WHO MEETING ON SURVIVORS OF EBOLA VIRUS DISEASE: CLINICAL CARE OF SURVIVORS

Meeting report
Freetown, Sierra Leone, 3-4 August 2015
WHO Meeting on Survivors of Ebola Virus Disease:
Clinical Care of EVD Survivors
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Meeting Report

Background

The unprecedented outbreak of Ebola virus disease (EVD) that began in West Africa in December 2013 has had a devastating impact on the region. With over 27,500 cases registered to date and despite a very high case fatality rate, there are likely over 13,000 EVD survivors in Guinea, Liberia, and Sierra Leone, a far greater number than all previous EVD outbreaks combined. Limited systematically collected data and accumulating anecdotal reports, demonstrate that EVD survivors still face myriad physical and mental health challenges after recovery from the acute disease. However, there are very limited data on the true frequency of the various reported health problems, their pathogenesis, or the best practices for clinical management.

Scope and Purpose

The meeting assembled stakeholders engaged in or seeking to provide care and/or conduct scientific research regarding EVD survivors. Clinicians, scientists, epidemiologists, and other public health practitioners shared their expertise and experience in order to advance networks and access to clinical care for EVD survivors, build consensus on best clinical management, share research data, and identify key knowledge gaps, with the goal of enhancing quality of care for EVD survivors everywhere.

Specific Objectives

The specific objectives of this meeting were to:

- Identify existing clinical services available to EVD survivors in West Africa and help link them to survivors in need of care
- Share expertise and experience regarding clinical management of EVD survivors to build consensus on best clinical management practices
- Identify gaps in clinical services and develop plans to meet them, including provision of technical expertise and infrastructure
- Discuss and develop common protocols for data collection and best clinical management of EVD survivors
- Review key research questions regarding EVD survivors, including the evidence for various health problems post-EVD and their pathogenesis, to enable improved care of survivors for this and future outbreaks.
Anders Nordström, World Health Organization (WHO) Representative to Sierra Leone, welcomed the participants. In his general introduction he highlighted the aim of securing the maximum support for EVD survivors.

The Sierra Leonean Deputy Minister of Social Welfare, Gender and Children’s Affairs, Hon. Mustapha Bai Attilla, emphasized the importance of understanding the needs of EVD survivors for the post-Ebola recovery phase. With immense medical and social challenges, Ebola affected communities require urgent support. Therefore, the President of Sierra Leone has launched a six to nine month recovery programme, working with partner organizations like WHO, to assist EVD survivors back to a normal life. EVD survivors need to be included in the planning process and lessons must be learned from their experience in order to be better prepared for future outbreaks.

The Deputy Minister of Health and Sanitation, Hon. Foday Sawi Lahai, thanked all participants for their support in finding best practice solutions for the clinical management and social support of EVD survivors. In his speech he also emphasized the need to include the EVD survivors themselves in planning activities to improve medical and psychosocial care.

Bruce Aylward, WHO Assistant Director General responsible for WHO’s Ebola response, stressed the importance of the EVD survivor’s voice in the meeting and the importance of the meeting itself in setting the global agenda for the post-Ebola recovery phase in West Africa. He mentioned specific issues, such as the necessity to improve collaboration and the sharing of information, which need to be discussed and that decisions must be made with urgency, flexibility and clear timelines to move the agenda faster.
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Review of Literature on Health and Psychosocial Problems of EVD Survivors
(Daniel Bausch, Epidemic Clinical Management Team, WHO)

There are few published reports on the health and psychosocial problems of EVD survivors. Most of these papers have been published during the recent Ebola outbreak in West Africa. A study conducted in Kenema District, Sierra Leone, in October 2014, describes the most common symptoms a group of 81 EVD survivors have self-reported following their discharge from the Ebola Treatment Unit (ETU). Their symptoms included joint pain, headache, muscle pain, sleeplessness, visual problems and depression. These reports show great similarities to two controlled studies, which were undertaken in Kikwit, Democratic Republic of the Congo (Rowe, 1999), and Bundibugyo, Uganda (Clark 2015): fatigue, sleep disturbance, blurred vision, arthralgias, myalgias, hearing loss, abdominal pain, and anorexia were the most common symptoms, many of which were still present at the end of the follow-up period (Democratic Republic of the Congo: 21 months; Uganda: 29 months). Interestingly, no differences in basic clinical laboratory parameters, including C reactive protein, were detected. Special attention on the high percentage of ocular findings seems to be necessary. Studies on EVD sequelae have described ocular symptoms like vision loss, uveitis conjunctivitis and blurred vision in a great number of EVD survivors (Bwaka et al. 1999, Kibadi et al. 1999, Wendo 2001, Clark et al. 2015, Nanyonga et al. 2015).

Another important issue is delayed virus clearance in immunologically protected body compartments, such as the male gonads/semen, chambers of the eye, placenta and fetus, and possibly also the central nervous systems and articular cartilage. There is no evidence that EVD causes a chronic infection, but the immune system seems to take longer to clear the virus from these compartments (e.g. Ebola virus has been detected in a survivor’s semen 82 days after disease onset).

The pathogenesis of EVD sequelae and delayed virus clearance is not well understood. There is some evidence for a sustained immune activation or a delayed hypersensitivity reaction to persistent virus antigen. Immune complex deposition could also be an explanation, especially for the arthralgias. Ebola virus antigen has been noted in the brain, eye, pancreas, thyroid, and lung of macaques with significantly delayed disease after treatment (Larsen et al. 2007) (Larsen, 2007). There is some evidence showing a correlation between the severity of the disease and the frequency of sequelae. IgG titres were found to be significantly higher in EVD survivors with arthralgia than in those without (Rowe, 1999) and sequelae were also more frequent in those with surrogate clinical markers of severe disease (seizures and melena) (Clark, 2015).

The WHO Ebola Survivors Support Network (WHO ESSN) has been set up to assist governmental and nongovernmental partners in the coordination of plans for EVD survivors, both in terms of service provision (first priority) and scientific study (secondary). The objectives of this network are to strengthen the links between all actors involved in the care of EVD survivors, to exchange best practice solutions and to identify research gaps. The Sierra Leonean Ministry of Health and Sanitation and Ministry of Social Welfare, Gender and Children’s Affairs together with WHO have, to this purpose, set up a Comprehensive Care for EVD Survivors platform, working on the following task groups: _______ (https://sites.google.com/site/evdsurvivors/)
In summary, EVD survivors experience many different physical and mental health sequelae, most of which appear to be treatable. More studies, especially those including control groups, need to be conducted to learn more about the true frequency and duration of various sequelae post-EVD, to better understand the pathogenesis and the relationship between acute disease severity and sequelae, as well as the effect of given treatment options. More data is also required regarding the mid-term and long-term consequences for Ebola-affected communities.
The Survivors’ Sounding Board
(President of the Sierra Leone Association of Ebola Survivors)

The aim of the Sierra Leone Association of Ebola Survivors (SLAES) is to effectively contribute to the elimination of EVD and to participate in the national development programmes. The members of SLAES have voluntarily begun to strengthen community sensitization by measures such as visiting quarantined households in order to raise awareness about the signs and symptoms of EVD and to inform communities about the necessary steps to take. SLAES has conducted anti-stigmatization campaigns in all 14 districts of Sierra Leone, lobbying traditional leaders to adopt laws to prevent the stigmatization of EVD survivors. SLAES has also successfully advocated for improved health care for survivors. The association consists of district and regional structures and maintains mutual communication with all partners and networks. The SLAES programmes are categorized as follows:

1. Short-term plans:
   - Advocacy on EVD survivors health care, especially in remote communities
   - Strengthening of the EVD survivors network
   - Nutritional support
   - Office equipment and funding
   - Advocacy for scholarship/educational opportunities for EVD survivors
   - Anti-stigmatization campaign.

2. Mid-term plans:
   - Capacity building and empowerment opportunities for EVD survivors
   - Technical training on psychosocial care
   - Micro-finance scheme
   - Advocacy on EVD survivors health care
   - Anti-stigmatization campaign.

3. Long-term plans:
   - Adult educational facilities for illiterate EVD survivors
   - Shelter facilities for EVD survivors
   - Anti-stigmatization campaign
   - Advocacy for EVD survivors health care
   - Agricultural and nutritional support for EVD survivors.

SLAES is very concerned about EVD survivors not being involved in the national post-Ebola reconstruction activities. The association calls for increased involvement in these discussions and is asking the Ministries for additional support for EVD survivors, especially those in remote communities. Stigmatization remains of great concern for the EVD survivors, who feel that the authorities are not active enough in this area. In addition, there is concern that the authorities are not sufficiently attending to the needs of Ebola orphans and for EVD survivors experiencing severe visual complications, especially those living in remote areas. Educational opportunities and scholarships are missing, and both nutritional and agricultural support are urgently needed for EVD survivors and their families.

In response to the SLAES concerns, the Sierra Leonean Deputy Chief Medical Officer emphasized the government’s willingness to support the EVD survivors, offering free health care at all government health facilities, working to ensure the inclusion of required medicines in the essential medicines list and including EVD survivors in the development of a 6 to 9 month recovery plan.
Mapping of Survivor Care Providers and Cohorts

(Ministry of Social Welfare, Gender and Children’s Affairs, Government of Sierra Leone &
International Medical Corps)

Supported by the Government of Sierra Leone’s Ministry of Social Welfare, Gender and Children’s Affairs, the International Medical Corps has funded and executed a mapping process using the IASC Guidelines for mental health and psychosocial support (PSS) in emergency settings (http://www.who.int/mental_health/emergencies/9781424334445/en/). The key objectives of this mapping process have been to provide a big picture of the size and nature of the response, inform and improve the coordination and avoid duplication, identify gaps, build and strengthen capacity of existing resources and establish referral systems. It will also serve to improve transparency and legitimacy through structures documentation and to learn from failures while identifying best practice examples. The process has not been specifically survivor oriented, but rather focused on more global EVD-affected populations and services, including child protection services. The mapping, which commenced in the “hot spots”, not only covers activities within the emergency and recovery period, but is also meant to support the Ministry’s Mental Health and Psychosocial Support (MHPSS) strategy for 2015–2018.

The standardized data collection tool of the IASC reference group has been adapted for the Sierra Leonean and EVD response context. A data collection spreadsheet has been completed by the organizations on the ground in different districts, assisted by a visiting implementation team to ensure the quality of the data. The types of activities are divided into four service categories: community-focused, case-focused, general and child protection.

Activities/Interventions:

1. Information dissemination to the community at large
2. Facilitation of conditions for community mobilization, community organization, community ownership or community control over emergency relief in general
3. Strengthening of community and family support
4. Safe spaces
5. Psychological support in education
6. Supporting the inclusion of social/psychosocial considerations in protection, health services, nutrition, food aid, shelter, site planning or water and sanitation
7. Psychosocial work (case-focused)
8. Clinical management of mental disorders by non-specialized health care providers (e.g. Peripheral Health Centres (PHC), post-surgery wards)
9. Clinical management of mental disorders by specialized mental health care providers (e.g. psychiatrists, psychiatric nurses and psychologists working at PHC/general health facilities/mental health facilities)
10. General activities to support MHPSS
11. Protection monitoring
12. Protection services.

(All these activities include several sub-activities.)

Preliminary outcomes of the mapping process (2 of 14 districts; Port Loko and Kambia):

- Most of the organizations contacted so far have reallocated their services to EVD-related response activities;
- Most activities are case management based: providing basic needs, linking to other resources, livelihood activities, psychological first aid (PFA);
- Information dissemination: mass campaigns; information, education and communication materials; advocacy mostly in reference to EVD;
- Other significant activities include training courses for service providers and traditional leaders, basic counselling services, and community focused programmes;
- Beneficiaries: 7% survivors, 64% EVD-related, 29% non-EVD-related; and
- Services include: basic counselling, support groups, livelihood assistance, linkage and referral, advocacy concerning stigma. These services are not specifically focused on EVD survivors, but relate to highly affected target groups.

Discussion points:
- Reintegration projects are important
- EVD-related orphans are being taken care of by governmental authorities and foster families
- A national registry of survivors has been set up by WHO, MoH and the EVD survivors. The geographical distribution and coverage of services for EVD survivors by existing health care facilities is currently being assessed by WHO / MoH EVD survivors working group.
Ebola Virus Persistence in Body Fluids after Recovery and Risk of Sexual Transmission

(Gibrilla Fadlu Deen, Ministry of Health and Sanitation and Ministry of Defence, Government of Sierra Leone; United States Centers for Disease Control and Prevention (CDC), WHO)

The persistence of Ebola virus in body fluids after recovery and the risk of sexual transmission are of great concern, especially due to the very high number of EVD survivors in the three most affected countries. To date the longest measured time of Ebola virus persistence is as follows:

In convalescent patients:

- Live EBOV isolated from semen (day 82), and urine (day 26)(virus isolation on cell culture) – (Rodriguez et al. 1999)
- EBOV-RNA detected in semen (day 199 – Liberia 2015), vaginal secretions (day 33), sweat (day 40) and urine (day 30), (RT-PCR)
- No virus detected in saliva in convalescents; report of positive RT-PCR rectal swabs in one woman on days 22, 29.

In the environment:

- EBOV survives in room temperature in liquid media for > 46 days; on solid media in the dark, for > two hours
- Duration of viable EBOV or viral RNA persistence in bodily fluids is largely unknown (lack of follow-up of semen).

(T mean and maximum duration of virus persistence remains unknown. The use of condoms by EVD survivors should therefore be highly encouraged to protect not only against EVD but also against HIV, Hepatitis B and other sexually transmitted diseases. Pores in condoms allowing leakage of small sized viruses and, particularly, the incorrect use of condoms due to the lack of experience, are issues of concern (Thorson et al. 2015, submitted). The key question in this context remains: Does sexual transmission of Ebola virus occur? In Liberia three cases of suspected sexual transmission from husbands to wives (Island Clinic ETU, 2014) as well as one case with a strong suspicion of sexual transmission (CDC MMWR 1, May 2015) have been reported. In Sierra Leone a dozen cases of suspected transmission from men to their female partners have been described, Guinea has only reported three cases of suspected transmission (based on epidemiological data). There is a need to better understand Ebola virus persistence in body fluids before conducting a cohort study of incident cases among sexual partners of EVD survivors to understand whether sexual transmission can occur.

A first research study to investigate the persistence of Ebola virus in body fluids in a cohort of EVD survivors has been initiated by the Sierra Leone Ministry of Health and Sanitation, World Health Organization, and United States Centers for Disease Control and Prevention. The pilot study incorporates a cohort of 100 men, collecting semen specimens and using real-time Reverse Transcriptase Polymerase Chain Reaction (RT-PCR) and virus isolation. Another objective of this study is to assess concordance between RT-PCR test results and viral isolation test results. These 100 male EVD survivors, recruited through the survivor’s network, have been tested at the 34th Military Hospital in Freetown, Sierra Leone, at different points in time. Trained counsellors provided them with pre- and post-test counselling, accompanied by a follow-up with provision of the results after two weeks. All men were offered additional care as needed (including HIV testing). During their first visit,
baseline data was collected through a structured interview covering sociodemography, comorbidity, sexual behaviour, EVD course and sequelae. Ebola testing of semen and HIV testing of blood were performed by real-time RT-PCR at the U.S. CDC laboratory in Bo. A key result of this study is the evidence that Ebola virus RNA can persist in semen up until at least 284 days (i.e. 9.4 months) post disease onset. However, the detection of Ebola virus RNA by RT-PCR does not necessarily indicate that infectious virus is present. The correlation between RT-PCR and virus isolation is presently unknown. Cell culture for virus isolation of these specimens is currently being planned.

The researchers suggest that current WHO recommendations regarding sexual transmission of Ebola virus should be followed: male EVD survivors who do not know the RT-PCR status of their semen should abstain from sex or use condoms when engaging in sexual activity for at least six months. In addition, new programmes to help EVD survivors to understand and mitigate the risk of sexual transmission should be launched. These must include the provision of semen testing and preventive behavioural counselling to male survivors as well as outreach activities to provide education about recommendations and potential risks to survivor communities and sexual partners of survivors. Within this context it is very important to consider the individual survivor’s situation, especially concerning stigmatization and EVD sequelae. Respectful and local anchoring in communities is crucial in mitigating further negative effects related to virus persistence.

Following this pilot study, the main study, which includes testing of additional body fluids from men and women, was scheduled to commence in September, 2015. The main study data analysis is planned for early 2016.
Men’s Health Screening Programme

(Jomah Kollie, Ministry of Health, Government of Liberia; in cooperation with WHO & CDC)

The Liberian Ministry of Health maintains a registry of about 1 500 EVD survivors, 58% of whom live in Montserrado County. In March 2015, strong evidence was found for a case of sexual transmission of Ebola virus in Monrovia. A woman tested positive for Ebola virus after having unprotected sex with a male EVD survivor. His semen contained Ebola virus 199 days after his recovery and sequence analysis showed that this could be closely matched with the Ebola virus found in the woman.

Current WHO recommendations are:

- Male survivors should be offered semen testing
- Those who test positive should be tested every month until they have two semen tests by RT-PCR which are negative for Ebola virus
- All Ebola survivors and their sexual partners should receive counselling on safe sexual practices
- Survivors should be given condoms.

The Liberian Ministry of Health has now implemented a Men’s Health Screening programme, funded by WHO, offering free testing of semen for Ebola virus. The purpose of this programme is to inform male survivors (≥ 15 years of age) of their risk of spreading EVD through sex and to empower them to make informed decisions to protect their partners. The programme was launched in Montserrado County in July 2015 and will now be expanded to other highly affected counties in Liberia. Potential clients will be identified through the Ministry of Health’s survivor registry, by referrals from EVD survivor clinics (e.g. MSF, ELWA) and by personal information through the survivor networks.

As part of this programme, counsellors will meet survivors every two weeks and survivors will be able to choose home visits or clinic visits, which are being offered at the Redemption Hospital, a government hospital providing free health care to all Liberians. Two mental health counsellors are already treating EVD survivors for mental health sequelae. Further capacity building within Redemption Hospital to ensure the sustainability of the programme is being envisaged. In addition, integration of this programme into the existing services and infrastructure provided by the government and supported by WHO is planned.

As part of the programme, participants are provided with counselling on safe sexual practices (with wife or girlfriend invited to join). Free condoms and instructions for use are provided, as well as reimbursement for travel and time, and a brochure listing all facilities providing health-care services to survivors. The semen samples are tested once a month for Ebola virus by RT-PCR. In case of a positive result, the man will be called to come for an appointment within 48–72 hours in order to receive further counselling and instructions following current WHO recommendations.

For the collection of the specimen and to ensure adequate infection prevention and control (IPC) measures, an IPC specialist and a hygienist play an important role in the programme. The role of the IPC specialist (or a specimen technician) is to supervise and train staff regarding IPC standards and cleaning procedures, monitor the hygienists’ cleaning and waste management, instruct participants on the collection of the specimen, and ensure proper handling, labelling and storage of the specimen.

In addition, to onsite at Redemption Hospital, there is a mobile unit serving Montserrado County. A second mobile unit will begin its work soon and meetings with county health teams to scale up the programme are being planned. To date 60 EVD survivors have been enrolled in the programme. Preliminary results are expected in the upcoming weeks.
Discussion points:

• Previous WHO recommendations included abstention from sexual intercourse for three months. This has been extended to six months → Final recommendations are pending based on complete results and data analysis
• Additional laboratory capacity needs to be created to provide semen testing for all male EVD survivors (in Liberia only 60 of 1500 male EVD survivors have been tested so far)
• Research on Ebola virus in vaginal secretions is lacking
• Condom use campaigns have often been unsuccessful in West Africa
• Communication about the possible risks of sexual transmission needs to be improved, taking into account the issue of stigmatization
• A structured operational research programme is strongly recommended to improve these programmes (WHO/TDR is offering support)
• The use of Ebola vaccines should be taken into consideration within this context
• Further research on the risk of sexual transmission is needed.
Management of pregnancy during an Ebola outbreak is very challenging. Appropriate screening, risk identification and the implementation of IPC precautions are critical. WHO and its partners are therefore developing an interim guidance for distribution in the Ebola affected countries, an example of which is outlined in Fig. 1.

Most pregnant woman infected with EVD will lose the unborn child sometime during the course of the disease. Women who recover from EVD with an intact pregnancy (no rupture of membranes or labour) require comprehensive IPC precautions to prevent exposure to intrauterine contents (i.e. amniotic fluid, placenta and foetus) during childbirth or complication management. Their neonates also require such precautions (Baggi et al. 2014). Precautionary measures include:

1. Provide counselling on neonatal outcomes (there are no reports of survival beyond the neonatal period);
2. Provide close follow-up and immediately refer to an ETU when rupture of membranes, labour or complications of pregnancy occur; and
3. If live birth, newborn should be cared for in an ETU using comprehensive IPC precautions as recommended for care of EVD cases for 21 days following birth.
Presently there are no data available on pregnancy outcomes of women who survive EVD and then become pregnant. WHO recommends preconception care including: provision of biomedical, behavioural and social health interventions to women and couples before conception to improve their health status, and to reduce behaviours as well as individual and environmental factors that contribute to poor maternal and child health outcomes (http://www.who.int/maternal_child_adolescent/documents/preconception_care_policy_brief.pdf?ua=1). For males, WHO recommends abstinence or the practice of safe sex through correct and consistent condom use after recovery from EVD, with testing of the semen at three months.

As strong evidence in the field of pregnancy issues related to EVD is lacking, systematic data collection and an EVD survivor registry are urgently needed. Additional diagnostic measures (e.g. ultrasound) and research to better understand the complex pathophysiology would also be of great value. All pregnant women, survivors, their partners and families should be shown respect, dignity and compassion.

Discussion points:

- Current IPC strategies for pregnant women who are not infected with Ebola virus
- Labour complications (stillbirth, premature delivery, etc.) can mimic EVD symptoms → If there are any doubts about EVD status, full personal protective equipment (PPE) is advised. The baby must also be closely observed
- Pathogenesis and risks related to Ebola virus in the placenta
- The placenta appears to be an immunologically protected site and thus a reservoir for the virus. Rupture of membranes brings a hypothetical risk of transmission, but conclusive evidence is still lacking
- Standard WHO guidelines and recommendations, including close monitoring, should be applied for female survivors who become pregnant following their discharge from ETU
- Induction of labour in pregnant women in general and especially EVD survivors
- For pregnant EVD survivors, the recommendation to return to an ETU for delivery will increase the problem of stigmatization
- Standard precautions are indicated for all women who become pregnant after they have been discharged, as there is no evidence that these subsequent pregnancies are at risk for Ebola virus persistence or transmission
- Obstetric care services in the national health systems need to be strengthened; ETUs should only be used for deliveries in the precisely defined cases at risk.

References


Clinical Experiences and Data from EVD Survivor Cohorts

Partnership for Research on Ebola Virus (PREVAIL III)
(Mosoka Fallah, Ministry of Health and Social Welfare, Liberia)

The Partnership for Research on Ebola Virus (PREVAIL) is a joint research programme by the Liberian Ministry of Health and Social Welfare and the US National Institutes of Health Clinical Center. The Ebola Natural History Study is an observational cohort/case control study to be conducted from June 2015 to 2020 (with an accrual period of two years). About 1 500 EVD survivors and 6 000 close contacts (household members and/or sexual partners) will be included. The objectives of the study are to characterize the EVD sequelae and to assess whether survivors can transmit infection to household members and sexual contacts. In addition, virus persistence will be assessed and more in-depth sub studies around clinical findings are planned or ongoing (including ophthalmologic and neurologic sub studies using additional system specific diagnostic modalities, e.g. MRI, sleep studies, EEG, EMG, neuropsychology testing).

Analysis of line-listed EVD SURVIVORS (n=1,536):
- EVD survivors in Liberia: 54% Female, 46% Male
- EVD survivors by ETU of discharge, see Fig. 2.

Figure 2:
The PREVAIL research team is partnering with the Liberian Ministry of Health and Social Welfare to provide clinical care for survivor needs identified by the research. An appropriate balance between treatment and research needs to be sought, especially within the EVD context. Survivors who do not agree to participate in the study still require appropriate care and also need to be referred to health facilities and other clinical care sites with diagnostic and specialist capacities. Of the 341 EVD survivors enrolled so far, the majority required specialist referrals (e.g. 82% ophthalmic problems, including 10% uveitis; 53% joint pain; 25% memory loss; 19% claudication). Most of them were referred to Redemption Hospital, ELWA Hospital and JFK Medical Center, although user fees at the tertiary care hospital, JFK, are a problem for the survivors. Eye problems (about 10%) were the main reason for referral. A total of 30 pregnant EVD survivors have been recorded within this study population (Age 16–40; gestational weeks 1–36; 1 still birth (full term), 3 miscarriages; 8 positive for syphilis, 2 HIV positive). Antenatal care (ANC) visits have been strongly recommended to these pregnant women as most of the women (72%) had only been examined once or twice during their pregnancy. A special support package through private donations, including food supplies, is being offered to improve ANC visits.

Additional challenges EVD survivors in Liberia currently face include the limited number health facilities that provide free clinical care, lack of required medicines and surgical capacities, unemployment, limited psychosocial support, adult illiteracy and lack of educational opportunities.
Potential innovative solutions:

- PREVAIL: providing medications for eye problems and prescription: Private Donors
- PREVAIL: ANC and delivery care package for pregnant survivors (NIH Foundation)
- PREVAIL: dedicated trackers to track pregnant survivors to enhance ANC visits
- Partnering with public and private health facilities
- Costing clinical care for survivors at the national referral hospital (JFK) to identify sponsors
- Collaborating with Survivor Network to develop a National Ebola Survivor Foundation: attract grants and funding
- Employment opportunities for survivors in social mobilization for PREVAIL-III.

Despite efforts to ensure free care through a patchwork of sources, gaps persist.
ELWA EVD Survivors Clinic
(John Fankhauser, Director of Medical Missions, SIM Liberia)

ELWA Hospital was founded in 1965 and has been used as an ETU during the second wave of the current Ebola outbreak when patients were turned away from regular clinics. Since January 2015 ELWA has been turned into an Ebola survivor’s clinic, offering free services, embedded in private doctors’ offices, for more than 130 EVD survivors in Monrovia (including clinic, psychosocial counselling, laboratory, imaging (ultrasound, x-ray), prenatal care, hospitalization, and non-elective surgery).

The most frequent symptoms observed in patients during the first four months were muscle and joint pain (53%), headache (48%), vision problems (36%), fatigue (32%), stomach pain (31%), depression (15%) and poor memory (13%). Many of these symptoms, including ocular problems, appear to be treatable, if detected and treated in an early stage. The ELWA Survivor’s Clinic, which has been able to secure funding for the next two years, is also addressing the needs of special populations, offering services in the fields of maternal health, rheumatology, ophthalmology and dermatology, as well as home health services for EVD survivors who are not able to attend the clinic due to complex wounds or transport difficulties. These home health services, including nursing care and “livelihood counselling” are strongly recommended. They have been transformational for many patients.

Despite these achievements certain gaps remain, including a schedule for routine follow-up of all EVD survivors, specialty referrals, advanced imaging and laboratory testing, vocational training and permanent housing.
Clinical Experiences and Data from EVD Survivors Cohort  
(Foday Sesay, Coordinator 34th Military Hospital Survivor Clinic, Ministry of Defence, Government of Sierra Leone)

Sierra Leone is estimated to have more than 4,000 EVD survivors. The government has therefore started to establish a detailed database of EVD survivors in the Western Area to systematically detect and treat medical and psychosocial EVD sequelae and to undertake research programmes related to all aspects of EVD. In addition to the provision of general medical assessments of all EVD survivors, the services offered at the 34th Military Hospital Survivor Clinic include the dispensing of medication, laboratory services, x-ray imaging, and psychosocial assessment. Some specialist services (e.g., rheumatology) can be offered only when the required specialists are available. During its first nine months of clinical operations, 241 EVD survivors have been seen in the clinic (52.3% women, 43.9% men, 3.7% children < 16 years). These patients were treated in various ETUs throughout Sierra Leone, the majority coming from MH34, PTS I & II, Kerry Town, MSF (Kissy, Bo, POW) and Kenema. Due to increasing demand, the clinic days have now extended from two to five per week.

Few systematic studies on post-EVD sequelae have been conducted so far. The recovery period appears to be prolonged in many patients, with both short- and long-term health problems observed. These include general weakness, fatigue, fever (15%), anorexia, costochondritis, headache (34%), myalgia and arthralgia (85%), abdominal pains, weight loss, anorexia (10%), alopecia, orchitis, parotitis, gastritis, ocular problems (25%, including eye pain, hyperlacrimation, photophobia, uveitis and blurred vision), tinnitus, decreased libido, impotence, pericarditis, amenorrhea, irritability, and psychosocial problems. Mental health problems appear to be especially frequent, including post-traumatic stress disorder, depression, anxiety disorders and survivor’s guilt. The severity of the illness, loss of family members and friends, and ongoing stigmatization are key factors preventing the full reintegration of EVD survivors into their communities.

Clinical management of EVD survivors during convalescence is largely symptomatic, including the use of warm packs, paracetamol, non-steroidal anti-inflammatory drugs, antidepressants, anxiolytics, nutritional supplements and psychological counselling as indicated. Ocular problems are managed with topical corticosteroids and antibiotics and referred to Dr Vandi, an ophthalmologist in Connaught Hospital. Referral for management of complications requiring specialist attention remains one of the great challenges. Obtaining a complete database of EVD survivors in the Western Area, reaching out to survivors residing in rural areas, verifying the survivor’s status, and lack of governmental funding for laboratory tests and basic medications are additional challenges.

Despite all these challenges, a great number of EVD survivors have received support for their ongoing health problems. A platform for data collection on clinical sequelae and for conducting basic research as well as a forum for the EVD survivor’s network have been created. The integration of EVD survivor services into the existing health system, provision of inpatient care, creation of an appropriate referral system, improvement of psychological support, and provision of a comprehensive EVD survivor database in the Western Area are among the activities currently under development.

Port Loko EVD Survivor Clinic, Sierra Leone  
(Joyce Chang, Partners in Health (PIH); in cooperation with Government of Sierra Leone; Baptist Eye Hospital, Lunsar; University of Toronto, International Medical Corps, GOAL, Emory Eye Center, WHO)
The main aim of the Port Loko EVD Survivor Clinic is to systematically detect and treat medical and psychosocial Ebola-sequelae in all survivors residing in Port Loko and Kambia Districts, with a special focus on ocular sequelae. The clinic started operations in mid-March (five days per week) and through 20 July a total of 643 EVD survivors have been seen. Activities include the identification of all known EVD survivors residing in the district and the provision of free transport to the clinic, utilizing PIH’s survivor network and SLAES for outreach and social mobilization undertakings. In addition, the provision of eye, general medical and psychosocial care for all EVD survivors is being offered. This includes checking vital signs, taking the patient history, physical and ocular examination (visual acuity, slit lamp, dilated fundoscopy), dispensing of medications, and psychosocial counselling and support, as well as referrals for chronic or acute care. On the first visit to the EVD survivor’s clinic, 75% of the patients complained of arthralgias, 61% had eye symptoms (especially uveitis), 26% had ear/hearing symptoms and 22% had sleeping difficulties. Fever, headache, costochondritis and gastro-oesophageal reflux disease have also been observed frequently.

Accomplishments so far:
- Nearly all survivors in Port Loko and Kambia Districts have been seen
- Better understanding of prevalence of various EVD sequelae
- Of 96 patients diagnosed with uveitis, 51 had improvement with treatment
- Survivors are very active in implementing the entire programme, including in outreach, in-clinic support, and follow-up
- Opportunities to engage survivors in existing health-care system for antenatal care, TB testing, etc.

Challenges and unknowns:
- Social outreach (absence of complete registry, ongoing fears about engaging with health care facilities, difficult to reach communities)
- Many survivors died in community not long after discharge—causes unclear
- Trying to “catch-up”, especially with time-sensitive interventions including reducing time from discharge to sequelae support
- Lack of curative treatment for joint pain (NSAIDs and steroids help temporarily; pain management and physical therapy is needed)
- Specialty care/diagnostics (especially neurological and ENT assessments)
- Currently, scope of “free care” can be very limited in practice
- Eye complications needing surgical intervention, with IPC concerns
- Psychosocial concerns including source of livelihood and finding employment (most prominent concerns), lack of money and loss of familial economic support (which also affects nutritional status) and housing problems.

Social Protection
(Gabriel Warren, PIH, Sierra Leone)
The aim of PIH’s social protection programme in Sierra Leone is to improve clinical access for EVD survivors, coordinate community outreach, and link EVD affected individuals and their households with partner organizations’ health facilities and government services. This is done in close cooperation with the Ministry of Social Welfare, Gender, and Children’s affairs. In addition, the programme focuses on increasing access to education and strengthening socioeconomic mobility for EVD survivors.

PIH works in close collaboration with multiple actors, including the Sierra Leonean government, SLAES, WHO, CDC, United Nations Children’s Fund (UNICEF), International Organization for Migration (IOM), and a great number of national and international NGO’s. To date reintegration efforts include (showing numbers of EVD survivors):

- Back-to-School Packages – 300
- Discharge Packages – 449
- Employment – 835 (maximum during peak time in March; e.g. for social mobilization activities)
- Clinical Care – 946
- ID Cards – 517 (a lot of personal identification and certificates were destroyed in ETUs)
- Bank Accounts – 490
- Adult Literacy – 450 (starting in September 2015 in Port Loko & Kambia)
- Vocational Support – 250
- Educational Accompaniment – 340

Discussion points:

- Need for inclusion of EVD survivor services in national health and social welfare services
- Sustainability of programmes?
- Costs for the services are a crucial issue. Despite the government offering free health care support, often EVD survivors still need to pay for services
- A referral system is needed, especially for EVD survivors from rural areas, where transportation support is especially needed
- Educational programmes and tuition fees
- Issues such as social reintegration of survivors and the role of religious leaders need more attention
- Identification of best practice solutions for home-based services
- For what length of time should EVD survivors with sequelae be monitored? How long will their immunity last?
- Is there more evidence supporting the observation that many EVD survivors have died in the community after discharge?
- The clinical guidelines for EVD in the area of discharge package need to be enriched, including things to look out for or do on discharge (HIV status, TB status, etc.) and during follow-up visits in order to reach the EVD survivors in need before the onset or progress of complications.
Maximizing our Knowledge from Existing Data: Core Data Elements, Data Banking and Analysis
(Sharmista Mishra, University of Toronto; on behalf of Laura Merson, ISARIC & Adam Levine, Brown University)

Maximizing our knowledge from existing clinical data ideally requires a systematic and harmonized data collection and sharing process. Charting the data collection during clinical care is very challenging in the EVD context, in which health-care workers are focused on patient care in full PPE inside the red zone, thus limiting the feasibility of data recording. Although the size and consequences of the current outbreak of EVD are unprecedented, there remains limited empiric or scientific evidence to inform advances in diagnosis, triage, management and follow-up of suspected and confirmed EVD patients. However, there currently exists a wealth of clinical, laboratory, and epidemiological data that have been collected in the three most affected countries and could be used to address these questions and to improve patient care. Knowledge on prediction models (disease, mortality, recovery, sequelae), management strategies (optimal hydration, resuscitation methods, antimalarial/antibiotic drugs, supplemental vitamins, treatment of sequelae) and operational strategies (community engagement campaigns, triage systems, optimizing clinical resources and service delivery) could be advanced.

Since individual facilities providing EVD care in the various districts use varied data recording methods, a comparison or combination of collected data is difficult. Until now no common repository of clinical, epidemiological, or laboratory data on EVD and its sequelae exists. Closer collaboration between all involved actors (clinics, ETUs, laboratories, ministries, NGO’s and UN system) and pooling of data are therefore urgently needed. Pooling of clinical data would lead to a number of benefits:

- Larger patient numbers allowing for greater statistical power to detect small differences in outcomes
- Ability to examine smaller sub-populations of patients (i.e. children, pregnant women, PLWHA)
- Increased external validity of findings
- Diversity of protocols across sites allowing for comparison of management strategies
- Better historical baseline for evaluating and designing trials
- Significant interest from journal editors, local governments, and humanitarian actors.

But there are many challenges to implementing a system that addresses the ethical, political, methodological, technical, scientific and operational difficulties of pooling data. Some of the issues that need to be addressed are:

- Ethical/Political/Operational challenges:
  - Many actors and agendas to align
  - Neutral central repository of data with the technical expertise
  - Governance and data sharing/authorship agreements
  - Data confidentiality and ethical approval.

- Technical/Methodological/Scientific challenges:
  - Sampling
  - Single/multiple imputation techniques
  - Propensity matching.
A harmonized modular charting system, adaptable to local circumstances, has therefore been developed for the care of EVD survivors. The general format includes five types of forms and additional optional modules:

- RAPID charting – most critical medical and outcome data (simplified, limited information)
- CORE charting – more detailed presentation and outcome data
- MONITORING charting – laboratory & investigations
- Directed FOLLOW-UP charting
- Other modules developed to expand on critical parts of ocular, neurological, psychosocial, joint, sequelae and care.

To address the many hurdles of building a platform and to maximize the knowledge gained from the available data, WHO is collaborating to design a platform that delivers the curation and governance necessary to enable responsible sharing of data. This system is being designed as a service to the data holders. The aim is to develop a neutral space to support the Ministries of Health, ETUs, and Ebola survivor clinics that hold the data to maximize the scientific output, and to facilitate the meta-analysis of data across facilities/clinics and across countries. In order to enable data analysis across datasets, a system with controls and quality assurance at every level is required.

The collaborative platform under development is designed on models that have been successfully used in the past. The platform will have the capacity to anonymize, convert the format, clean the data, extract key variables, validate, standardize and store data. This will be a secure process ensuring no unauthorized access to data in any form. Data will remain under the control of the data owners at all times. Standardized reports and formats will be returned to the data providers for their own use and analysis. The standardization of datasets enables the pooling of data, which can be accessed for approved analyses across all data contributors. The outputs can result in publication, treatment guidelines and improved policy to address future outbreaks. A high level of technological expertise will be required to deliver this platform and established systems and software providing robust mapping of all modifications to the data will therefore be used. Secure storage by a neutral party able to manage the governance, administration and technical requirements of the platform is key. The platform will leverage the expertise, systems and resources available at the University of Oxford. The platform will incorporate data visualization methods to ensure that the largest possible audience is aware of the types of data available in order to stimulate a broad source of scientific ideas.

Discussion points:
- Should a collaborative, national (or 3-country) EVD survivor clinical database be considered?
- What are the pros and cons and tangible next steps?
- Governance, implementation, etc.
- How could clinical data already being collected help answer operational and clinical questions rapidly for the clinic, and for wider generalizability via pooling?
- Harmonized data forms and databases are also intended for use in future outbreaks
- Ownership of data and security issues are very important, especially for Ministries of Health
- The WHO Country Office in Sierra Leone is working with MoHS on harmonizing existing data sets and protection policies
- The process needs to be driven at the grass roots level.
Psychosocial and Community Impacts of EVD
(Tina Davies, Ministry of Social Welfare, Gender and Children’s Affairs, Government of Sierra Leone)

Most of the people affected by EVD (including survivors; bereaved people; children and youth who have been quarantined, unaccompanied, separated or orphaned; guardians who are caring for children as a result of EVD; and health workers) are experiencing great challenges in their social reintegration process. It is therefore very important to identify resources and strategies to foster wellbeing and bring about resilience at the family and community levels (Fig. 5).

Among the barriers to social integration of EVD-affected people are the lack of information regarding the whereabouts of people due to a lack of information during the early days of the epidemic, difficulties in identifying families and communities willing to accept orphans, and challenges around rebuilding trust between family and community members and in public health services. The challenges related to social and religious factors also need to be faced. The implementation of safe and dignified burials has proven to be essential in the control of this Ebola outbreak but an outcome has been significant distress among families and communities due to the way deceased EVD patients were treated (e.g. “thrown away in black body bags in an unknown place”).

Children have been affected in many ways by the EVD outbreak. Affects have included separated from or losing parents and other family members, the closure of schools, other non-treated illnesses (e.g. malaria, pneumonia, diarrhoea) and an increasing number of teenage pregnancies. Women have also been especially affected due to their traditional role as caregivers causing increased exposure to blood and body fluids. A higher incidence of EVD, loss of livelihood, and an increase in gender-based violence and non-Ebola related illnesses and deaths (e.g. an increase in maternal mortality) have all been reported in the female population.

EVD survivors, who have often lost multiple family members and friends, frequently experience loss of livelihoods too. They commonly present with EVD sequelae and psychological problems, including discouragement, depression, sleep deprivation, abnormal behaviour and post-traumatic stress syndrome. In recent months, as people try to find coping mechanisms, the intake of sleeping tablets, sedatives and non-prescription medication (e.g. paracetamol) as well as alcohol and nicotine have increased in Sierra Leone.

Psychosocial support through PFA livelihood support and skills training are urgently needed. Additional recommendations are:

- Community ownership in current and future response activities;
- Memorialization and collective remembrance and mourning ceremonies (e.g. community healing, closure “cleansing”, purification rituals, religious practices);
- Community-based group support, integrating psychosocial support and skills using existing structures, particularly women’s groups and other welfare committees, health promotion groups, protection networks, peer groups and school based clubs, play and recreation support (community playgrounds);
- Community based family-focused interventions concentrating on resilience;
- Participatory learning approaches (interpersonal skills, conflict resolution);
- Programmes to promote stress reduction, calming/relaxation techniques, and emotional regulation;
- Accompanied dialogue and the use of conflict resolution techniques around specific relationship difficulties.

Psychosocial skills need to be mainstreamed and integrated into other programmes, including for child protection, nutrition programming, livelihoods programming, women’s empowerment, public health training, nursing and medical training and social work training.
Discussion points:

- Has the government already started working on these issues? A needs assessment to prepare for the nine month recovery plan is under way, with implementation to be based on available funding
- Risk of misuse and overdosing of paracetamol (if used as coping mechanism)
- How to facilitate community ownership? Training and working with religious leaders, traditional healers, teachers, and advocacy groups
- Referral pathways are not clear.
Biosocial Perspectives on Accompanying EVD Survivors
(Paul Farmer, Harvard Medical School & PIH)

Within the populations of the three most affected countries discussions continue on claims of causality: Why did this outbreak spread here? Why not somewhere else? It is critically important to understand the relations between both the spread of the disease, the fraction of the people who survive the disease and the care of survivors. In addition, it is important to always keep the long list of potential pathogens causing fever in a patient living in a sub-Saharan country in mind (e.g. malaria, cholera, enteric fever, Lassa fever, dengue fever, measles, influenza, etc.). The lack of health infrastructure and the recent wars that have affected all three countries continue to affect the health situation, since the recovery processes from the war has failed to include investments into functioning and strong health systems.

While the economic growth rates of the countries following the wars have been among the highest worldwide, public expenditures in health systems have been far too small. In comparison, Rwanda, one of the poorest war-torn countries, and one which has received even less aid than West African countries once the influx of aid following the genocide subsided, has invested heavily in social protection, education and in building a health-care delivery system. Rwanda could be a good example, not only for the post-Ebola phase, but for other future epidemics as well. Medical conferences need to include in discussions factors like political economy, history, anthropology and culture.

How did the Ebola outbreak in West Africa spread so quickly? The epidemic travelled through communities, especially the medical community (nurses, doctors), due to a lack of adequate infection prevention and control. But this has to be understood in a wider context, including consideration of the broader political economy, poverty, inequality and basic human rights. Despite some prominent articles (e.g. in Newsweek), there is no evidence that people have become infected with Ebola virus during this outbreak by eating bushmeat. The spread of the virus is more reflected in the political economy and the absence of an effective health-care system. Unsafe burials are also attributed to the spread of EVD, despite the same burial rituals (e.g. respecting the death, washing the deceased, burying the body with dignity) being used in many cultures around the world. The absence of effective medical and mortuary services to help manage the care of the sick and burial of the dead do, however, appear to be two of the primary risk factors for the spread of the virus.

Many different forms of assistance are needed, including structural changes such as creating jobs and, especially, enhancing access to medical care. For many individuals with EVD, consultation with traditional healers was the only option at the beginning of the outbreak. It is important to avoid claims of causality by blaming culture, because the culture of EVD patients is much the same as that of their caregivers and other professionals.

PIH has recruited more than 700 EVD survivors as colleagues, supporters and patient advocates. Some EVD survivors have lost 20 or more family members and friends, figures usually only seen in disasters and genocides. They face many medical and psychological problems, like other diseases, malnutrition, malaria and distress. But they can be very helpful to others facing similar issues, as they understand the cultural context. Often the recovery of EVD survivors has been improved by involving them in meaningful work.

What never happens with emergency response?
- Health systems strengthening
- Training/capacity building
- Research
A best practice example from the recovery phase can be seen in Rwanda where the Rwandan government, the Clinton Foundation, and PIH have worked collaboratively on the Human Resources for Health Program, starting by training community health workers to reach the rural population and affected communities. Specialists, nurses, laboratory technicians and other health-care workers need to be trained in mid- and long-term approaches to strengthening health systems. Investments in higher education, district hospitals and clinics as training centres also need to be made to support the great number of talented young people in affected countries.

PIH currently employs more than 16 000 people worldwide. More than half of these are community health workers. PIH has built a 300-bed solar-powered public university hospital in Haiti in order to provide local capacity. Rebuilding health systems and investing in general infrastructure (roads, transport, hospitals etc.) is essential in the recovery period. The international aid community and national governments in the affected countries need to establish sustainable programmes (e.g. for IPC), teaching hospitals (including nursing training) and centres for EVD survivor care. Restoring basic structures and strengthening human resources for health are fundamental to a nation's full recovery from an epidemic.
Clinical Management Practices: Working Toward Comprehensive Care Guidelines for EVD Survivors in Sierra Leone
(Mauricio Calderon, Technical Work Group for Ongoing Comprehensive Care & Support for EVD Survivors, WCO, Sierra Leone)

The Technical Working Group (TWG) for Ongoing Comprehensive Care & Support for EVD Survivors has been active for the last four months and has been approved by the Steering Committee of EVD Survivors, co-led by the Sierra Leonean Ministry of Health and Sanitation and the Ministry of Social Welfare, Gender and Children’s Affairs, supported by the WHO country office in Freetown, Sierra Leone. The TWG meetings take place every Monday and all stakeholders in the care of EVD survivors are invited to join. The aim of the TWG is to develop and implement a Comprehensive Care & Support for EVD Survivors Guideline in cooperation with all organizations involved in caring for EVD survivors, especially the survivors themselves. The Guideline will respond in a comprehensive manner to the needs of EVD survivors with pertinent, opportune, sufficient, secure and sustainable services.

The TWG has identified nine key tasks in order to fulfil its mandate:

- **TG1 EVD Survivor Cohort**
- **TG2 Survivor Care Needs Assessment**
- **TG3 Harmonization of Clinical Data Collection Forms and Information Flows**
- **TG4 Service and Programme Costing and Financing**
- **TG5 Service Location/Distribution following equitable/effective access criteria**
- **TG6 Facility Network Improvement**
- **TG7 Referral Pathways & Case Management**
- **TG8 Three Country Meeting for Care Guideline Final**
- **TG9 Systematic Monitoring, Evaluation, Analysis & Report Process**

**TG1 EVD Survivor Cohort**
- Identification, location and classification of EVD survivors in Sierra Leone in order to identify catchment areas
- Reviewing and cross-checking all available data sets in the country

**TG2 Survivor Care Needs Assessment**
- Identification of the needs for the care and support of EVD survivors, including health and psychosocial care
- Integration of MHPSS Assessment
- This care should be prospective and preventive, rather than reactive
- EVD Survivor Discharge/Re-engagement package. This as an essential initial step to enable proactive care with a baseline overall assessment of the EVD survivors at discharge/re-engagement, including:
  - The systematic documentation in the discharge notes (that should accompany the survivor to the Survivor Clinic) outlining key events during the acute EVD episode (e.g. inflammatory eye disease, uveitis, focalized neurological deficits) that might represent indications of complications during convalescence
  - Detailed instruction to the survivor on “red flags” that should prompt immediate demand of care at the Survivor Clinic (e.g. acute eye symptoms, acute onset auditory loss)

The comprehensive assessment of EVD Survivors in Moyamba District (May 2015) provides a good example in this context. This district had 208 confirmed EVD cases, of whom only 85 survived. Responding to growing concerns related to post-EVD complications, a study was conducted to
assess the general situation of EVD survivors several weeks after their discharge, including their medical condition, psychosocial wellbeing, socioeconomic condition and their reintegration into the communities.

96% of all survivors interviewed showed post-EVD medical complications (e.g. joint problems, headache, neurologic and eye problems, etc.). These medical findings led to a number of recommendations:

- Severe cases identified must be referred urgently to clinics and specialized centres
- National/District health plans for all EVD survivors must be developed
- Information campaigns need to take place and space for discussion needs to be created
- Public Health Units should play a key role in medical and mental health treatment and monitoring.

Forty-seven per cent of all EVD survivors interviewed had lost multiple family members, 42% had also lost their livelihoods, and 15% suffered from psychological symptoms (discouragement, bad feelings, abnormal behaviour, unhappiness and trauma). The EVD outbreak had a significant impact on children surviving the disease in Moyamba District, with 50% having lost at least one family member, 23% affected by the long-lasting closure of schools and 10% reporting loss of the family livelihood. Stigmatization remains a great concern for most of the EVD survivors in the district, especially in the chiefdoms of Fakunya, Kaiyamba and Kori. These psychosocial findings led to a number of recommendations to establish/support:

- Psychosocial support programmes with a family and community approach
- Integrated and individualized programmes of livelihood and psychosocial support for EVD survivors and their families, including basic needs coverage (food and non-food items), vocational training, and further formal and non-formal education
- Mentoring programmes for EVD survivors and families
- Reinforce awareness raising campaigns in the chiefdoms with particular focus on stigma and rejection
- Capacity building for Public Health Units, schools, and community structures on mental health and psychosocial support is essential to address psychosocial residual issues related to EVD
- Individual and group therapy for the EVD affected
- Support any local initiatives such as survivors associations and networks
- Urgent livelihood integrated support for most vulnerable groups (income generating activities, non-food items and food distribution)
- Educational support and vocational training
- Livelihood assistance should take into account the health status of the survivors and medical referral should be prioritized or implemented in parallel with any livelihood activity.

Through this assessment the most vulnerable groups have been identified: orphans and children without appropriate family care, children (girls in particular) of low-income families without any educational support, widows without livelihood support, and widowers in charge of children and without livelihood support.

Additional recommendations derived from this assessment are:

- Replicate and cross-check similar assessments in all districts
- Coordinate the work of the international community using a holistic approach
- Map actors and their activities
- Build local and national capacity through long term programmes
- Ensure that programmes reach the most vulnerable groups and all EVD-affected families and communities, not only survivors.
TG3 Harmonization of Clinical Data Collection Forms and Information Flows
→ Bases for National EVD Archive Database (see earlier presentation: “Maximizing our knowledge from existing data” p.22)

TG4 Service and Programme Costing and Financing
→ Cost assessment and overall programme costing
→ Structured funding request to potential donors
(→ Ongoing exercise: current estimates around US$ 3.8 million + cost of social programmes → most of this is not covered yet)

TG5 Service location/distribution following equitable/effective access criteria
→ EVD Survivors Network Map, including current distribution of services, is currently being updated

TG6 Facility Network Improvement Plan
→ Improve EVD survivor support network, including infrastructure at facilities, equipment and supplies, human resources (hiring/training)

TG7 Referral Pathways & Case Management
→ Develop referral pathways to required specialized services: referral and counter-referral

TG8 Three Country Meeting for Care Guideline Final
→ Recent meeting: 3/4 August in Freetown, Sierra Leone

TG9 Systematic Monitoring, Evaluation, Analysis & Report Process
→ Design and implementation of a systematic monitoring and evaluation process

Comprehensive Care for EVD Survivors – Task Group Collaborative Platform:
https://sites.google.com/site/evdsurvivors/

Strategy for Stewardship and Development and Strengthening of Capacity

The Sierra Leonean Government strategy, with the key priority areas for the next six to nine months, includes free care and support for 4 000 Ebola survivors. The WHO Ebola Survivors Support Network (WHO ESSN) will be assisting governmental and nongovernmental partners in the coordination of plans for EVD survivors, both in terms of service provision (first priority) and scientific study (second priority), serving as a vehicle for donor support. Unfortunately a large funding gap remains.

To implement this strategy, a number of initial, enabling actions have been taken by the Sierra Leone Chief Medical Officer:

- All District Medical Officers have been requested to take responsibility for the stewardship and implementation of comprehensive care and support for EVD survivors, including the evaluation and reporting on the care provided. In addition, in cooperation with the implementing partners, the register should be updated quarterly with data on reported health and social care problems, including the outcomes of the services provided for each survivor in the district.

- Implementation of a **Survivor Health Advocate** (SHA), who will:
  - be the link between survivors in the community and the care and support providers
  - ideally be a Health Care Worker Survivor themselves, chosen following a three day training and examination period
- be responsible for organizing, identifying, and accompanying survivors to care facilities for screening
- support a patient with EVD sequelae and/or psychosocial problems to receive the necessary care and support, including referrals and follow-up home visits.

A timeline for an immediate action plan for the next weeks has been discussed, aiming at finalizing a first working draft on a Comprehensive Care and Support guideline for EVD survivors by early October 2015.

EVD crisis and impact does not end with medical treatment and zero Ebola cases; health, social, economic and psychological long-term assistance need to be planned to build resilience. There is still a long winding road to overcome EVD impact. EVD has shattered the survivors’ life projects. We have a duty to enable the reconstruction of sustainable life projects characterized by dignity and fair social opportunity.

Discussion points:

- What are the plans for EVD survivors, who need to be admitted to hospital?
- The national eye-care campaign inclusion of services for EVD survivors
- Funding of services and potential for Health Systems strengthening by the Global Fund
- Enabling access and providing free care for EVD survivors, especially for patients from rural areas, as services are mainly centralized.
Ebola Survivors’ Clinical Care: Special Considerations for Post-EVD Conditions Guidelines in Liberia
(Moses Soka, Ministry of Health and Social Welfare, Government of Liberia)

The Ministry of Health and Social Welfare in Liberia established a Survivors Clinical Network in February 2015, followed by the drafting of a special guideline for post-EVD conditions. The overall objective of this guideline was to provide primary and secondary frontline health-care workers with user-friendly guidance on how to manage post EVD-conditions. By including key stakeholders and external partners, the content was finalized and a guideline validation meeting was held on 1 August, 2015. During the validation meeting working groups reviewed assigned chapters. Following whole group discussions, it was decided to move the eye section into a separate document and to add more content into the paediatric section. The reviewed guideline draft will be shared with additional external partners, then finalized and published as soon as possible.

Guideline scope:

- Integrated care and summary of referral criteria
- Routine follow-up care
- Medical conditions (history, examination, intervention):
  - Musculoskeletal pain, including patient education for self-management
  - Abdominal pain
  - Headache
  - Sexual health including counselling dysfunction & urogenital complaints
  - Pregnancy
  - Pediatrics
  - Eye Diseases.
- EVD specific mental conditions:
  - PTSD, psychosis, substance misuse.

The need for integrated care and referrals was also highlighted during the validation meeting. Health services need to be managed and delivered to ensure that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services, through the different levels and sites of care within the health system, and according to their needs throughout the life course of the disease. A referral system is also required when specialist medical care is needed.

The participants of the validation meeting identified a number of gaps that need to be addressed. There is still a poor understanding of the clinical pattern of the post-EVD syndrome. The differentiation between EVD and non-EVD related symptoms during the recovery period of the survivors is difficult. As survivor care needs a crosscutting approach, it cannot be separated from the general medical (e.g. hypertension, HIV, hepatitis), surgical (e.g. treatment for hernias, lipomas, myomas) and psychosocial needs. In addition, the lack of specialist care and training as well as the problem of limited resources needs to be addressed.

Mental health and psychosocial problems play an important role in the care of EVD survivors. Previous studies have shown that somatic expression of depression has a high prevalence in African and non-western societies and has been shown to be the predominant expression of mental illness. Depression is a common feature of somatization and in the majority of cases the clinical presentation of depression is dominated by somatic symptoms such as headaches, constipation, weakness, or general aches and pains. However somatization is not limited to depression and other psychiatric disorders, and may not always represent pathology.
Similar symptoms have been observed in previous Ebola outbreaks. Many survivors in the Kikwit outbreak reported fear and denial as the first feelings. After release from hospitals, many experienced stigmatization, being abandoned by friends and family more often than expected. The most negative experience was witnessing suffering and the loss of one or more loved ones to EVD. During the current outbreak in Liberia, around one fifth of survivors seen at Redemption Hospital had moved from their original residence in attempt to avoid stigma. A high percentage of EVD survivors have presented with evidence of post-traumatic stress disorder, depression, reduced libido and impotence, fatigue, lack of energy, sleeping disorders and weight loss. Referral for psychosocial support and mental health counselling has led to an improvement in most of the patients.

Of 45 survivors seen in Redemption Survivors Clinic within the first three weeks of the operation, 65% reported stigma and significant psychosocial issues. Symptoms of fatigue, headache and body pains were more common in survivors with a history of losing one or more loved ones in the ETU and suffering from some form of stigma after discharge. Survivors with eye complaints were referred to eye clinics and all EVD survivors presenting to the Redemption Survivors Clinic continue to be followed-up to facilitate understanding of the clinical progression of their symptoms.

As part of the government’s EVD survivor initiative, primary care physicians have been requested to explore modifications in patient–clinician communication in order to fully understand the medical, psychosocial and mental health needs and to improve care outcomes.
Eye Problems in EVD Survivors in Sierra Leone
(Matthew Vandy, National Eye Health Programme Coordinator, Sierra Leone)

Eye complications have been observed in many EVD survivors in Sierra Leone. Currently there is not much data available, but observations indicate that these can occur in early or late stages of the disease and convalescence. Typical symptoms are conjunctival injection (48–58%), subconjunctival haemorrhage, pain, hyperlacrimation, loss of vision and uveitis. Anterior and posterior uveitis in EVD survivors have also been reported up to 42–72 days following an Ebola outbreak in the Democratic Republic of the Congo in 1995.

Eye health care situation in Sierra Leone:

- 2 ophthalmologists (Freetown – Connaught Hospital; Kissy Hospital; Port Loko – Baptist Eye Hospital Lunsar)
- 6 cataract surgeons (cataracts cause 35–40% of all blindness cases in the world)
- 46 ophthalmic nurses
- 1 optometrist
- 6 optometric technicians
- 6 optical technicians
- 3 eye hospitals (Kissy, Lunsar, Serabu)
- 3 eye departments within tertiary hospitals (Connaught, Bo and Kenema Government Hospitals)
- 6 eye units within district hospitals (Kabala, Moyamba, Bonthe, Pujehun, Kono, and Kailahun Government Hospitals).

Since November 2014, 926 EVD survivors have presented with eye problems in Sierra Leone (Lunsar, UMC, Kissy, Connaught, Bo, and Kenema). Of 130 EVD survivors attending Connaught hospital, 41% presented with a uveitis, 28% with conjunctivitis and 16% with a refractive error. In addition, cataracts (5.4%), corneal scars (2.3%) and ulcers (1.5%) were diagnosed. Almost 30% of patients presenting with uveitis turned blind (unilaterally or bilaterally). In Port Loko, 18.1% of 277 EVD survivors presented with uveitis (45.6% anterior, 26.5% posterior, 2.9% intermediate, and 25% pan-uveitis).

An association between the viral load in acute EVD and uveitis in convalescence has been observed. Patients with uveitis had lower CT values (median 22.4 versus 26.8, p<0.0001) at presentation with acute EVD and even after controlling for other variables, a decrease in CT value by 5 points was associated with increased risk of uveitis by 3.36 (95% CI: 1.88–6.01).

In the Port Loko cohort the time between the discharge from the ETU to the onset of eye symptoms was about three weeks on average (range: in ETU to four months after discharge) and the time between the onset of symptoms and the first consultation at an eye clinic was 2.6 months. Of the 94 uveitis cases diagnosed, 54.2% have improved following the consultation. Prednisolone (1%), Atropine (1%) and systemic steroids (depending on type of uveitis) are commonly used for the treatment of uveitis, with weekly or bi-weekly follow-up. For conjunctivitis, antibiotic eye drops were used (Chloramphenicol 0.5% or Ciprofloxacin 0.3%, either Q4hrs or 4x/day). In cases of refractive error, patients were refracted and spectacles prescribed.

To tackle the challenges related to ophthalmic complications in EVD survivors, a national screening and treatment programme will be developed in cooperation with partner organizations during a weekly meeting. A training programme for eye health personnel has been started in the Western Area and will be cascaded down into other regions soon. A comprehensive care package for EVD survivors is still required and the eye component needs to be rolled-out rapidly in order to prevent vision loss. This is being implemented through an interagency collaboration under the leadership of the National Eye Health Programme and will be supported by existing eye centres (Connaught, UMC, Lunsar, Kenema,
Bo) and by using mobile eye clinics. Survivor Health Advocates will be supporting outreach, medication adherence and follow-up activities. Until now 253 EVD survivors in the Western Area have been seen in the clinic, 44 of them have been treated for uveitis, including weekly home visits by a Survivor Health Advocate. In Tonkolili a mobile eye clinic, hosted by MSF Holland, has screened 22 EVD survivors and the Ministry of Health and Social Welfare and specialists from Emory University have provided ophthalmic care. In addition, an EVD Survivor Eye Care Symposium has been held with 78 ophthalmic clinicians/nurses from various districts.

A number of challenges remain, including limited mobility for monitoring and outreach services, lack of eye instruments and equipment, inadequate drugs and consumables, lack of funding and evidence-based treatment options. More information is also needed on the time until the Ebola virus is cleared from the fluid of the eyes (no evidence has been presented for Ebola virus transmission through tears), which is especially important to perform intraocular operations in EVD survivors (e.g. cataract surgery). A collaborative, coordinated, observational prospective study should therefore be conducted on the national level, led by the National Eye Health Programme, to learn more about eye complications in EVD survivors and to develop treatment protocols for these.
Eye Disease in EVD Survivors in West-Africa
(Steven Yeh, Emory University, USA)

Uveitis is an inflammation of the eye involving the uveal tract (iris, ciliary body, choroid) and surrounding tissues, which usually is differentiated into an anterior (iris, ciliary body), intermediate (vitreous) or posterior uveitis (retina, choroid) as well as a panuveitis (including all parts).

At Emory University in Atlanta, USA, a medically evacuated patient with EVD presented with an aggressive, sight-threatening panuveitis to which the presence of replicating Ebola virus inside the eye apparently contributed. This patient was treated with topical, oral and retroseptal steroids and an experimental antiviral, which led to disease resolution and improvement of vision. To learn more about the relation between EVD and its ocular sequelae, plus the experiences of the West African eye care providers and the possibility of translating their own experiences to assist in the management of eye sequelae in West African patients, the Emory team started collaborations with a number of partners in Sierra Leone and Liberia.

Current knowledge about EVD related eye uveitis is limited. Only one isolated case series has been published following an Ebola virus epidemic in the Democratic Republic of the Congo in 1995. Three survivors from a cohort of 20 and one survivor outside the cohort had been diagnosed with uveitis. These findings developed 42–72 days after the onset of Ebola virus disease and both anterior and posterior uveitis were identified. All of the symptoms resolved with topical corticosteroids and cycloplegics, although long-term follow-up was unavailable for these patients.

Through the Emory–SIM initiative, an eye clinic for the care of EVD survivors was established at ELWA hospital in Monrovia, Liberia, in April 2015. The objectives of the clinic are to provide screening and care for EVD survivors with ophthalmic symptoms, to exchange information with providers and the Ministry of Health and Social Welfare, and to consider strategies and challenges in regard to the required medications and equipment. By discussions with vendors and by receiving medications as donations, the costs for eye clinic supplies needed for the ELWA hospital could be reduced from an estimated US$ 93 000 to US$ 11 500. Multiple so-called clinical stations, (see Fig. 6) for care and technical instruction in ophthalmic examination, were set up and family practice doctors, ophthalmic technicians/nurses, and MOHS Liberia personnel were trained.
In Sierra Leone the Emory University team continued discussions with Dr Vandy and Dr Mattia (National Eye Health Programme) as well as other partners to assess the clinical needs for EVD survivors and to develop clinical forms and treatment protocols as well as flow charts. These are especially important since the treatment options are considerably dependent on the anatomic location of the uveitis. In addition, a mobile eye care unit for the Tonkolili District has been set up with PIH and MSF. By conducting a symposium on “Eye disease in EVD survivors”, a number of treatment protocols, flowcharts, materials and hand-outs could be discussed and finalized. WHO supported all of these activities in Sierra Leone.

Knowledge about the epidemiology and clinical features of eye disease associated with EVD is still limited. The at-risk period is thought to be at least 100 days. While the uveitis prevalence in EVD survivors is estimated to be between 10–20%, the incidence remains unknown. Therefore, screening and treatment should be initiated within the first 100 days after discharge from the ETU to reduce the risk of serious ophthalmic complications, including visual impairment and blindness.

Summary
1. A spectrum of ocular inflammatory findings (i.e. location of uveitis) ranging in severity is observed post-EVD.
2. Structural complications associated with visual morbidity are seen with natural history, although there is emerging evidence that steroid-based therapies improve outcomes.
3. Mobile eye clinic implementation for EVD screening is scalable – technical challenges require a considered yet urgent approach.

Open questions
1. What is the prevalence of Ebola virus persistence in EVD survivors with or without uveitis?
2. What is the time frame post-acute EVD in which patients will develop uveitis (i.e. how much time do we have to screen EVD survivors and treat before visual morbidity ensues)?
3. How do we scale up mobile eye clinics and free-standing eye clinics to address EVD screening in thousands of EVD survivors in the three countries?
4. Once identified, how do we improve treatments for active disease?
5. How do we treat structural complications that may require invasive procedures and prevent risk to individual patients, health care providers and the public?
Eye Disease in EVD Survivors in Liberia (PREVAIL III Study)
(Rachel Bishop, NIH & Allen Eghrari, Johns Hopkins University, USA-Recorded Video)

The objectives of the PREVAIL III eye sub study in Liberia are:

• Explore the causes of decreased vision and other ocular problems reported by EVD survivors
• Relate the timing of ocular complaints to disease course and other systemic problems
• Classify the ocular pathology present in EVD survivors and define the nature of associated ocular inflammation
• Facilitate treatment for EVD-associated vision loss
• Follow patients longitudinally for up to five years.

About 200 EVD survivors have been enrolled in the study so far (52% female, 48% male; median age 31 years; range: 11–70 years). In collaboration with local ophthalmologists, health-care workers are being trained in using ophthalmological equipment for diagnosis and treatment, including slit-lamps and ocular coherence tomography (OCT) devices.

Summary of findings among EVD survivors:

• Through microscopy, collections of inflammatory cells and debris on the back surface of the cornea have been identified and should be monitored over time for response to treatment
• In some patients the inflammation in the eye results in scaring from the iris to the lens surface (posterior synechiae)
• 3–4% of EVD survivors developed visually significant cataracts that will require surgery to improve vision
• By examining the vitreous with a microscope a high presence of inflammatory cells and signs of degeneration (syneresis) could be observed
• Up to 10% of EVD survivors were found to develop epiretinal membranes (abnormal layer of cells inducing folds in retina, distortion and loss of vision)
• Approximately 10% of patients show collections of fluids between the layers of the retina (post-inflammatory or through breakdown of adhesion between retina layers)
• Many patients have focal retinal lesions (seen on OCT)
• Neuro-cognitive changes:
  - Prevalence and features are poorly defined at this point
  - Disc swelling may serve as an indicator of central nervous system involvement
  - Many survivors experience difficulty with vision and visual tasks, which might be due to global cognitive changes
  - 6 of 7 eye patients examined by a neurologist had significant neurologic deficits

→ Plan for PREVAIL III Neurology Sub study.

Recommendations for managing EVD – related eye conditions:

• Consider value of treating the “red eye” (conjunctival injection), particularly if coupled with pain and/or sensitivity to light
• Basic slit lamp examination significantly aids in diagnosis of ocular inflammation and non-ophthalmic medical personal could be trained to operate this
• Topical and/or oral steroids are helpful in many cases
• Role for non-steroidal anti-inflammatory medication yet to be determined
• Greater risk of cataract and glaucoma
• Ideal taper regimen must be tailored to patient response. Follow-up is critical
• Safe cataract management needs to be explored given the persistence of the virus in the eye.
Comments:

- Many patients experienced blurred near vision during acute Ebola infection. This likely results from reduced accommodation, which resolves, and testing patients with reading glasses will help distinguish this from more concerning eye pathology.
- It was observed that most participants did not require glasses to optimize their vision for distance. However, a significant number of patients benefited from reading glasses and some also benefited from correction width glasses for distance. These will be made available through a partnership with a private donor.
- Patients frequently complained of itching, tearing and burning. In addition, to sun-induced damage, frequent dry eyes and incomplete blinking have also been noted in some patients. Forty-two per cent of EVD survivors included in this study were treated with artificial tears for ocular surface symptoms.

Features and limitations of this study:

- Some of the ocular pathology in the study has been subtle and would be difficult to capture on standard exam without imaging. OCT imaging may help reveal the pathophysiology of Ebola in the eye (acute and chronic).
- High prevalence of other infectious diseases in West Africa → Studying age-matched controls will allow identification of which changes are due to EVD vs. other causes (a study will begin in September 2015; all participants will be tested for HIV and syphilis).
- This study captures late findings, which can be combined with studies of more acute presentations to provide a full picture of pathology and response to treatment.
Mental Health and Psychosocial Support (MHPSS)
(Lieve Millisen, UNICEF, in cooperation with Ministry of Social Welfare, Gender and Children’s Affairs, Ministry of Health and Sanitation, Government of Sierra Leone)

The Ebola outbreak has led to major life changes and losses within the population of Sierra Leone. The psychosocial wellbeing of individuals and their families has been compromised in many serious ways. This distress interferes with behaviour, overall atmosphere, focus, recovery and return to normality.

The activities in this field are based on the Intervention pyramid of the Interagency Standing Community showing the multi-layered support, see Fig. 5.

What has been done so far?

Level One: Basic Needs and Advocacy:

- Food and non-food item distributions for EVD affected, quarantined homes, survivor’s kits, recreational kits, educational kits etc.
- Water and sanitation programmes
- Livelihood activities
- Ongoing advocacy by MHPSS work group: Importance of MHPSS capacity building activities, community access to services
- Formalization of survivor associations on national and district level
- Start-up mapping of MHPSS services, including major international players.

Level Two: Community-based support:

- Family tracing and reunification
- Activation of social networks such as community-run clubs or groups
- Participation in community and peer group activities
- Education, including life skills programmes and back-to-school packages
- Children’s play and early childhood development programmes, social and recreational activities
- Encouraging positive coping
- Supporting communities in carrying out traditional ceremonial reintegration and healing activities adapted to the context.

Level Three: Focused non-specialized support:

- Addressing identified and assessed psychosocial problems that require specific attention
- PFA for EVD-affected individuals who may experience distress reactions in centres, quarantined homes, and communities
- Case management support for following up, linking and supporting individuals and their families for problems both directly (survivors, orphans) and indirectly related to EVD (e.g. sexual and gender-based violence, increased teen pregnancy)
- PSS at Observational Interim Care Centres, ETU – by survivor caretakers
- PSS and stress management for responders (e.g. burial teams and health workers)
- Training in PFA and PSS at central, district and community levels for social welfare officers and implementing partners → Starting up coordinated PSS referrals and support on district level with multi-partners (including Ministry of Social Welfare, Gender, and Children’s Affairs [MSWGCA], MoHS, survivors, implementing partners in districts, community-based partners)
- Survivor conferences at district level
• Development and adaptation of MHPSS training manuals and tools (MSWGCA, MEST).

**Level Four: Specialized support:**

- Interventions with individuals showing signs and symptoms of complex or severe mental disorder and/or distress and/or functional impairment at District Mental Health Units, EVD centres and Survivor Clinics
- Mental health nurses deployed in referral hospitals in 14 districts of the country
- Mental health nurses trained intensively with follow-up training provided
- Community health officers trained in Mental Health Gap Action Programme interventions and assessments
- Mental health referrals formalized in referral document.

Initially the lack of recognition of these mental health and psychosocial care activities as an essential component of the EVD response created some challenges to be overcome. A strong push and support by the pillar leads at the responsible ministries and by other partners has led to the inclusion of MHPSS in EVD centres and results have been used to secure further support by donors. UNICEF and WHO have also been very supportive in this respect. Additional challenges to tackle are the weak systems and structures on the ground, weak referral systems, lack of monitoring and evaluation systems, and lack of human and financial resources in the involved ministries. This has partially been overcome by extensive training in PFA for different health-care and social workers, volunteers and community workers and by the deployment of mental health nurses to all districts as well as the establishment of District Mental Health Units.

**Key achievements so far have been:**

- Recognition of MHPSS as an essential component of EVD emergency response and recovery
- MHPSS minimum services packages document providing framework for interventions
- MHPSS Strategy 2015–2018 providing framework for sustainable, coordinated MHPSS services provided by multi-governmental and nongovernmental partners beyond Ebola emergency response and recovery
- Resources for EVD response have improved existing services
- Creation of Mental Health Coordination Unit and 14 functional District Mental Health Units
- Training of health professionals, social workers and community structures in PFA
- Creation of Observational Interim Care Centres in all districts
- Establishment of survivors associations at national and district levels
- Survivors Clinic and provision of PFA for survivors and affected communities
- Registration and verification of EVD-affected children, including orphans
- Improved coordination and collaboration on district level (District Ebola Response Centre (DERC), MHPSS work group, referrals).

**Way forward:**

- Including more survivors in planning and implementation of MHPSS initiatives
- Strengthening community structures and traditional activities before turning to more professionalized, focused approaches, including:
  - More community engagement
  - Community-based initiatives
  - Capacity building (short and longer term)
- More livelihood initiatives for EVD-affected individuals and families
- Formalizing of multisectoral partnerships
- Formalizing of clear referral pathways
- Improved, standardized, centralized reporting systems
- Sustainable funding with donors' support aligned with government strategies.
Nutritional Support for Ebola Survivors in Sierra Leone
(Solade Pyne-Bailey, Ministry of Health and Sanitation, Government of Sierra Leone)

During a visual nutritional assessment of EVD survivors, signs of anaemia, muscle wasting, physical weakness and micronutrient deficiencies have been observed in many cases. The provision of nutritious and well balanced diets to EVD survivors is therefore an essential component of their recovery. A Standard Operational Procedure on Nutritional Response Support for EVD affected and infected persons was developed in close collaboration with external technical partners. EVD survivors should receive an adequate amount of food sufficient for the whole family for one month. The survivor should additionally receive high fortified, blended food to be consumed for two weeks. Malnourished survivors should receive therapeutic supplies according to nutritional status. The World Food Programme (WFP) and UNICEF provide support for food packages in Sierra Leone. One household ration (five persons) for 30 days includes rice (50kg), pulses (9kg), vegetable cooking oil (4.5l), corn soy blend (9kg), salt (0.75kg) and BP100 (a ready-to-use therapeutic food). Infants and young children receive special packages. Following the receipt of food package for the first month, cash is provided by WFP for the 2nd and 3rd month (Le 265,000 each; SL costs for reference: bag of rice = Le 150,000; 4.5l Oil = Le 40,000).

EVD survivors have been depleted of nutrients and energy during the disease. Therefore, they require additional food, supplements and care, including nutritional education counselling to aid their recovery. Since Ebola virus has been found in the breast milk of survivors, mothers should discontinue breastfeeding. The safest replacement feeding for infants less than six months is “Ready to Use Infant Formula”. Further research needs to be done on the duration of the virus in breast milk, the relationship between the Vitamin A status and the eye defects seen in EVD survivors, and the growth pattern of children surviving EVD.

Requirements to improve the nutritional status of EVD survivors:
- Survivor household food packages should cover nutritional needs of all family members (not limited to five) since some affected households are far larger than five
- Diets should be complemented with items such as fresh fruits and vegetables since most households are not able to farm
- UHT milk should be added to the survivor’s packages for children 6–12 months old, in order to increase their mineral and vitamin status
- Livelihood support should be provided through training in agricultural skills and rearing of animals
- Nutritional status of all survivors should be monitored regularly and nutrition education promotion should be continued.

Discussion points:
- Attention to agriculture is very important. More support by government/donors is needed
- Many EVD survivors did not receive packages (just some financial support)
- SLAES needs to be included in the planning of nutritional activities
- SLAES representatives report not having received any nutritional support
- Coordination of delivery of packages and cash distribution needs to be improved
  → MoHS, WFP and other partners to work on improvements.
Managing Disability in Sierra Leone
(Handicap International)

Handicap International is aiming at the identification of people with specific needs, such as EVD survivors with disabilities, to support and refer them to adapted services and structures, as well as to follow-up on their development. This identification process is challenging and strongly relies on survivor self-identification. Social workers from the Ministry of Social Welfare, Gender and Children’s Affairs and NGOs are reaching out to community focal points, such as community-based rehabilitation volunteers, rehabilitation centres and EVD survivor associations, but it remains crucial that EVD survivors identify their own needs for rehabilitation services and that they are made aware of their rights and the availability of services in the country. It is also important to improve the coordination between all actors supporting EVD survivors in this area of work, including their transparency and communication, as well as community capacity building (e.g. resources and health-care workers) for early detection of disabilities.

The referral of persons with specific needs to specialized centres is especially challenging since the number of structures at the national level (e.g. rehabilitation centres, PPS, eye health clinics) is limited. Presently there are only four governmental rehabilitation centres offering physiotherapy and occupational health services and nationwide there are only four physiotherapists registered for a population of 6 million. In addition, health-care and social workers often have limited knowledge about the existing services. The distance to available services may lead to transportation and, in some instances, accommodation costs for the EVD survivor.

Recommendations:

- Capacity strengthening at existing rehabilitation centres
- Creation or strengthening of rehabilitation and specific needs curricula for health and social workers in collaboration with MoSH and MSWGCA
- Establishment of and communication on a services directory
- Transportation – creation or strengthening of ambulance networks at national level
- Assessment of current and future needs of EVD survivors
- Increasing accessibility to local services, avoiding stigmatization issues
- Strengthening of expertise in research and development activities, including follow-up of EVD survivors
- Strengthening of knowledge and capacity of public and private partners by establishing a multidisciplinary inclusion technical unit.
**Operational Research Opportunities: The WHO TDR SORT IT Programme**

(Andrew Ramsay, WHO/Special Programme for Research and Training in Tropical Diseases)

“Our country is data rich, but information poor” – Minister of Health, Fiji

Operational Research (OR) needs to be included in public health programmes to learn more about the appropriateness and effectiveness of the selected measures and to implement improvements. Research within the Structured Operational Research and Training Initiative (SORT IT) programme is usually based on routinely collected data. Operational research is evolving around three main questions:

1. What is happening within our public health programme?
2. Is it what we want?
3. Why is it happening like this?

The benefits of OR could improve many projects concerning the care of EVD survivors or health problems related to the care of survivors, such as programmes on HIV, tuberculosis, maternal and child health or nutrition. The results of this research could then support the strengthening of these elements within the national health plans. An example of a possible use for OR is the Men’s Health Clinic in Liberia. The clinic could use the EVD survivor registry as a basis to find out how many male survivors have accessed their services, had their semen tested for Ebola virus, or received advice on sexual health.

**SORT IT – Improving health systems through research**

SORT IT was started to support public health programmes to engage in simple research that could improve their performance and public health, to link professional researchers with these programmes (and their data) and to highlight the fact that OR results can be powerful advocacy tools. SORT IT aims to help countries to conduct OR in accordance with their own priorities, to develop adequate and sustainable OR capacity in their public health programmes and to create an organizational culture of policy and practice that is informed by OR and leads to improved programme performance.

The SORT IT programme has eight phases:

- **Phase 1**: Planning exercise with the MoH to identify the OR research needs and plan capacity-building
- **Phase 2**: Conducting of OR and training through a three workshop plan
- **Phase 3**: Dissemination of results to the people who need them and publication of the results
- **Phase 4**: Development of an evidence brief for policy presented to MoH
- **Phase 5**: Policy dialogue through WHO Regional and Country offices to ensure the recommendations for policy and practice are being considered
- **Phase 6**: Consolidation phase (including small research grants, additional training courses, data sharing networks)
- **Phase 7**: Leadership development (funding for a four year OR fellowship programme, publication of eight papers)
- **Phase 8**: Assessment of the complete programme and its impact.

Phase 2 is a model that was initially developed by the International Union against TB and MSF, who are key implementing partners in SORT IT. More than 330 people have entered the programme in more than 75 countries, particularly in Asia and sub-Saharan Africa. A number of global programmes,
such as the Global Malaria Elimination Programme, partner with TDR and SORT IT for their operational research and capacity building activities.

The purpose of SORT IT Phase 2 is also to teach the practical skills for conducting and publishing operational research using an approach to combine training with implementation, which includes the following factors:

- Product–oriented [a submitted research paper]
- Modular approach [three workshops over 10 months]
- Milestones which need to be achieved to stay in the training programme
- Targets which must be achieved to keep the brand.

The programme targets implementers (doctors, nurses, public health workers, epidemiologists, data analysts, and monitoring and evaluation officers). Approximately 12 participants take part in the three Phase 2 workshops. The participants are selected by national MoHs in order to scale up OR capacity. They must be competent in the language of instruction and be computer literate. Research undertaken is prioritized by national public health programmes/MoH and financed by the MoH or other sources. Since it is based on routinely collected data, the research is usually very inexpensive and carried out as part of the participant’s daily job.

Outline of SORT IT integrated operational research and capacity building in public health programmes

**Workshop 1: Protocol development (six days)**
- Define the research question
- Develop the protocol
- Consider and manage the ethical components of the research
- Outcome on Day 6 – written draft protocol.

**Workshop 2: Data management and analysis (six days)**
- Develop an electronic data entry capture tool using EpiData software
- Develop skills for data analysis
- Develop a plan of analysis including dummy tables
- Outcome on Day 6 – draft electronic data entry instrument

*Between Workshop 2 and Workshop 3 – complete the study, enter the data into an electronic software package and analyse the data*

**Workshop 3: Paper writing (six days)**
- Learn the principles of writing a scientific paper
- Learn how to do online submission to a peer-reviewed journal
- Learn how to deal with peer review, write point-by-point responses to editors and reviewers and revise the paper
- Outcome on Day 6 – written draft paper

*After Workshop 3, finalize draft paper and submit to peer-reviewed journal*

**Milestones for the course:**
1. Submission of protocol and Ethics Committee Review form within three weeks of completing Workshop 1
2. Submission of EpiData documentation sheet within two weeks of completing Workshop 2
3. Submission of proof of study completion and data collection about six weeks before Workshop 3
4. Submission of paper to peer-reviewed journal within four weeks of end of Workshop 3

Previous and ongoing Phase 2 SORT IT programmes have shown that the model is successful. A recent evaluation reported that 90% of the 236 participants starting the course finished with all milestones completed, 247 papers have been submitted to peer-review journals, and 84% of these have been published or are currently in press. The emphasis on papers has been chosen to include a quality control standard, to use a critical way to disseminate knowledge and to inform policy makers using evidenced-based papers. Another analysis showed that 74% of SORT IT participants reported that their research had changed policy and/or practice in their public health programme or health facility, 50% went on to publish further papers after their SORT IT training and 43% went on to train others in OR courses.

TDR hopes to fund SORT IT Phase 1 meetings in Sierra Leone, Liberia, and Guinea in Q4 2015/Q1 2016. TDR is seeking further funds for Phases 2 and 3 in each country.
Next Steps
(Daniel Bausch, Epidemic Clinical Management Team, WHO)

- A meeting report with key points will be distributed to all stakeholders and posted on the WHO website;
- A draft Comprehensive Care Plan for EVD Survivors will be produced as a result of the meeting, with follow-up communications between stakeholders for revision as needed to produce a final document;
- A short summary of all research projects focusing on EVD survivor-related questions will be published on the WHO website.
### Annex 1 – Agenda

WHO Meeting on Survivors of Ebola Virus Disease:

Freetown, 3–4 August 2015

**Day 1 (Aug. 3)**

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker/s</th>
<th>Moderator/s</th>
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<tbody>
<tr>
<td>8:30-9:00</td>
<td>Registration</td>
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<tr>
<td>9:00-9:30</td>
<td>Welcome</td>
<td>Deputy Ministers of SL MOHS and MOSWGCA; Anders Nordstrom, WHO SL; Bruce Aylward, WHO HQ</td>
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<tr>
<td>9:30-10:00</td>
<td>Objective of meeting and expected outcomes; Review of literature on health and psycho-social problems of EVD survivors</td>
<td>Daniel Bausch, WHO HQ</td>
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<tr>
<td>10:00-10:30</td>
<td>The survivors’ sounding board</td>
<td>Sierra Leone Association of Ebola Survivors</td>
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<td>10:30-11:00</td>
<td>Coffee break</td>
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<td>11:00-11:30</td>
<td>Mapping of survivor care providers and cohorts</td>
<td>SL MOH/MOSWGCA; UNICEF</td>
<td>Faïqa Radovnikovic, WHO SL</td>
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<td>11:30-12:15</td>
<td>Virus persistence and risk of sexual transmission</td>
<td>Gibrilla Fadlu Deen, Connaught/COMAHS; Jomah Kollie, WHO Liberia</td>
<td>Nathalie Broutet, WHO HQ</td>
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<tr>
<td>12:15-12:45</td>
<td>EVD in pregnant survivors</td>
<td>Lisa Thomas, WHO</td>
<td>Dina Pfeifer, WHO HQ</td>
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<td>12:45-14:00</td>
<td>Lunch</td>
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<td>14:00-16:30</td>
<td>Clinical experiences and data from EVD survivor cohorts (short presentations followed by discussion):</td>
<td>Brima Kargbo, SL MOHS; April Baller, WHO HQ; Pauline Vetter, MSF-Switzerland</td>
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<td>- Guinea: TBD</td>
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<td>- Liberia: Mosoka Fallah, Liberia MOHSW; John Fankhauser, ELWA</td>
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<td>- Sierra Leone: Foday Sesay SL MOD; Joyce Chang, Partners in Health</td>
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<td>16:30-17:30</td>
<td>Day 1 Wrap Up: Knowledge gaps regarding clinical care for EVD survivors</td>
<td>Alie Wurie, SL MOHS</td>
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<td>17:30</td>
<td>Day 1 adjournment</td>
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# Day 2 (Aug. 4)

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<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker/s</th>
<th>Moderator</th>
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<tbody>
<tr>
<td>8:30-</td>
<td>Maximizing our knowledge from existing data: Core data elements, data</td>
<td>Sharmistha Mishra, U. of Toronto</td>
<td>Erin Shedd, IMC</td>
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<td>9:00</td>
<td>banking and analysis</td>
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<td>9:00-</td>
<td>Psychosocial and community impacts of EVD</td>
<td>Tina Davies, SL MSWGCA</td>
<td>Sarian Kamara, SL MOHS</td>
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<td>9:45</td>
<td>Anthropological perspectives in accompanying EVD survivors</td>
<td>Paul Farmer, Partners in Health</td>
<td>Patrick Faley, National Ebola Survivors Network of Liberia</td>
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<td>10:15</td>
<td><strong>Coffee break</strong></td>
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<tr>
<td>10:45</td>
<td>Clinical management practices: Working toward comprehensive care</td>
<td>Mauricio Calderon, WHO SL</td>
<td>James Russel, Connaught/COMAHS</td>
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<td>11:15-</td>
<td>guidelines for EVD survivors</td>
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<td>11:15</td>
<td>General medical problems: Arthralgia, headache, fatigue, etc.</td>
<td>Soka Moses, Liberia MOHSW</td>
<td>Janet Scott, Liverpool</td>
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<tr>
<td>11:45</td>
<td>Central nervous system and auditory problems</td>
<td>Ian Crozier, Uganda</td>
<td>Marta Lado, Connaught Hosp.</td>
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<td>12:15</td>
<td><strong>Lunch</strong></td>
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<td>13:15</td>
<td>Eye problems</td>
<td>Matthew Vandy, SL MoHS; Steven Yeh, Emory U.; Libby Higgs, USA NIH</td>
<td>John Mattia, UMC Eye Hosp.</td>
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<tr>
<td>13:45</td>
<td>Mental health and psychosocial support</td>
<td>Tina Davies, SL MOSWGCA; UNICEF</td>
<td>Nisar Ul-Khak, IOM Liberia</td>
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<tr>
<td>14:15</td>
<td>Nutrition</td>
<td>Sholadae Pyne-Bailey, SL MOHS</td>
<td>Mohamed Vandi, SL MOHS</td>
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<tr>
<td>14:45</td>
<td><strong>Coffee break</strong></td>
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<tr>
<td>15:15-</td>
<td>Managing disabilities</td>
<td>Handicap International</td>
<td>Jodi-Anne Mills, WHO HQ</td>
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<tr>
<td>15:45-</td>
<td>Operational Research Opportunities: The WHO TDR SORT IT Programme</td>
<td>Andrew Ramsay, WHO TDR</td>
<td>Daniel Bausch, WHO HQ</td>
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<td>15:45-</td>
<td>Concluding remarks and next steps</td>
<td>Daniel Bausch, WHO HQ</td>
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<td>17:00</td>
<td><strong>Day 2 adjournment, followed by group picture and cocktail reception</strong></td>
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Annex 2 – Summary of Literature on Sequelae Post-EVD
(As of August 3, 2015)

4) Bausch DG. Sequelae after Ebola virus disease: even when it's over it's not over. Lancet Infect Dis. 2015:S1473-3099(15)70165-9
Annex 3 – List of Participants

CANADA
Dr Sharmistha Mishra
University of Toronto

GUINEA
Dr Ansoumane Camara
Dr Lansana Diaby
Dr Mandjou Diakite
Dr Mamadou Oury Safiatou Diallo
Survivor Clinic
Dr Alpha Amadou Sank Diallo

LIBERIA
Dr April Baller
WHO
Mr Philip Bemah
National Ebola Incident Management System
Patrick Faley
Liberia Ebola Survivors Network
Dr Mosoka Fallah
Dr John Fankhauser
SIM/ELWA Hospital
Rev. Meekie Glayweon
Liberia Ebola Survivors Network
Jomah Kollie
WCO Liberia
Dr Soka Moses
Ministry of Health and Social Welfare
Dr Nisar Ul-Khak
IOM Mobile Clinic

SIERRA LEONE
Jay Achar
MSF Rep 3
Dr Mohamed Ali
MSF Belgium
Dr James Bangura
Sherry Bangura
PIH

Dr Sarah D Bennett
CDC
Nell Bond
Ebola Survivor Corps
Joyce Chang
PIH
Dr Roland Conteh
Dr Tina Davies
MoH
Dr Gibrilla Fadlu Deen
Fanny Del
Handicap International
Dr Kerry Dierberg
PIH
Phil Doyle
West African Medical Missions
Deanne Evand
Save the Children
Tamsin Evans
Enabling Access
Sr Frances Fornah
Carmenza Galves
MSF Belgium
Dr Peter George
Dr Sahr Gevao
Gary Gottlieb
PIH
Dr Libby Higgs
NIH
Lt Dr Mohamed Boie Jalloh
Dr Kabineh
Ent Connaught Hospital
Dr Sarian Kamara
MoH
Abdul Kamara
<table>
<thead>
<tr>
<th>Name</th>
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<td>West African Medical Missions</td>
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<tr>
<td>Dr Rashida Kamara</td>
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<td>Dr Abdul Kamara</td>
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<td>Dr Joseph Kandehe</td>
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<td>Dr Brima Kargbo</td>
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<td>SL MOHS</td>
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<td>Dr David Kargbo</td>
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<td>Dr Alimany Koroma</td>
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<td>Joshi Kshitij</td>
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<td>Dr Marta Lado</td>
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<td>Dr Victor Matt Lebby</td>
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<td>Dr Nathalie MacDermott</td>
<td>Imperial College</td>
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<td>Silvia Madejon</td>
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<td>Medicos del Mundo</td>
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<td>Capt Dr Massaquoi</td>
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<td>Tommy Mbalu</td>
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<td>Dr Andrew Muana</td>
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<td>Kissy Mental Hospital</td>
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<td>Dr James RW Russel</td>
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<td>Prof Foday Sahr</td>
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<td>Sallieu Sesay</td>
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<td>District Medical Officer</td>
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<td>Capt Dr Foday Sesay</td>
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<td>Simeon Sessay</td>
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<td>West African Medical Missions</td>
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<td>Erin Shedd</td>
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<td>International Medical Corps</td>
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<td>Dr Joan Shephard</td>
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<td>Dr James Squire</td>
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<td>Amanda Tiffany</td>
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<td>MSF Rep 2</td>
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<td>Patrick Trye</td>
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<td>Dr Mohamed Vandi</td>
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<td>Dr Matthew Vandy</td>
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<td>Dr Pauline Vetter</td>
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<td>MSF Rep 1</td>
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<td>Gabriel Warren</td>
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<td>Yaron Wolman</td>
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<td>Dr Alie Wurie</td>
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<td>MoH</td>
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Hossinatu Mary Kanu
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David Joffrey Koroma
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Mbalu Tomory
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USAID/OFDA

Margo Nowakowski
USAID

Angela Sherbenou
USAID Office of Foreign Disaster Assistance

Suzanna McDonnalnd
WHO

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Liverpool School of TM

UNITED STATES OF AMERICA
Tomas Cihlar
Gilead

Dr Ian Crozier
Uganda

Dr Paul Farmer
Partners in Health
Partners in Health

Dr Anders Nordström
WCO Sierra Leone

Dr Tim O’Dempsey
WCO SL

Dr Dina Pfeifer
WHO HQ-Clinical Group

Dr Faiqa Radovnikovic
WHO HQ-Clinical Group

Dr Andrew Ramsay
WHO/TDR

Dr Mercedes Tatay
WHO SL

Dr Lisa Thomas

Sandra Laney
Paul Allen Foundation

Nicki Weston
Paul Allen Foundation

Dr Steven Yeh
Emory University

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WHO HQ-Clinical Group

Dr Mathias Bonk
WHO HQ-Clinical Group

Dr Nathalie Broutet
WHO HQ

Dr Mauricio Calderon
WHO HQ-FMT

Dr Kyobe Henry
WCO SL

Dr James Kiarie

Pierre Formenty
WHO HQ

Jody-Anne Mills
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Dr Maggie Nanyonga
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