

REFLECTION



Strengthening National Ebola Survivor Networks: Successes and Challenges

INTRODUCTION

The 2014–2016 Ebola outbreak in West Africa resulted in more than 11,300 deaths and over 10,000 survivors in Guinea, Liberia, and Sierra Leone (Table 1). The crisis also contributed to severe set-backs for the economies of the affected countries and broken health systems that reflected fear and mistrust, leading to millions of dollars in donor aid spent to rebuild health systems.

In the immediate post-Ebola period, national survivor networks composed of small district, county, or regional groups of survivors were established in each country. Registered Ebola survivors were encouraged to join the local survivor ‘chapter,’ which led to representation in their national networks based in the capital cities of Conakry, Monrovia, and Freetown.

In Guinea, Ebola survivors pay a small fee (approximately \$10 per year) in membership dues to cover administrative costs and small income-generating projects among survivors, although the structures and strategies vary across the three countries. Each network was established to unite people who had suffered from the outbreak and to help them overcome the major challenges that they were facing, including loss of work and livelihood, medical complications, and stigma from colleagues and neighbors.

Table 1: Ebola Population by Country

Country	# Cases*	# Deaths*	Case Fatality Rate (%)	Est. # Survivors**
Guinea	3,811	2,543	67	1,268
Liberia	10,675	4,809	45	5,866
Sierra Leone	14,124	3,956	28	10,168
Total	28,610	11,308	N/A	10,001-17,302

*Includes suspected, probable, and confirmed Ebola virus disease cases.

**Estimates based on number of cases minus number of deaths. WHO cites >10,000 total survivors; actual totals may vary.

Source: WHO, <http://www.who.int/csr/disease/ebola/en/>



The two-year Ebola Transmission Prevention and Survivor Services (ETP&SS) program was created with USAID funding under the Advancing Partners & Communities (APC) project, implemented by JSI Research & Training Institute, Inc. to work with the ministries of health, the World Health Organization (WHO), CDC, nongovernmental organizations, and other stakeholders in the three countries most affected by the Ebola outbreak. The program's objectives were to strengthen coordination and management of activities for Ebola survivors, improve survivors' access to health services, and build health system capacity to prevent or respond to further outbreaks. The ETP&SS program also aimed to address the myriad secondary medical complications (i.e., ophthalmic, mental health, and rheumatologic) reported among survivors.

EVOLUTION OF EACH NETWORK

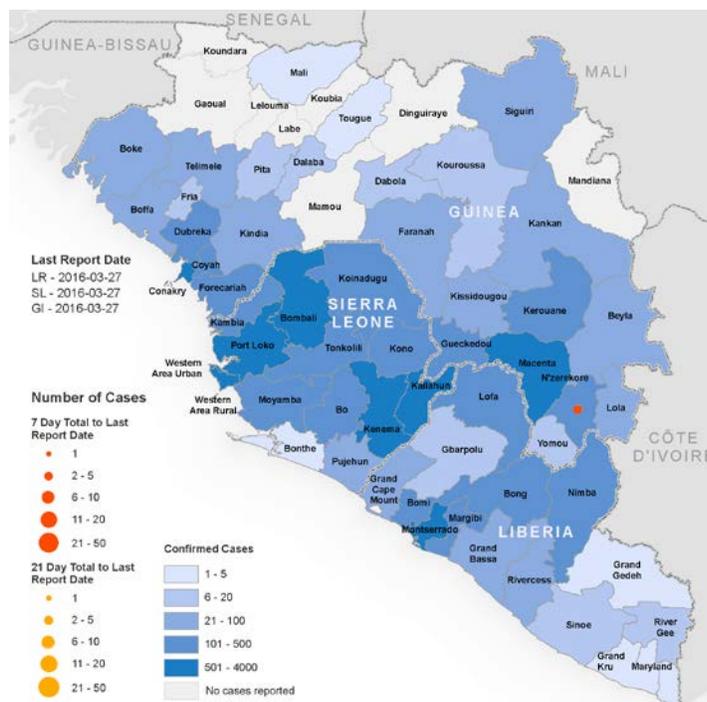
Guinea's survivor network, called RENASEG (*Réseau National des Survivants d'Ebola en Guinée*), was created in January 2016 via United Nations Development Program (UNDP) funding with technical support from the Ministry of Health National Agency for AIDS Action.

Despite being established in name and having an elected administrative board (including president, vice president, treasurer, and communications officer), the organization was largely inactive until it held a general assembly in October 2017 to conduct elections for new leadership. Since then, RENASEG has been active on multiple fronts. This includes promoting its own organizational development; leading trainings modeled after the one provided by ETP&SS for its 24 member associations; leading various livelihood projects to benefit Ebola survivors; and supporting sensitization activities for men to enroll and remain in the national semen testing program. RENASEG has renewed its partnership with and has begun a new project with UNDP funding, which will integrate gender programming, strengthen its relationship with the 24 member associations, and help it improve reporting, monitoring, and evaluation.

The National Ebola Survivor Network of Liberia (NESNL) was established in February 2015 and incorporated as a civil society organization in June 2017. Comprising a central leadership arm and 11 county chapters, the network has received support from the U.S. National Institutes of Health's (NIH) Partnership for Research on Ebola Vaccines in Liberia (PREVAIL) study to facilitate advocacy, social mobilization, and stigma-reduction activities for the survivor population. NESNL also promoted a recreational activities camp for survivors.

The Sierra Leone Association of Ebola Survivors (SLAES) was established in January 2015. SLAES has been supported by the Ministry of Social Welfare, Gender, and Children's Affairs, and has advocated for the government's Comprehensive Program on Ebola Survivors, which enables survivors to access free health care. SLAES activities over the years have included working with HIV organizations on stigma reduction and advocacy; providing cash transfers to survivors in targeted districts (funded by UNDP/UNWomen); conducting a business management skills training for female survivors (funded by Oxfam); and organizing cash and food distribution to Ebola orphans in Sierra Leone's Western Area.

Figure 1: Map of Ebola Cases per Country, as of 27 March 2016



Source: WHO

ETP&SS PROGRAM SUPPORT TO NETWORKS

The ETP&SS program’s health activities focused on mitigating the risk of Ebola resurgence, ensuring the effective delivery of health care related to survivors’ needs, and strengthening critical health services. The national Ebola survivor networks were set up with a clear mission: to unite Ebola survivors, gain public visibility, and provide livelihood support. Activities intended to build organizational capacity among the survivor networks were included in ETP&SS annual country work plans as USAID requested during the design phase of activities.

In addition to strengthening health services via training and infrastructure improvements, ETP&SS provided support to the survivor networks through in-kind resources such as funding their office spaces and equipment, and providing motorcycles to facilitate their work. Program staff also led capacity-building trainings, strategic planning, and a regional workshop with the other national networks. The networks provided ETP&SS’s in-country and DC-based teams with key insights into survivors’ concerns through regular communication and representation at larger stakeholder workshops. These workshops, financed or co-financed by the program, included stakeholders such as the three Ministries of Health, WHO, NIH, CDC, USAID, and implementing partners contributing to the post-Ebola response effort and increased network visibility among partners. The networks were also a great support to surveillance efforts and anti-stigma training (Guinea); helped identify survivors (Liberia, Guinea); and led business-management skills trainings (Sierra Leone). Ideally, the ETP&SS program would have provided livelihood support to the survivor recovery effort, as this area was cited as a key gap by each of the survivor networks, but the program mandate was to fund health activities.

Program support to the national Ebola survivor networks included the primary interventions listed in Table 2.

Table 2: Intervention by Date and Country

Intervention	Date	Network Country/s
Baseline OCA	Oct 2016, Nov 2016, Mar 2017	All
Strategic planning	Dec 2016, Feb 2017, Feb 2017	All
Network regional capacity-building workshop	Mar 2017	All
Stakeholder Regional Workshops	Dec 2016, Jun 2017, Sept 2017	All
Ongoing TA	Aug 2016 – Jul 2018	All
Endline OCA	Jun 2018	Guinea

- **Baseline organizational capacity assessment (OCA):** Using a tool developed and refined by APC’s Local Capacity Initiative program in countries such as Zimbabwe, Guyana, and Haiti, the ETP&SS team led a three-day self-assessment workshop for each Ebola survivor network to consider its ability in five primary areas: governance, human resources, financial management, organizational management, and program management. The output of each workshop was a scorecard and action plan describing necessary steps, persons responsible, and timeframe for achieving a level of proficiency in each area.
- **Strategic planning:** Each network participated in a 1–3 day workshop led by ETP&SS staff to develop a five-year strategic plan, outlining goals, objectives, activities, sub-activities, and resources necessary to complete each activity.
- **Network regional capacity-building workshop:** Eight network representatives per country were invited to participate in a workshop held in Guinea that focused on building skills in advocacy, resource mobilization, and communication. As a result of the workshop, all three networks were given a flash drive full of resources on these topics and a list of all participants’ contact information. Following the workshop, the program established a Facebook page for network members and leadership to stay connected.
- **Stakeholder regional workshop:** At least two survivor representatives per country participated in the stakeholder regional workshops that ETP&SS organized or co-organized. Specific events and topics included:

technical and planning opportunities (December 2016 Liberia); viral persistence in semen (June 2017, Liberia, with WHO and NIH); and post-Ebola health challenges in West Africa (September 2017, with NIH).

- **Ongoing technical assistance** provided by ETP&SS staff in-country and based in DC and in-country grantee staff (International Medical Corps in Guinea and Partners in Health in Sierra Leone) on strengthening network staff capacity to lead their organization's activities.
- **Endline organizational capacity assessment:** In June 2018 in Guinea, the ETP&SS team organized a second end-of-project assessment of change in capacity in the five areas assessed at baseline.

SUCCESSSES AND CHALLENGES

Key successes witnessed by the program with respect to the national Ebola survivor networks:

- 1) Cross-country collaboration and learning at multiple ETP&SS-led regional workshops: at a meeting in Liberia on technical and planning opportunities for regional coordination in December 2016; a workshop designed for network leadership to learn skills in advocacy, communication, and resource mobilization in Guinea in March 2017; the WHO's viral persistence in semen meeting in Liberia in June 2017; and at a major scientific conference co-hosted by NIH on post-Ebola health challenges in West Africa, in Guinea in September 2017. Leadership of the national survivor networks valued sharing critical research findings that they could in turn share with survivors in their respective countries.
- 2) Networks supported livelihood projects to help Ebola survivors across the three countries regain economic opportunities. In Guinea, the national network also contributed to community sensitization efforts and encouraged semen testing of male survivors, which improved surveillance data country-wide.

Key challenges that the program faced in working with the survivor networks:

- 1) Enforcing limits to the scope of support provided. There was a sense among some network leadership that the ETP&SS program did not provide enough livelihood support or work fast enough to get specialty medicines intended for Ebola survivors in-country. Both are valid and important actions, but there are reasons behind the omission (in the case of livelihoods) and delay (in arrival of specialty medicines). Livelihood support (e.g., assisting survivors with income-generating activities or finding new employment) was outside the program mandate and funding on this aspect was not permitted by USAID. Procurement and delivery of specialty medicines to each country were delayed frequently for reasons outside control of the program, which was not authorized to procure medicines, so had to rely on USAID's central procurement mechanism. There were also distribution delays related to the MOH procurement systems.
- 2) Encouraging network leadership that was inclusive and pragmatic. While it is important to have strong leadership in any organization, the program noticed that the voice of one or two leaders sometimes dominated conversations with stakeholders, and therefore dictated network priorities. In another network, leadership was missing for more than a year after the outbreak, with a president who existed in title only until they elected new leadership. The weak leader in the post-Ebola period resulted in lacking momentum for that network for an extended period of time.

LESSONS AND WAY FORWARD

Lesson 1: Set clear parameters from the start regarding the relationship and the extent of anticipated financial and technical involvement. If program funds cannot support an essential component of the organizational goal (such as livelihood support due to a health mandate), the partner should try to connect the survivor group to an organization that might fund this component (addresses Challenge 1).

Lesson 2: In organizational capacity building and leadership training, encourage inclusive democratic behavior within the organization so that all members, including women, and those who may not speak the dominant language, have the opportunity to express their ideas and opinions (addresses Challenge 2).

ETP&SS values and appreciates the Ebola survivor networks in Guinea, Liberia, and Sierra Leone, and the program hopes for their success in the future. We faced successes and challenges, but learned in the process, and are better prepared to respond to future outbreaks that may create a community of survivors and advocates.