for 52% of survivors is petty trade and business. Montserrado and Margibi have the highest proportion of survivors dependent on family and friends for income, at 9% and 7% respectively, whilst Bong has the highest proportion engaged in agriculture and farming at 35% of respondents surveyed. Figure 6 outlines the breakdown in further details.

Figure 6: Primary income source of survey respondents by county



Income Generating Skills

The survey respondents were asked to identify whether they had income generating skills, only 48% confirmed that they had skills that enabled them to generate income. Respondents in Lofa County were least likely to identify as having income generating skills, with only 31% confirming they have income generating skills compared to 62% of respondents in Margibi County. Of those who identified as having skills, the primary income generating skills were soap making, professional skills[19] and catering. Figure 8 presents a detailed breakdown of the skills held by the survey respondents.

[19] Professional skills was defined as skills developed through a university qualification such as nursing, accounting etc.

Figure 7: Survey respondents having income generating skills, by county (self-identified)

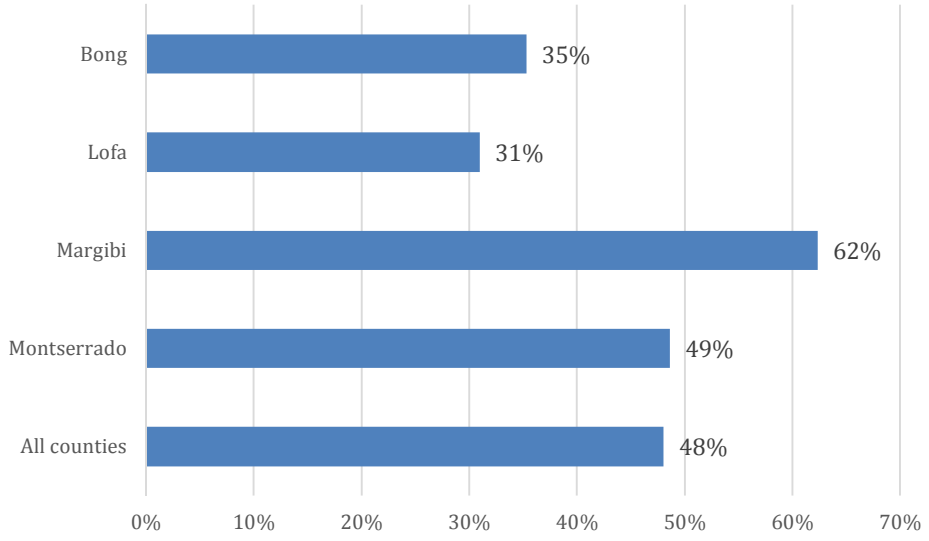
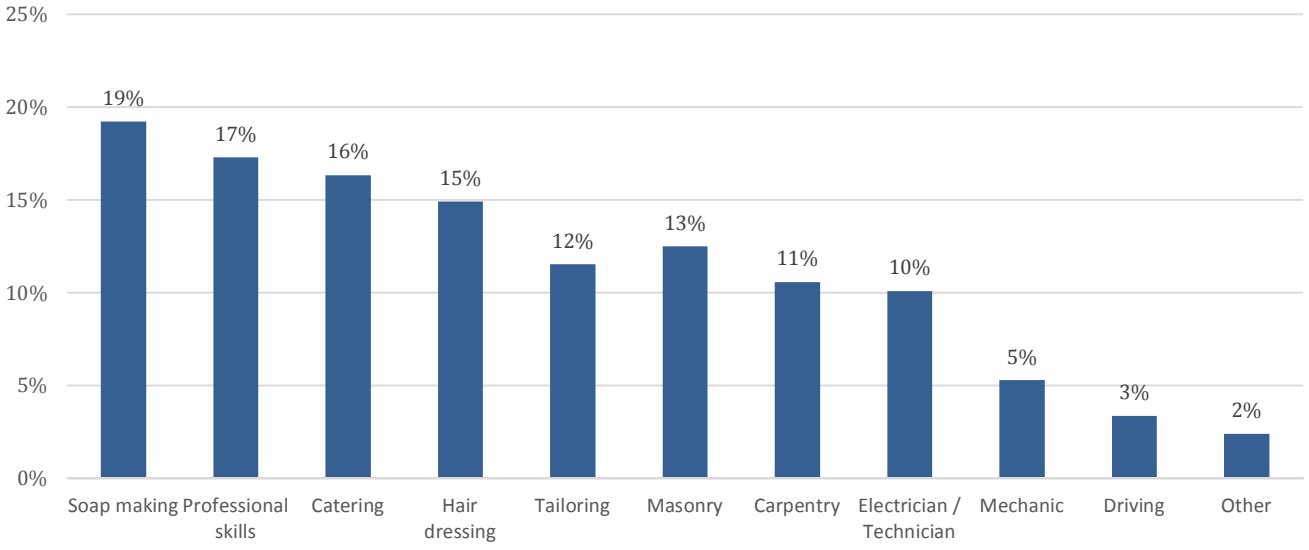


Figure 8: Types of income generating skills from individuals that self-identified as having skills



ANNEX II: Quantitative and Qualitative Tools

A. Quantitative Survey Tool

PART A: BENEFICIARY INFORMATION			
NO	**QUESTION**	**RESPONSE**	**SKIP**
A1	Partipant ID Number		
A2	Gender	☐ Male .....1 ☐ Female 2	
A3	County	☐ Bong .....1 ☐ Lofa.....2 ☐ Margibi .....3 ☐ Montserrado 4	
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?	☐ Yes.....1 ☐ No.....2	If 1, skip to A11
A10	Why do you go to __*say name of health facility previously mentioned*__?	_____	
	Beneficiary General Information		
A11	What is your age group?	☐ 18-24 years old .....1 ☐ 25-34 years old .....2 ☐ 35-44 years old .....3 ☐ 45-54 years old .....4 ☐ 55-64 years old .....5 ☐ 65 years or higher 6	
A12	Are you Christian or Muslim?	☐ Christian .....1 ☐ Muslim 2	
A13	Are you the head of your household?	☐ Yes.....1 ☐ No.....2	
A14	Were you a trained health worker during the Ebola outbreak? (eg. Doctor or nurse)	☐ Yes.....1 ☐ No.....2	
A15	What is the highest level of schooling you have completed?	☐ Kindergarten .....1 ☐ Primary school (Grade 1-6) .....2 ☐ High school (Grade 7-12) .....3 ☐ TVET .....4 ☐ University .....5 ☐ Never attended school 0	
A16	How many children do you take care of?	_____	

A17	What are your three greatest needs right now? *(Select only three)*	☐ Psychosocial support .....1 ☐ Medical care .....2 ☐ Financial support .....3 ☐ Education/ Training .....4 ☐ Employment opportunities .....5 ☐ Community reintegration support .....6 ☐ Other _____.....97	
A18	What is your main source of income for the household?	☐ Agriculture /Farming/ Livestock .....1 ☐ Petty Trade/ Business .....2 ☐ Daily laborer .....3 ☐ Help from family/friends .....4 ☐ Formal employment .....5 ☐ Other _____.....97	
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?	☐ Yes.....1 ☐ No.....2	If 2 selected, skip to Part B
A21	What type of skills/trade? (Please select all that apply?	☐ Carpentry.....1 ☐ Masonry .....2 ☐ Mechanic .....3 ☐ Pastry .....4 ☐ Soap making .....5 ☐ Hair dressing .....6 ☐ Tailoring .....7 ☐ Electrician/Technician.....8 ☐ Professional skills (accounting, nursing, social work etc.) .....9 ☐ Other _____.....97	

PART B: Health Seeking Behavior and Quality of Health Care			
NO.	**QUESTION**	**RESPONSE**	**SKIP**
	I am now going to ask you some questions about your health and your experience at health facilities.		
B1	Have you had any health problems in the past 6 months?	☐ Yes.....1 ☐ No.....2	If 2 selected, skip to B9
B2	When you had this problem, did you go to a clinic or heath facility to get treatment?	☐ Yes.....1 ☐ No.....2	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?	☐ Community Health Worker / gCHV .....1 ☐ Trained Traditional Midwife .....2 ☐ Pharmacy .....3 ☐ Country doctor .....4 ☐ Pastor / Imam .....5 ☐ Community leader .....6 ☐ Drug sellers / Black baggers .....7 ☐ Other _____.....97 ☐ No where 0	Skip to B9

B4	What type of facility did you visit? *(Select all facilities visited)*	☐ Clinic .....1 ☐ Health Centre .....2 ☐ Hospital 3	
B5	How many times did you go to the clinic or facility to solve this health problem?	☐ Once .....1 ☐ Twice.....2 ☐ Three times .....3 ☐ Four times or more .....4 ☐ Don't know 98	
B6	Did the facility refer you to a bigger or different facility to get better treatment?	☐ Yes.....1 ☐ No.....2	If 2 selected, skip to B9
B7	Were you able to go to the referral facility to get the treament?	☐ Yes.....1 ☐ No.....2	If 1 selected, skip to B9
B8	Please explain why not. (Select all that apply)	☐ Transport costs / Distance .....1 ☐ Cost of treatment at referral facility .....2 ☐ Fear .....3 ☐ Employment obligations .....4 ☐ Family obligations .....5 ☐ Other _____ .....97 ☐ No response 99	
	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".		
B9	How often did the medical staff talk to you nicely and treat you well?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
B10	How often did the medical staff listen carefully to what you had to say?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
B11	How often did the medical staff explain to you clearly about the problem you were having or the tests they were doing?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
B12	How often did the medical staff answer the questions you were asking?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
B13	How often is there a good place to sit when you are waiting to be seen by the doctor/nurse?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
B14	How often does the doctor/nurse hurry too much when providing treatment?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
B15	How often do you have to wait a long time	☐ Every time 1	

	before you get to see the doctor/nurse?	☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
B16	How often does the staff member finds a private place to talk so other people can't hear?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
B17	How often does the doctor send you to another (bigger) facility if they cannot help you with the health problem?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
B18	In the past year, have you received any mental health support or counselling on your Ebola experience?	☐ Yes.....1 ☐ No.....2 ☐ No response 99	If 2 or 99 selected, skip to Part C.
B19	Where did you receive this support or counselling?	_____ _ _____ _	

PART C: Barriers to Accessing Health Care		
NO.	**QUESTION AND RESPONSE**	
C1	Among the list of challenges I am going to read out, please rank the three things that make it the hardest for you to go to the health facility? (Enter numbers 1 to 3 in 3 boxes. 1 is the hardest, 2 the second hardest and 3 the third hardest)	☐ Long distance to the facility .....1 ☐ Cost of transportation to the facility ……..…….....2 ☐ Finding someone to care for the children .....3 ☐ Getting time off work /someone to mind your business .....4 ☐ (Women only) Your boyfriend/husband allowing you to go…… 5 ☐ Long wait periods/ ticket system at health facility……..….....6 ☐ Shortage of medication/equipment at facility ……..7 ☐ The way the health staff treat you.....8 ☐ The cost of services/tests at the facility .....9 ☐ (Women only) The lack of a female doctor at the facility.....10 ☐ No major challenges ……..……11 ☐ Other _____ .....97 ☐ No response 99

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
	I am now going to ask you some questions on what you know about organizations or groups which represent Ebola survivors.		
D1	Do you know of any group which represents survivor interests? *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?*	☐ Yes.....1 ☐ No.....2	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?	☐ Yes.....1 ☐ No.....2	If 2 selected, skip to D10
D4	From your knowledge, what do they do?/ what is their role? *Correct understanding: The Network is responsible for advocating and assisting with the well-being of Ebola Survivors. They help link Survivors to services where possible.*	☐ Correct understanding .....1 ☐ Partial understanding .....2 ☐ Incorrect understanding .....3 ☐ Don't know .....98 ☐ No response 99	
D5	Are you a member of the National Ebola Survivors Network?	☐ Yes.....1 ☐ No.....2	
	For the following questions please respond on whether you "agree I, neither agree or disagree, or disagee"		
D6	*(Integrity)* Whenever the survivor network makes an important decision, I know it will be concerned about people like me	☐ Agree .....1 ☐ Neither agree nor disagree .....2 ☐ Disagree .....3 ☐ No response 99	
D7	*(Dependability)* I think it is important to watch the survivor network closely so I can be confident that they are doing a good job	☐ Agree .....3 ☐ Neither agree nor disagree .....2 ☐ Disagree .....1 ☐ No response 99	
D8	*(Competence)* I feel very confident about the survivor network's ability to get better support for people like me	☐ Agree .....1 ☐ Neither agree nor disagree .....2 ☐ Disagree .....3 ☐ No response 99	
D9	*(Satisfaction)* I am happy with the work that the survivor network is doing	☐ Agree .....1 ☐ Neither agree nor disagree .....2 ☐ Disagree .....3 ☐ No response 99	
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?	☐ Yes.....1 ☐ No.....2	

D11	Have you heard of a group within the Ministry of Health called the National Ebola Survivors Secretariat?	☐ Yes.....1 ☐ No.....2	If 2 selected, skip to D17
D12	From your knowledge, what do they do?/ What is their role? *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.*	☐ Correct understanding .....1 ☐ Partial understanding .....2 ☐ Incorrect understanding .....3 ☐ Don't know .....98 ☐ No response 99	
	For the following questions please respond on whether you "agree I, neither agree or disagree, or disagee"		
D13	*(Integrity)* Whenever the secretariat makes an important decision, I know it will be concerned about people like me	☐ Agree .....1 ☐ Neither agree nor disagree .....2 ☐ Disagree .....3 ☐ No response 99	
D14	*(Dependability)* I think it is important to watch the secretariat closely so I can be confident that they are doing a good job	☐ Agree .....3 ☐ Neither agree nor disagree .....2 ☐ Disagree .....1 ☐ No response 99	
D15	*(Competence)* I feel very confident about the secretariat's ability to get better support for people like me	☐ Agree .....1 ☐ Neither agree nor disagree .....2 ☐ Disagree .....3 ☐ No response 99	
D16	*(Satisfaction)* I am happy with the work that the secretariat is doing	☐ Agree .....1 ☐ Neither agree nor disagree .....2 ☐ Disagree .....3 ☐ No response 99	
D17	If person did not have the correct understanding, explain the correct understanding of the Secretariat. *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*		

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?	☐ Yes.....1 ☐ No.....2 ☐ Don't know .....98 ☐ No response 99	
E2	If yes, how did they know?	☐ I told them .....1 ☐ Someone else told them with my consent 2	

		☐ Someone else told them without my consent ...3 ☐ They treated me when I had Ebola .....4 ☐ Don't know .....98 ☐ No response 99	
	*In the past **12 months**, has any of the following things happen to you at a health facility because you were an Ebola survivor?*		
E3	The doctor/nurse refused to treat you or refused to do relevant tests	☐ Yes.....1 ☐ No.....2	
E4	You had to wait longer for the doctor/nurse to treat you than other patients	☐ Yes.....1 ☐ No.....2	
E5	The doctor/nurse appeared nervous or uncomfortable treating you	☐ Yes.....1 ☐ No.....2	
E6	The doctor/nurse gossiped about your survivor status	☐ Yes.....1 ☐ No.....2	
E7	You received less care/attention than other patients	☐ Yes.....1 ☐ No.....2	
E8	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	☐ Yes.....1 ☐ No.....2	

PART F: SEXUAL BEHAVIOR

NO.	QUESTION	RESPONSE	SKIP
	For Women Only: Now I am going to ask you some questions about man business. You can feel free to tell me anything.		
F1	Were you in a relationship before you had Ebola?	☐ Yes.....1 ☐ No.....2	*If no, skip to F3*
F2	Are you still in the same relationship now?	☐ Yes.....1 ☐ No.....2	*If yes, skip to F4*
F3	Are you in a new relationship now?	☐ Yes.....1 ☐ No.....2	*If no, skip to F7*
F4	Are you married? (Ask if still in relationship from before or in a new relationship now)	☐ Yes.....1 ☐ No.....2	
F5	In the last 12 months, have you done man/woman business with your husband/boyfriend?	☐ Yes.....1 ☐ No.....2 ☐ No response 99	
F6	When you do man/women business with your husband/boyfriend, how often do you use a condom?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
F7	In the last 12 months, have you done man/woman business with a man who is not your husband or boyfriend?	☐ Yes.....1 ☐ No.....2 ☐ No response 99	
F8	When you do man/women business with a man	☐ Every time 1	

	outside your partners, how often do you use a condom?	☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
F9	Since you had Ebola, have you had any child born to you?	☐ Yes.....1 ☐ No.....2 ☐ No response 99	
F10	How many children have you given given birth to, since you had Ebola?	_____ number	
	For Men Only: Now I am going to ask you some questions about woman business. You can feel free to tell me anything.		
F11	Were you in a relationship before you had Ebola?	☐ Yes.....1 ☐ No.....2	*If no, skip to F13*
F12	Are you still in the same relationship now?	☐ Yes.....1 ☐ No.....2	*If yes, skip to F14*
F13	Are you in a new relationship now?	☐ Yes.....1 ☐ No.....2	*If no, skip to F18*
F14	Are you married? (Ask if still in relationship from before or in a new relationship now)	☐ Yes.....1 ☐ No.....2	
F15	In the last 12 months, have you done man/woman business with your wife/girlfriend?	☐ Yes.....1 ☐ No.....2 ☐ No response 99	
F16	When you do man/women business with your wife/girlfriend, how often do you use a condom?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
F17	In the last 12 months, have you done man/woman business with a woman who is not your wife or your girlfriend?	☐ Yes.....1 ☐ No.....2 ☐ No response 99	
F18	When you do man/women business with a woman outside your partners, how often do you use a condom?	☐ Every time .....1 ☐ Some times .....2 ☐ One one time .....3 ☐ Never .....4 ☐ No response 99	
F19	Since thie Ebola business finished, have you ever had your semen tested for Ebola?	☐ Yes.....1 ☐ No.....2 ☐ No response 99	If 2 or 99 selected, skip to G17
F20	When was the last time you had your semen tested for Ebola?	☐ One month ago .....1 ☐ Two months ago .....2 ☐ More than two months ago .....3 ☐ Don't know .....98 ☐ No response 99	
F21	Do you know the results of your last semen test?	☐ Yes.....1 ☐ No.....2 ☐ No response 99	
F22	Have you received any counselling or advice after your semen tests?	☐ Yes.....1 ☐ No.....2 ☐ No response 99	

	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?		

B. Qualitative Key Informant Interview Tool

Network Representatives Interview Guide

Hello, I am from JSI R&T 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 R&T 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.

<u>Health needs and barriers to access:</u>

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 R&T 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.

<u>County Health Team engagement with Survivors</u>

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?

<u>Health needs and barriers to access:</u>

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?

ANNEX III: Statistical tables for assessment indicators

Table 6: Statistical table for indicator 1

	% of individuals who believe that they are treated respectfully by health facility staff on a regular basis	Sample Size
Gender		
Male	63.59%	195
Female	62.33%	215
County		
Montserrado	67.67%	266
Margibi	44.12%	68
Bong	58.82%	34
Lofa	66.67%	42
Education level		
University	74.36%	39
High School / TVET	65.71%	210
Primary School	53.23%	62
Kindergarten / No school	58.59%	99
Age Group		
18-24 years old	64.44%	90
25-34 years old	61.82%	110
35-44 years old	59.66%	119
45-54 years old	64.29%	56
55-64 years old	74.07%	27
65 years or higher	62.50%	8
Total	62.93%	410

** Independence significant at 1% level * Independence significant at 5% level

Table 7: Statistical table for indicator 2

	% of individuals reporting two or more occurrences of being stigmatized by health care providers (From those who have sought health care in past 6 months)	Sample Size
Gender		
Male	32.14%	140
Female	33.95%	162
County		
Montserrado	29.74%*	195
Margibi	43.31%*	52
Bong	51.85%*	27
Lofa	21.43%*	28
Education level		
University	21.74%	23
High School / TVET	36.77%	155
Primary School	31.82%	44
Kindergarten / No school	30.00%	80
Age Group		
18-24 years old	40.00%	60
25-34 years old	36.14%	83
35-44 years old	30.77%	91
45-54 years old	25.00%	40
55-64 years old	31.82%	22
65 years or higher	16.67%	6
Total	33.11%	302

** Independence significant at 1% level * Independence significant at 5% level

Table 8: Statistical table for indicators 3 and 4

	% of individuals aware of the existence of the Network	Sample size	% of individuals confident in the work of the Network (from those who know the Network)	Sample size
Gender				
Male	93.17%*	205	84.29%	191
Female	85.53%*	228	82.56%	195
County				
Montserrado	90.28%*	288	84.62%*	260
Margibi	94.20%*	69	72.31%*	65
Bong	82.35%*	34	82.14%*	28
Lofa	78.57%*	42	96.97%*	33
Education level				
University	100.00%**	40	77.50%	40
High School / TVET	93.33%**	225	84.29%	210
Primary School	90.77%**	65	86.44%	59
Kindergarten / No school	74.76%**	103	81.82%	77
Age Group				
18-24 years old	87.76%**	98	89.53%	86
25-34 years old	96.58%**	117	84.96%	113
35-44 years old	89.43%**	123	84.55%	110
45-54 years old	86.67%**	60	75.00%	52
55-64 years old	77.78%**	27	66.67%	21
65 years or higher	50.00%**	8	75.00%	4
Total	89.15%	433	83.42%	386

** Independence significant at 1% level * Independence significant at 5% level

Table 9: Statistical table for indicators 5 and 6

	% of individuals aware of the existence of the Secretariat	Sample Size	% of individuals confident in the work of the Secretariat (from those who know the Secretariat)	Sample Size
Gender				
Male	34.63%*	205	70.42%	71
Female	23.68%*	228	75.93%	54
County				
Montserrado	28.13%*	288	74.07%*	81
Margibi	24.64%*	69	47.06%*	17
Bong	29.41%*	34	80.00%*	10
Lofa	40.48%*	42	88.24%	17
Education level				
University	47.50%**	40	68.42%	19
High School / TVET	32.89%**	225	70.27%	74
Primary School	27.69%**	65	72.22%	18
Kindergarten / No school	13.59%**	103	92.86%	14
Age Group				
18-24 years old	35.71%	98	71.43%	35
25-34 years old	29.91%	117	74.29%	35
35-44 years old	30.89%	123	71.05%	38
45-54 years old	20.00%	60	83.33%	12
55-64 years old	18.52%	27	60.00%	5
65 years or higher	0.00%	8	N/a	0
Total	28.87%	433	72.80%	125

** Independence significant at 1% level * Independence significant at 5% level

Table 10: Statistical table for indicator 7

	% of male individuals reporting consistent condom use with all sexual partners	Sample Size
County		
Montserrado	28.57%	126
Margibi	13.79%	29
Bong	23.08%	13
Lofa	38.89%	18
Education level		
University	33.33%	27
High School / TVET	28.81%	118
Primary School	20.00%	25
Kindergarten / No school	12.50%	16
Age Group		
18-24 years old	26.19%**	42
25-34 years old	23.73%**	59
35-44 years old	28.30%**	53
45-54 years old	30.43%**	23
55-64 years old	33.33%**	9
65 years or higher	N/A	0
Total	26.88%	186

** Independence significant at 1% level * Independence significant at 5% level

Table 11: Statistical table for greatest barriers to care

	Distance	Transport Costs	Family obligations	Work obligations	Wait time	Shortage of equipment	Behavior of health staff	Treatment Costs	Lack of female doctor	Sample Size
Gender										
Male	26.83%	24.88%	1.46%	5.85%	6.34%	9.76%	1.95%	16.59%	0.00%	192
Female	30.70%	26.32%	7.89%	3.51%	6.58%	4.39%	0.88%	14.04%	0.44%	216
County										
Montserrado	29.51%	20.49%	3.13%	6.25%	7.29%	7.64%	1.39%	18.40%	0.35%	272
Margibi	23.19%	43.48%	4.35%	2.90%	1.45%	5.80%	2.90%	13.04%	0.00%	67
Bong	38.24%	38.24%	2.94%	0.00%	2.94%	0.00%	0.00%	8.82%	0.00%	31
Lofa	26.19%	21.43%	19.05%	0.00%	11.90%	9.52%	0.00%	2.38%	0.00%	38
Total	28.87%	25.64%	4.85%	4.62%	6.47%	6.93%	1.39%	15.24%	0.23%	408

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