

# ADVANCING PARTNERS & COMMUNITIES

Post-Ebola Health Challenges in West Africa  
Technical Report on the September 7-9, 2017  
West African Sub-Regional Conference  
Conakry, Guinea

November 2017



## **Advancing Partners & Communities**

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

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Photo Credit: Alan Giron

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# ACRONYMS

APC	Advancing Partners & Communities Project
ANSS	Guinea National Health Security Agency ( <i>Agence nationale de sécurité sanitaire</i> )
CNLE	Guinea National Coordination to Fight against Ebola ( <i>Coordination nationale de la lutte contre Ebola</i> )
CPES	Sierra Leone Comprehensive Program for Ebola Survivors
ETP&SS	Ebola Transmission Prevention & Survivor Services
ETU	Ebola Treatment Unit
EVD	Ebola Virus Disease
EVDS	Ebola Virus Disease Survivor
GHET	Global Health Ebola Team (USAID)
GHSA	Global Health Security Agenda
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
JSI	John Snow, Inc., and John Snow Research & Training Institute, Inc.
ICU/DCU	Intensive care unit / high density unit
IgG	Immunoglobulin G antibody
INSERM	French National Institutes of Health ( <i>Institut nationale de la santé et de la recherche médicale</i> )
MOH	Ministry of Health
NESL	National Ebola Survivor Network of Liberia
NGO	Non-governmental organization
NIH	U.S. National Institutes of Health
PIU	Sierra Leone Program Implementation Unit
RENASEG	Guinea National Ebola Survivor Network ( <i>Réseau national des survivants d'Ebola en Guinée</i> )

RNA	Ribonucleic Acid
SA-Ceint	Guinea Active Ring Surveillance ( <i>Surveillance Active en Ceinture</i> )
SLAES	Sierra Leone Association of Ebola Survivors
TB	Tuberculosis
USAID	U.S. Agency for International Development
USG	United States Government
WAC	West African Clinical Research Consortium
WHO	World Health Organization



# EXECUTIVE SUMMARY

JSI's Advancing Partners and Communities (APC) project supported the coordination, logistics, and facilitation of the West African Clinical Research Consortium's third annual conference in Conakry, Guinea from September 7 to 9, 2017. The conference, which was jointly funded with the National Institutes of Health, brought together leading public health researchers, clinicians, practitioners, and other experts in West Africa to discuss the latest health challenges facing the region since the 2014-2016 Ebola outbreak. APC's support to the conference focused on Ebola survivor issues; in particular, how to improve clinical care, address stigma, and support policy related to survivors.

Over 150 people attended the three day conference, which was structured into three morning plenary sessions and approximately 40 afternoon presentations, of which about 13 addressed survivor issues.

Key findings included:

- The evidence base around survivor needs is being rapidly populated with new and recently published information on public health and specialty care (e.g. mental health, neurology, eye care) topics;
- All three affected countries face the challenge of attending to urgent care needs while addressing the uncertain public health risks of survivors; and
- Ebola survivor needs are ongoing and in multiple domains.

Despite containment of the outbreak, there is a clear need for ongoing support, testing, and treatment of survivors' health complications at the country level.

## BACKGROUND

For Ebola survivors, the ongoing persistence of the Ebola virus continues to be of notable concern due to the various health problems that they are facing. The management of health problems due to viral persistence is an important policy and programmatic issue for Ministries of Health and others. The West African Clinical Research Consortium (WAC), composed of leading public health researchers, clinicians, and topic experts from Guinea, Liberia, Mali, and Sierra Leone, organized its third annual conference with the theme *Post-Ebola Health Challenges in West Africa*. The conference took place from September 7-9, 2017 in Conakry, Guinea, with the financial and logistical support of two primary donors:

- USAID, through JSI's Advancing Partners & Communities (APC) Project, for costs related to the venue and food provided during the three-day workshop, as well as funding of travel for Ebola survivor program participants and JSI/APC staff from the three affected countries;
- U.S. National Institutes of Health, for costs of simultaneous translation, travel of its staff and selected participants not sponsored by their own institutions, printing, materials, and other costs.

APC's Ebola Transmission Prevention & Survivor Services program (ETP&SS), through the financial support of the Global Health Bureau of USAID, funded participants who have a role in Ebola survivor

programs and/or research in Guinea, Liberia and Sierra Leone (25 participants), while the majority of participants (approximately 150 in total) were funded by NIH or their own organizations. (See Appendix I for full list of participants.)

Participants supported by APC/ETP&SS funds included:

- MOH/government representatives directly involved in their respective survivor programs,
- University and NGO representatives who participate in survivor related programs,
- National survivor association leaders, and
- APC/ETP&SS clinical/technical staff.

All were from Liberia, Sierra Leone, Guinea (local costs only), or the US.

### **The ETP&SS Regional Program:**

In terms of the overall ETP&SS regional program, the workplan includes several major regional meetings, with additional support to smaller, topic or group specific events. The support for this meeting is an example of one of the major regional meetings.

Past meetings supported by the ETP&SS include:

- December 2016 Technical and Planning Meeting for Regional Coordination in Monrovia, Liberia;
- March 2017 Ebola Survivor Network Meeting on Advocacy, Resource Mobilization, and Communication in Conakry, Guinea;
- June 2017 WHO Meeting on Persistence of Ebola Virus RNA in Semen and Public Health Implications in Monrovia, Liberia.

The outcomes of the conference as described in this report will to be used to inform the continued evolution and implementation of survivor care programs in ETP&SS and other countries as well as for the growth and development of the Consortium. As the focus of ETP&SS program is on Ebola survivors, this report will also focus on survivor services and related themes, rather than all of the technical content that was presented during the conference.

## **CONFERENCE THEMES**

As noted in the Agenda in Appendix I, the meeting had four major themes, as follows:

1. Improving Clinical Care, Addressing Stigma and Policy-Related Issues of Survivors
2. Advancing Vaccines, Therapeutics and Diagnostics for Emerging Infectious Diseases
3. Strengthening Research Collaboration, Capacity Building and Community Empowerment
4. Strengthening Collaboration on “One Health” Strategy on the Global Health Security Agenda (GHSA) in the Sub-Region

For APC/ETP&SS, the primary technical and programmatic theme was #1, Improving Clinical Care, Addressing Stigma and Policy-Related Issues of Survivors. Accordingly, the majority of notes from the survivor abstract sessions (see Part V, Results) fall into this category. On the meeting agenda (Appendix I), they are listed in the first column, mainly taking place in Room A.

## CONFERENCE GOALS

The overall conference also had three primary goals, as follows:

1. To advance regional preparedness for global health security and compliance with International Health Regulations.
2. To leverage comparative advantages and share regional research, best practices, and evidence to inform infectious disease policy.
3. To discuss ongoing research and advance new studies and policies in the region.

Each of these conference goals were supported by APC/ETP&SS, with a particular emphasis on **Goal 2**.

## RESULTS: NOTES FROM SURVIVOR RELATED PLENARY AND ABSTRACT SESSIONS

### September 7, 2017: Day One

1. **Plenary session:** *“Using evidence to update the survivor clinical care guidelines (notes from a steep learning curve)”* (Ian Crozier, JSI Consultant, United States)
  - a. **Context:** what did we know then? Comparison of the recent West African outbreak to the original 1976 Yambuku, Zaire outbreak (the first time Ebola survivors were identified) provided historical context and illustrated how little we learned in the decades prior to this outbreak about EVD survival, highlighted by the fact that only one controlled study had been published prior to 2014.
  - b. A case study of an EVD survivor with joint pain was used to highlight and make practical the need for the right care to be informed by the right evidence to the audience; it was revisited at the end of the session to do the same
  - c. The emergency within the emergency: early in this outbreak (highlighted by reports out of Kenema and case reports in med-evacuated survivors) it became clear that health systems needed to attend to unanticipated EVD survivor needs, many of them in areas

not previously well-characterized. WHO survivor care guidelines were developed (oriented around key areas), adapted in each country, disseminated, and HCW training undertaken. Decision-making around *which care to which survivors in which facilities* was difficult, especially given how rapidly the evidence base was changing and the fact that health systems were not equipped to deal with some needs.

- d. **What do we know now?**
  - i. The evolution of the evidence base was summarized, starting from symptom surveys to case reports to small clinical cohorts and looking forward to larger studies (the Post-Ebogui study in Guinea) and ongoing studies with results still pending (PREVAIL III).
  - ii. An overview of the implications of viral persistence in immune-privileged sites emphasized the *individual clinical* consequences (highlighting case reports of uveitis and meningoencephalitis associated with viral persistence in med-evacuated EVD survivors) and the *public health* consequences (highlighting semen persistence and the risk of sexual transmission, though this was not covered in more detail in this session).
  - iii. West African cohort studies summarizing emerging understanding of uveitis and neurologic syndromes were summarized briefly.
  - iv. The audience was updated on current status of efforts to determine whether the virus persists in the eyes of West African EVD survivors with cataract after uveitis (the EVICT study in SL, the upcoming PREVAIL VII effort in Liberia) or in the cerebrospinal fluid of survivors with neurologic syndromes (PREVAIL III, Neurology sub-study).
  - v. The recent findings of the Post-Ebogui study were discussed in some detail, highlighting the overall findings, the biochemical results, and the first look at some of the neuropsychiatric clinical disease in EVD survivors.
- e. **A key challenge:** attending to urgent patient care needs while also thinking about uncertain public health risks in EVD survivors was emphasized (highlighted by the example of cataract care) and the need for both individual care needs and public health risk management to be informed by high quality AFRICAN research. An example provided of the clinical uncertainty was the prevalence of renal disease in EVD survivors and some early data from the PREVAIL study that, when combined with similar information from Post-Ebogui, move significantly toward answering that very clinical question. Another challenge is how to address EVD survivor-specific care needs as survivor care is folded into broader integrated care models.
- f. **What do we need to know:** a number of key unanswered questions about EVD survivors were highlighted, particularly the questions remaining around:
  - i. EVD IgG AB positive survivors who never had or do not recall clinical disease and the clinical, public health, and policy implications.
  - ii. Unanswered questions around the maximum duration and implications of semen viral persistence
  - iii. Further understanding the neuropsychiatric needs of EVD survivors, especially in children
- g. **Recommendations:**
  - i. Continued support for ongoing research studies attempting to carefully define survivor needs, ensuring that emerging research data nimbly informs and is made available to clinical providers on the ground
  - ii. Continued support at country levels for HCW training, facility capacitation, and provision of EVD survivor-specific care needs even as EVD survivor care is integrated into broader health systems.

- iii. Ongoing updates to survivor care and testing guidelines are needed, particularly around semen EVD RNA persistence, eye care
- 2. **Abstract session:** “*An observational study of pregnant Liberian EVD survivors and their children*” (Dr. Sia Wata Camanor, PREVAIL, Liberia)
  - a. **Background:** little is known about pregnancy outcomes, peri-partum viral persistence, or long-term humoral immunity in EVD survivors and their children.
  - b. This prospective observational study of pregnant EVD survivors and their children has the following **objectives:**
    - i. To ascertain the presence of Ebola virus in relevant body fluids and tissues of pregnant Ebola survivors during and after delivery and
    - ii. Measure IgG antibody levels in their children.
  - c. **Methods:** from December 24, 2015 to January 10, 2017, the following samples were tested by PCR for Ebola virus RNA: cord blood, placenta tissues, vaginal swabs, maternal blood, and breast milk. Maternal and infant serums were tested for Ebola specific IgG antibody levels. A total of 74 pregnant women and 77 children were enrolled.
  - d. **Results:**
    - i. Thirty-nine cord blood, 39 maternal blood, 39 placenta swabs, 38 placenta tissue samples, 331 breast milk samples and 339 vaginal swabs were collected → all samples tested negative for Ebola virus RNA.
    - ii. All neonatal cord blood samples contained Ebola specific IgG at levels similar to those observed in maternal samples. In 19 infants with follow-up serology samples, levels of Ebola specific IgG declined in a manner consistent with transplacental transfer of maternal IgG
  - e. **Conclusion and recommendation:** In infants with 6-month follow-up samples, Ebola specific IgG levels declined consistent with transplacental transfer of maternal antibody. There was no evidence for the persistence of viral RNA in breast milk or secretions. These results should inform policy on reproductive health and breastfeeding practices in female EVD survivors.
- 3. **Abstract session:** “*Sex practices and awareness of EVD in Male survivors and their partners in Guinea: a cross-sectional study*” (Professor Mandy Kader Kondé, CEFORPAG, Guinea)
  - a. **Background:** The sexual behavior of EVD survivors has not been well characterized, especially given the risk of sexual transmission and re-ignition of outbreaks
  - b. **Objectives:** To assess the number of Ebola survivors who have unprotected sex and to understand the differences between those who are aware of the risk posed by unprotected and unconscious sex
  - c. **Methodology:**
    - i. Definitions of “survivor” “partner” and “control” were discussed
    - ii. After a completed informed consent form, a questionnaire was administered to all participants
    - iii. A blood and sperm sample was taken care of EVD survivors (HIV, Syphilis, EVD)
    - iv. In-depth interviews were used to explore barriers to communication between partners and condom use.
    - v. Finally, a sexual health promotion intervention was provided to all participants in the study
  - d. **Results:**

- i. 234 Male EVD and 256 Sexual Partners and 65 Controls tested → 3 (+) HIV, 3 (+) syphilis
    - ii. Generally, rates of safe sexual behavior (safe, abstinence, condom use) and awareness of risk were higher in EVD survivors than their partners and controls: EVD survivors were 5x more likely to engage in safe sex and be aware of the risk than the control group.
    - iii. However, there was still a very low prevalence of safe sex practices among survivors and their partners, with only 22% of survivors regularly using condoms, compared to 14% of the control group.
    - iv. Over half of the partners of EVD survivors were unaware of the risk of Ebola associated with unprotected sex.
  - e. **Conclusions and recommendations:**
    - i. EVD survivors had higher rates of safe sexual behavior and risk awareness compared to controls.
    - ii. Safe sex was still relatively uncommon among all groups.
    - iii. Research in these areas can significantly inform current and future prevention efforts, but should use enrollment of partners of survivors (as in this study).
    - iv. Sexual behavior change is an important pathway to prevent sexual transmission of EVD.
4. **Abstract session:** Evidence Based Guidelines for Supportive Care of Patients with EVD (Dr. Ama Edwin, Korle Bu Teaching Hospital, Ghana)
- a. Background: there is renewed interest in evidence-based guidelines around the provision of supportive care to patients with EVD
  - b. Scope and focus: delivery of supportive care measures to patients in Ebola treatment units where health care resources are limited, i.e. a typical context, but also could be relevant to other infectious diseases with clinical syndromes similar to Ebola that are managed in isolation facilities (e.g. other village health facilities).
  - c. Methodology:
    - i. Literature search (Medline, Medline In-Process, Embase, Cochrane Database of Systematic Reviews, Cochrane Central, African Index Medicus, PubMed (supplemental for non-Medline records) for papers published between the first available date in each database and February, 2016). Also did a systematic scoping review of interventions for shock and shock-like syndromes in resource-limited settings, included an extensive list of illnesses that share characteristics with EVD (shock, cholera, sepsis, and other severe diarrheal illnesses) and did not limit the search to specific interventions.
    - ii. Group makeup: 34 participants: 10 critical care physicians (two specialists in pediatric care), one critical care nurse, two emergency medicine physicians, two general practice physicians, five infectious diseases physicians, one lawyer, one psychologist and bioethicist, four public health experts, three health research methodologists, one qualitative researcher, one survivor of Ebola virus disease, and three WHO staff observers
    - iii. Timing: the panel met for two days in London, UK, in August, 2016, and voted on six recommendations. The panel finalized two additional recommendations during two follow-up teleconferences in October 2016.
    - iv. Voting: The panel voted on the direction and the strength (strong or conditional) of each recommendation. Voting on recommendations was by secret ballot. For a *strong* recommendation, 80% of votes in favor were required. A smaller proportion in favor of a strong recommendation resulted in

a *conditional* recommendation. In making recommendations, the panel considered the magnitude of benefits and harms, the quality of supporting evidence, and underlying values and preferences.

- d. Results: See table below summarizing the specific recommendations detailed in the presentation (from the cited paper, exactly reproduced in slides shared at workshop).<sup>1</sup>
- e. Recommendations: applying these recommendations could improve current outcomes, aid data collection, and aid future practice.

**Table 1:** Summary of Evidence-based guidelines for supportive care of patients with EVD

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<sup>1</sup> Lamontagne F et al, “Evidence-based guidelines for supportive care of patients with Ebola virus disease.” *The Lancet*. 2017 Oct 17.

Recommendation	Population	Intervention	Comparator	Outcomes	Strength of recommendation	Confidence*	Comment	
1	Oral rehydration	Patients with suspected, probable, or confirmed Ebola virus disease	Administration of oral rehydration solution in adequate amount	Non-standardised rehydration	Mortality; transmission of Ebola virus to health workers	Strongly in favour	Moderate	Rating increased because of large effect size
2	Parenteral administration of fluids	Patients with suspected, probable, or confirmed Ebola virus disease who are unable to drink or who have inadequate oral intake	Parenteral administration of fluids	No parenteral administration of fluids	Mortality; transmission of Ebola virus to health workers	Strongly in favour	Moderate	Rating increased because of large effect size
3	Systematic monitoring and charting of vital signs and volume status	Patients with suspected, probable, or confirmed Ebola virus disease	Systematic frequent monitoring and charting of vital signs and volume status, at least three times per day	No monitoring and charting	Mortality; transmission of Ebola virus to health workers	Strongly <sup>2</sup> in favour	Low	Rating decreased because of inconsistency and indirectness
4	Serum biochemistry	Patients with suspected, probable, or confirmed Ebola virus disease	Measurement and charting of serum biochemistry (eg, electrolytes, glucose, and blood gas) with correction of abnormalities when clinically necessary	No measurement or charting of serum biochemistry or correction of abnormalities	Mortality; transmission of Ebola virus to health workers	Strongly in favour	Low	NA
5	Staffing ratio	Patients with suspected, probable, or confirmed Ebola virus disease	Higher intensity clinician care of patients, with Ebola treatment unit ratio of $\geq 1$ clinician at the bedside per 4 patients, including the following considerations: patient assessment $\geq 3$ times per day, continuous (24 h per day) presence of personnel inside the Ebola treatment unit to allow prompt recognition of and reaction to acute changes in condition	Appreciably lower intensity clinician care, not including elements above	Mortality; transmission of Ebola virus to health workers	Strongly in favour	Moderate	Rating increased because of evidence of a dose-response in observational data
6	Communication with family and friends	Patients with suspected, probable, or confirmed Ebola virus disease	Facilitating communication with family and friends while isolated in the Ebola treatment unit	Not facilitating communication with family and friends while isolated in the Ebola treatment unit	Psychological distress; Ebola virus transmission to family and friends	Conditionally in favour	Low	NA
7	Analgesic therapy	Patients with suspected, probable, or confirmed Ebola virus disease who are in pain	Use of analgesic therapy sufficient to control pain, including parenteral opioids if necessary	No pain medication	Pain; adverse effects of analgesic medications	Strongly in favour	High	NA
8	Antibiotics	Patients with suspected, probable, or confirmed Ebola virus disease with high severity of illness	Prompt administration of broad-spectrum antibiotics	No administration of broad-spectrum antibiotics	Mortality; transmission of Ebola virus to health workers; adverse effects of antibiotics; antibiotic resistance	Strongly in favour	Moderate	Rating increased because of large effect but decreased for indirectness

NA=not applicable. \*Confidence is based on the quality of the evidence for main outcome.

5. **Abstract session: “Ebola Virus Disease Survivors Care Program in West Africa: Experience from Guinea, 2016** (Dr. Mory Keita, National Consultant, Central Coordinator for Epidemiological Surveillance, WHO Guinea Office)

a. **Background:** The March 2016 “flare” in Guinea brought renewed attention to strategies to minimize re-emergence of the virus that need to occur in the larger context of an integrated program to address medical and psychosocial needs of EVD survivors, ultimately leading to establishment of the SA-Ceint program

b. **Methods:**

i. SA-Ceint structure described at four levels: (see slide)

1. Community level: the SA-Ceint Unit and focal point
2. Village level: the SA-Ceint platform
3. Health District level: the SA-Ceint management team
4. National level (the ERCU): the SA-Ceint Strategic Management Team

- ii. Observational Cohort Study following ALL EVD Survivors discharged from any ETU from April to September 2016, collecting epidemiologic data on health events around survivors and their families
  - iii. **Objective of the strategy:** To reduce the risk of resurgence of Ebola virus in Guinea
  - iv. Several slides detailed the coordination between multiple levels of the program and the survivors and their SA-Ceint Unit and focal point
- c. **Results:**
- i. Surveillance indicators were notable for reaching 1128 of 1270 survivors targeted, with 48 deaths prior to surveillance and 4 during the SA-Ceint period. Of 52 deaths in survivors, leading causes were “Kidney failure” (37), “Malaria” (5) “High blood pressure” (3), and “Pulmonary tuberculosis (3), with single diagnoses of “septicemia,” “brain tumor,” “Accident,” and “Suicide.”<sup>2</sup>
  - ii. Biological monitoring:
    - 1. 4 (of 817) survivors had semen testing (+), 3 were treated with oral favipiravir, and 3 cleared the semen. The geographic distribution and overall longitudinal testing analysis of the male survivors tested was shown (see slide)
    - 2. Other body fluids tested without any detection of EVD RNA were: urine (150), breast milk (69), vaginal secretions (41), blood (8), lochia (7), and amniotic fluid (2).
  - iii. Mental health: mental health was assessed as part of the program: of 683 survivors assessed, 122 had depression, 54 had PTSD, and 26 were classified as “Pathological Bereavement”<sup>3</sup>
- d. **Conclusion:** SA-Ceint was an effective strategy for heightened monitoring of EVD survivors and an innovative strategy to control and reduce residual risk.
- e. **Recommendation:** Internal review is already completed and is to be incorporated into future iterations as needed. Similar strategies could be of use in other countries and for future outbreaks.
6. **Abstract session:** Tertiary care provision for Ebola survivors in Sierra Leone (Dr. Fenella Siegel, Sierra Leone)
- a. **Background:** in Sierra Leone there are 5,116 estimated, 4,052 discharged, and 3,466 registered EVD survivors, many of whom are cared for now in established survivor clinics. The distribution of EVD survivors was shown. There is a presidential priority established integrated free health care for EVD survivors.
  - b. **Overview: CPES: the Comprehensive Program for EVD Survivors** was led by MoHS & MSWGCA (in close collaboration with WHO) and implemented through DFID funded CPES/ESCC project (2016-2017) and USAID funded ETP&SS project (2016-2018) in 12 districts by consortium of partners (GOAL, PIH, MDM, IMC, Save the Children, WHI, Welbodi, KSLP)

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<sup>2</sup> These were clinical diagnoses (only without any biochemical or other evaluation provided)

<sup>3</sup> These data can be compared to results discussed in the Crozier plenary session from the Guinean Post-Ebogui cohort (Depressive symptoms among survivors of Ebola virus disease in Conakry (Guinea): preliminary results of the Post-Ebogui cohort. *BioMed Central*; 2017 Apr 4;17(1):127.)

- c. CPES referral process was reviewed including community, district, and referral/tertiary levels, focusing on Connaught Hospital
  - i. Structure: MoHS adult tertiary hospital with 24 hour A&E → 28 beds (12 medical, 12 trauma, 4 resuscitation) and 278 inpatient beds, including adult medicine, adult/pediatrics, surgery with 12 isolation unit beds and 10 ICU/HDU beds. Also includes specialty outpatient clinics.
  - ii. Partnership: King's Sierra Leone Partnership (an implementing partner for CPES) provided support for referral coordinator and internal medicine / infectious diseases and embedded within Connaught Hospital to liaise with all specialties
  - iii. Referrals from PHUs, District Hospitals, other hospitals in Western Area, and self-referrals / walk-ins
- d. **Methods:** We conducted a service evaluation of Connaught tertiary service provision under CPES from July 2016 – July 2017 using a secure electronic database for all CPES referrals (administrative) → referral episode details extracted into anonymized study database → analysis of patient numbers, demographic details, referring PHU, and categories of presenting complaint
- e. **Results:** July 2016 – July 2017: 150 patients received 160 episodes of care
  - i. 91 (53%) female, most patients between ages of 20-34
  - ii. Median time from ETU discharge = 758 days (IQR 630–862)
  - iii. The time of year was described for patient visits
  - iv. Location: 84 referrals from Western Area (from 17 PHUs and hospitals), 11 from either Port Loko, Konmo, Makeni, and for 65 referrals, the location was unknown (likely self-referrals)
  - v. Presenting complaint were detailed with the most common being a non-specific medical problem, eye problem, dental problem, or elective surgical problem. The most common non-EVD related sequelae were malaria and dental issues. The most common (likely) EVD-related problems were visual, joint pain, tinnitus, mental health, gynecologic, and liver issues.
  - vi. Roughly 1/3 of presentations & up to 965 days post discharge represented ongoing needs in survivors, especially visual issues. The absence of neurologic disease was noted, though noted that a previous actively followed up cohort of EVD survivors with neurologic symptoms was NOT included in these data. Also noted that few mental health referrals as typically referred through mental health nurse while and inpatient in hospital.
- f. **Limitations:** Only represents referrals under CPES and many patients seen pre-CPES, especially eye and neurologic disease; some remain under ongoing follow-up; passive cohort; no data on patients with tertiary care needs not referred or seen at other facilities; no controls (but non-EVD survivor referrals very limited; as database was primarily administrative), clinical details minimal
- g. **Conclusion:** Survivors have ongoing important needs; the highest number of survivors is in Western Area but there are disproportionate referrals with many barriers to referral especially from more remote areas: transport cost covered but many other barriers that include other costs (e.g. food), long distance and absent social support, often survivors can't travel with significant disability. There is a real need to further strengthen referrals and provide more services in districts, including utilization of new ambulance services.
- h. **Recommendations:** Ongoing needs related to EVD-sequelae include district hospital care provision and referral system requires improving. The high burden of non-EVD sequelae presentations represents an important lesson on the need for free healthcare for survivors and the general population of Sierra Leone. Despite free provision of care,

barriers remain and the government of SL and international donors must continue to commit to support free healthcare.

7. **Abstract session:** “*The Response to and Impact of the Ebola Epidemic: Towards an Agenda for Interdisciplinary Research*” (Dr. Abdourahmane Diallo, FOSAD)<sup>4</sup>
- a. **Background:** As part of identifying an agenda for interdisciplinary research arising from the Ebola outbreak, this work aimed
  - b. **Aim:** To identify the priorities for health and social care research with and for survivors of EVD in Guinea, with the long-term goal of co-developing a research proposal with partners in Guinea.
  - c. **Methods:** In addition to interviews with key stakeholders, health practitioners, and community representatives, discussion groups were held with 12 male and 12 female survivors from two distinct communities, with questions focused on several domains (family, health, relationships, well-being, economics)
  - d. **Results:**
    - i. Discussions with survivors revealed
      1. physical and mental health symptoms that survivors are still experiencing (see slide lists)
      2. social (stigmatization, exclusion, and isolation from families and communities) and economic implications (losing jobs, accommodation, reduced income) were as important as the physical
    - ii. Community leaders and health practitioners identified community misunderstanding and lack of trust, disruption of community cohesion, challenges in reintegration, and capacity challenges to meet health care needs especially those in mental health.
    - iii. Key stakeholders identified an important lack of knowledge, especially around complexity of their unmet needs, the heterogeneity in the outbreak between areas, and social science analysis gaps.
  - e. **Recommendations / research questions moving forward:**
    - i. What is the long-term socio-cultural, economic and health impact of the EVD epidemic on the country of Guinea?
    - ii. What is the nature and impact of social stigma associated with EVD, and what are the factors that have contributed to the stigmatization of survivors?
    - iii. What can we learn from the local, national and international responses to the EVD outbreak about the nature of communication required for effective community engagement?
    - iv. Why was the response to and effect of the Ebola virus so variable between different communities?
    - v. What is the impact of the EVD outbreak on non-infected community members as compared to infected survivors?
    - vi. Are the neurological symptoms experienced by EVD survivors a consequence of direct effects of the virus, or the unmet mental health needs associated with the experience the survivors went through?
    - vii. How did the response to and impact of the EVD outbreak vary between different countries in the region?

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<sup>4</sup> The content discussed has been accepted for publication in Calnan et al, *The Response to and Impact of the Ebola Epidemic: Towards an Agenda for Interdisciplinary Research*. IJHPM Sept 2017.

## September 8, 2017: Day Two

- I. **Plenary session:** “*Post-Ebola Health Challenges: Balance Sheet and Prospects*” Presenter: Dr. Fascinet Yattara, substituting for Dr. Sakoba Keita (Directeur de l’Agence Nationale de Sécurité Sanitaire, Guinea)
  - a. **Context:** In providing a Guinean overview, Dr. Yattara noted that 1,270 people survived the disease, of which 1,178 (93%) were found and are being followed. The key management bodies were the National Health Crisis Committee and the national coordination unit for the fight against Ebola. Contributing factors to the overall epidemic included late detection (inadequate surveillance networks), the absence of a pre-existing rapid response mechanism. 211 health care workers were infected with 115 deaths. He reviewed the history of the surveillance system in Guinea, noting distinct periods: 1958-2000 (unintegrated partial surveillance and establishment of sentinel surveillance sites), 2001-2013 (introduction of IHR and mobile phone data transmission), and 2013-2017 (peri-outbreak strengthening oriented to EVD). Three distinct periods of the outbreak were described.
  - b. **Overview of the Guinean response:**
    - i. March to Sept 2014: key response strategies were the establishment of management bodies (committees responsible for supervision, management, communication, logistics, and coordination) and an inter-ministerial monitoring committee. Key activities for the case management and logistics committees were highlighted with representative photographs. The challenges of this period included: increase in the number of cases, number of prefectures affected, community reluctance in active households; delays in the execution of activities; insufficient financial resources; poor assessment of the extent of the disease; uncontrolled movement of bodies and contacts; absence of drug and vaccine countermeasures. The analysis of these difficulties resulted in the creation of the National Coordination to Fight against Ebola (CNLE).
    - ii. Sept 2014 to June 2016: characterized by the creation of the National Coordination of Ebola, the start of clinical trials (vaccine and therapeutic trial, viral persistence study in fluids, introduction of rapid diagnostic tests), the implementation of new response strategies (zero Ebola in 60 days, active research campaigns coupled with awareness raising), and the implementation of 'micro-strapping' (Guinean approach to confinement). Key activities included: capacity building activities for epidemic management, training (in surveillance, prevention and control of infections, laboratory techniques, social mobilization, case management, and logistics management), infrastructure construction, equipment and supply deployment, and provision of ambulances (150) and motorcycles (3,000).
    - iii. June 2016 to present - the “post-epidemic” period: highlights were the creation of the National Agency for Health Security (ANSS), emphasizing: 1) continued strengthening of surveillance; 2) strengthening of health care; 3) establishment of a museum and an Ebola library at the headquarters of the ANSS; and 4) ongoing studies of risk management strategies. Strengthening surveillance would occur through training, ensuring the supply of computer equipment and data transmission, the establishment of community-based surveillance, ERARE and EPARE teams and pre-regional and regional points of contact, the establishment of confirmation laboratories for epidemic-prone diseases in regional capitals, the provision of a P3 laboratory by the Russian government, and construction in progress of the Pasteur Institute of Guinea. Health care strengthening would

focus on continued HCW training, completing and equipping the institute, and pre-positioning inputs for the case management of epidemic-associated diseases. The museum/library would ensure storage of all articles published on Ebola in Guinea, exhibition of materials received during crisis management, and storage of recorded video images during the epidemic. Highlighted ongoing studies were: the combined PREVAC vaccination trial, GamEvak-Combi (Russian Federation), counter-measure drug trials, and the SA-Ceint active surveillance strategy around EVD survivors.

- c. **Challenges moving forward:** Maintaining and improving laboratory diagnostic capability (shortened period from 3 months to 48 hours); maintaining and improving the current capacities of the decentralized level in investigations and response (ERARE, EPARE); sustaining decentralized management capacities of diseases with epidemic potential by ensuring the correct and permanent functioning of the CTEPI (from 2 ETUs in 2014 to 39 CTEPI at the moment); maintaining and improving the active participation of the community in monitoring (scaling up and sustaining community-based surveillance); shortening the response time by creating a reliable mechanism for mobilizing financial resources.
  - d. **Key lessons learned:** indispensable involvement of socio-anthropologists in understanding the behavior of the population; failure to take into account the customs and habits has had a negative influence on the community management of cases and deaths due to EVD; the inadequacy of the messages disseminated at the beginning of the epidemic had a counterproductive effect on the behavior of the community
  - e. **Important recommendations to meet these challenges included:**
    - i. Expanded computerized management of surveillance data at health centers
    - ii. Scaling up of community-based surveillance
    - iii. Involvement of hospital structures in epidemiological surveillance
    - iv. Implementation of electronic surveillance in hospitals
    - v. Integration of private structures into the surveillance network
    - vi. Strengthening laboratory network to reduce the time for confirmation of samples
    - vii. Construction of ANSS headquarters and the National Institute of Public Health
  - f. **Conclusion:** Though challenging, the presenter emphasized the opportunity to better identify weaknesses in the Guinean system, to strengthen emergency management and response capacity, and to improve knowledge about Ebola disease, new response strategies, new diagnostic tools, and new drugs and vaccines.
2. **Abstract Session:** “*Ebola Virus RNA persistence in the semen of male survivors: an immunomodulatory or immune-privileged mechanism? (A review)*” (Nowiah Gorpudolo-Richmond Dennis, OB/GYN department, Redemption Hospital, Liberia)
- a. **Summary:** In the context of the overall outbreak and the finding of long-term persistent RNA in the semen of male survivors, the presenter drew a distinction in this review between the “immune-privileged” testes (highlighting the unknowns around the mechanisms of long-term persistence and clearance) and the “immune-modulated” vagina and uterus (highlighting the absence thus far of similar persistence in the female reproductive organs but questioning whether glandular epithelium might be of importance). The author’s literature review was described. Regarding the testes, the presenter questioned whether preleptotene spermatocytes external to the blood-testes-barrier might represent portals of entry through the blood-testes barrier, and whether spontaneous apoptosis and regenerative spermatogenesis might explain intermittent detection in some men. New data was not presented. Given the importance of understanding the maximum duration of viral

persistence (using the long-term presence of anti-Mumps virus antibody for > 10 years as an outlier), the need for new therapeutics to penetrate this space, and well as consideration of “gender-appropriate therapy,” the presenter recommended re-phrasing the discussion incorporating the vocabulary described above.

3. **Abstract Session:** “*Patterns in Distribution of Reading Glasses among Ebola Survivors in Monrovia, Liberia*” (Jennie Chuku Sackor, PREVAIL, Liberia)
  - a. **Summary:** In a background of EVD-related ocular complications that includes accommodative difficulty (presbyopia), this work aimed to determine the frequency of distribution of reading glasses by conducting a retrospective review of the refraction exams conducted in patients participating in the eye sub-study of the PREVAIL III cohort of Ebola survivors and close contacts. From June 2015-June 2016, reading glasses were given to 110/639 (17%). Of these, 92/110 survivors who needed reading glasses were > 40 years, and EVD survivors > 40 were significantly more likely to receive reading glasses ( $P<.0001$ ) and to require more corrective power. There were not differences between men and women. The Rapid Assessment of Avoidable Blindness (2012) study did not include assessment of presbyopia in Liberia; the work presented is the first to document presbyopia in a Liberian setting. The presenter highlighted the importance of the next steps to ensure access to reading glasses for the population. An audience member queried whether comparison of EVD survivors to the close contact controls revealed any differences between the two groups: thus far, that comparison has not been done and only EVD survivor data was presented.
  
4. **Abstract Session:** “*Stigma and other barriers to health services experienced by Ebola Survivors in Sierra Leone*” (Kwame Oneill and Nicki Brown, MOHS and JSI ETP&SS, Sierra Leone)
  - a. **Background:** EVD survivors faced stigma and discrimination on return to their communities, this study aimed to look at how this impacted on their access to health services and what, if any, impact the Comprehensive Program for Ebola Survivors (CPES) had on this
  - b. The study used a mix method approach, including both quantitative and qualitative data collection methods, focused on understanding direct EVD survivor experiences as well as gathering perspectives and accounts from key stakeholders and implementing partners.
  - c. The CPES program provides national, district and community level support to EVD survivors, focused on health while recognizing the need to address stigma and discrimination to improve EVD survivor well-being.
  - d. **Results and discussion:**
    - i. Over 50% of EVD survivors reported facing stigma at some time, but this was reduced through the sustained intervention of the CPES program in both communities and health facilities
    - ii. Stigma was not the only barrier to accessing healthcare with EVD survivors reporting issues such as transport and distance to health facilities as other significant barriers to accessing healthcare
    - iii. During the acute phase of the CPES program, transport refunds and medications were provided, but in the transition into the next phase the focus will be on strengthening the referral system and ensuring improved clinical care.
  - e. **Conclusion and recommendations:**
    - i. The health needs of EVD survivors have reduced over time but there are ongoing needs and concerns

- ii. EVD survivors report high levels of satisfaction with their care, but are affected by wider health sector issues such as drug stock-outs. The sustainability of this program is dependent on wider health system strengthening in order for the long term needs of this group to be met.
- 5. **Abstract Session:** “*Indications for Clinical Follow-up Visits in PREVAIL III Eye Sub-Study: First Six Months*” (Catherine Gargu, PREVAIL, Liberia)
  - a. **Summary:** In a background of uncertainty around ongoing needs for EVD survivors with eye complaints, this work examined the indications for follow-up visits in the PREVAIL III eye sub-study (Liberia). The analysis indicated that one in five Ebola survivors presenting to the PREVAIL III ophthalmology clinic required separate clinical follow-up, most frequently for uveitis, dry eye and/or cataract. The team conducted a retrospective review of clinical data from the first six (6) months of the eye sub-study (June to December 2015) looking for patients who presented with acute eye problems through a non-routine (unscheduled) study visit. 67 of 420 participants (16.0%) returned for clinical follow-up during this period with a mean of 1.6 visits per patient. The most common indications for return were uveitis (34.3%), dry eye (9%), cataract (4%), corneal scar (4%), and pinguecula (4%), with a longer list of much less frequent but important indications (e.g. - 4.5% returned with glaucoma, an important and potentially blinding condition that needs immediate treatment). The presenter highlighted the importance of this data to immediate care needs and for informing future care models. Ongoing work at PREVAIL will describe how these needs change over time.
- 6. **Abstract session:** “*Factors Predicting Ophthalmic Follow-up of Ebola Survivors in the PREVAIL Longitudinal Eye Sub-Study in Monrovia, Liberia*” Augustine CD Wallace, PREVAIL, Liberia)
  - a. **Summary:** This study sought to determine the factors affecting whether or not patients enrolled in the PREVAIL III eye sub-study returned for routine study follow-up visits with a retrospective chart review from June 2015 to March 2016. Data collected and analysis methods were presented. Overall, 1374/1447 (95.0%) presented for follow-up eye exam, including 635/661 (96.1%) survivors and 726/766 (94.8%) close contact controls. Only 73 participants did not complete a follow-up exam. Age, educational level, and geographical distance (in or outside Montserrado) were significantly associated with the lack of follow-up. Differences between survivors and controls were not presented. The presenter emphasized the importance of understanding and targeting these factors to best aid the design of future research endeavors so as to avoid early termination of studies and waste of resources. He also emphasized the unique use of social mobilization and tracking used in this effort.

## September 9, 2017: Day Three

- I. **Plenary session:** “*Experience of West African EVD Survivors (Liberia, Sierra Leone and Guinea) in Post-Ebola Healthcare Delivery System*” (Presenters: Abu Kanneh (Liberia) and Mariatu Kargbo (Sierra Leone))
  - a. **Summary:** Two EVD survivors provided EVD survivor-specific insight that highlighted key areas of improvement as well as ongoing challenges for EVD survivors, their families, and other vulnerable groups. They expressed gratitude for survivor representation at the consortium meeting and recognized multiple partners for this and prior Ebola-

related efforts over the past three years. Key areas of noted improvement included HCW capacity building, construction and rehabilitation of health facilities, provision of medical drugs and equipment for survivor health care, research efforts around for EVD treatment, and the reduction of stigma and discrimination of EVD survivors. They called for continued and improved efforts to: i) improve delivery of medical care and support for EVD survivors and families, ii) provide focused attention to vulnerable survivor groups (orphans, widows, the disabled), iii) improve strategies for psychosocial support iv) provide livelihood supports (skill training, employment, grants, etc.), v) improve educational supports (scholarship, financial aid, essential school materials), vi) develop policies for social protection and societal integration, and vii) facilitate survivors regional leadership coordination (conferences) as a means of empowering and sustaining the cohesion among EVD survivors of West Africa. In all of this, they emphasized survivor willingness to participate in these processes, a holistic approach, and “teaching us how to fish” for sustainable change.

## FINDINGS AND CONCLUSIONS

- The evidence base around the multi-faceted needs of EVD survivors is being rapidly populated. Early symptom surveys and case reports have been replaced with small cohort studies, and more recently, with data from longitudinal cohorts of EVD survivors.
- New and recently published information about individual and population level clinical needs (including mental health), as well as public health issues related to EVD persistence, were discussed at the meeting, both in broad overview plenary sessions and in granular detail in abstract sessions related to specific issues around EVD survivor sequelae. For example, abstracts reporting on varied aspects of ophthalmic findings from EVD survivors in the PREVAIL III Eye sub-study were reported.
- A repeated challenge in all three countries was the need to simultaneously attend to urgent care needs while also dealing with the uncertain public health risks that EVD survivors pose. Strategies to address these issues in survivors were discussed, with the Guinea SA-Ceint model of EVD survivor surveillance discussed in some detail.
- A repeated message from all three countries was that survivor needs are ongoing and in multiple domains. This was highlighted by a plenary session presented by two EVD survivors reviewing ongoing challenges for survivors, their families, and their communities. It was also highlighted as part of the Guinea SA-Ceint program and session reporting from direct interviews of survivors in Guinea.

# RECOMMENDATIONS

1. Need for continued support at country level for health care worker training, facility capacitation, and provision of EVD survivor-specific needs, even as EVD survivor care is being steadily integrated into the broader public health system of each of the three countries.
2. Key gaps in understanding require support for ongoing and new research, particularly in the following areas:
  - The maximum duration and public health implications of viral persistence in the semen of male EVD survivors.
  - The maximum duration and public health implications of viral persistence in other locations of the body, for example, the eyes.
  - The clinical, public health, and policy implications of EVD IgG AB-positive EVD survivors who never had or do not recall having clinical symptoms.
  - Understanding the neuropsychiatric needs of EVD survivors, especially children.
3. Ongoing updates to survivor care and testing guidelines are required, particularly around semen viral persistence, surgical care of post-uveitis cataracts, etc., and efforts to coordinate and enable cross-border regional sharing of experience and new research findings should continue, with emphasis on making sure that emerging research data can nimbly inform clinical care services on the ground.

# APPENDIX I: Conference Agenda



# 3rd West African Sub-Regional Conference

7 – 9 September 2017

Conakry, Guinea

## Post-Ebola Health Challenges in West Africa

### Themes:

1. Improving Clinical Care, Addressing Stigma and Policy-Related Issues of Survivors.
2. Advancing Vaccines, Therapeutics and Diagnostics for Emerging Infectious Diseases.
3. Strengthening Research Collaboration, Capacity Building and Community Empowerment.
4. Strengthening Collaboration on “One Health” Strategy on the Global Health Security Agenda (GHSA) in the Sub-Region.

### Conference Goals:

1. To advance regional preparedness for global health security and compliance with International Health Regulations
2. To leverage comparative advantages and share regional research, best practices, and evidence to inform infectious disease policy.
3. To discuss ongoing research and advance new studies and policies in the region.

DAY I: Thursday 7 September 2017, 8AM-5PM Venue: Main Hall, Noom Hotel, Opening Program		
Time	Session	Speaker(s)
7:30 – 8:00 AM	Registration	
8:00 – 8:30 AM	Welcome & Introduction	Dr. Moses Massaquoi Chair, WAC
8:30 – 10:00 AM	Opening Remarks MOHS, WHO, NIH, JSI, CDC, INSERM, MRU, WAHO	
10:00 -10:30 AM	Official Opening	Hon. Minister Dr. Abdourahmane Diallo, Ministry of Health, Republic of Guinea
10:30 – 11:00 AM	<i>Group Photo and Coffee Break</i>	
11:00 – 11:30 PM	WHO R&D Platform & Lessons Learned on Viral Persistence from WHO Meeting in Monrovia, June 2017	Pr. Akanmori Dicky WHO
11:30 – 12:00 PM	Using Evidence to Update the Survivor Clinical Care Guidelines	Dr. Ian Crozier USA
12:00 – 12:30 PM	University Clinical Research Center (UCRC) of Bamako: an initiative for a Regional Clinical Research Capacity development in West Africa	Pr. Seydou Doumbia Mali
12:30 – 1:30 PM	<i>Lunch</i>	



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Day I Time	Room A Moderators: Jeff Sanderson	Room B Moderators: Dr. Fatorma Bolay and Dr. Abdoul Beauvogui	Room C Moderators: Pr. Mandy Kader Kondé and Dr. Mohamed Samai
1:30-1:50 PM	<b>An observational study of Pregnant Liberian EVD survivors and their children</b> <i>Presenter: Dr. Sia Wata Camanor</i>	<b>A Comparison between Two Enzyme-linked Immunosorbent Assays for Detection of Antibodies to Ebola Virus Glycoprotein</b> <i>Presenter: Dr. Lisa Hensley</i>	<b>Community Engagement and Communications for Ebola Clinical Trials: Lessons Learned</b> <i>Presenter: Dr. Elizabeth Smout</i>
1:50-2:10 PM	<b>Sex Practices &amp; Awareness of Ebola Virus Disease in Male Survivors and their Partners in Guinea: a Cross-Sectional Study</b> <i>Presenter: Prof. Barry Abdoulaye</i>	<b>EBOVAC-Salone: lessons learned from implementing an Ebola vaccine trial in an Ebola-affected country</b> <i>Presenter: Dr. Thomas Mooney</i>	<b>The response to and impact of the Ebola epidemic: towards an agenda for interdisciplinary research</b> <i>Presenter: Dr. Abdourahime Diallo</i>
2:10-2:30 PM	<b>Evidence-Based Guidelines for Supportive Care of Patients with Ebola Virus Disease</b> <i>Presenter: Dr. Ama Edwin</i>	<b>Antimicrobial therapy in the context of Post Ebola outbreak at Ignace Deen Teaching Hospital Conakry Guinea in West Africa</b> <i>Presenter: Pr. Moussa Koulibaly</i>	<b>Envisioning and Nurturing Clinical Research Environments to Strengthen Health Systems</b> <i>Presenter: Dr. Jo Anne Bennett</i>
2:30-3:00 PM	<b>Q&amp;A</b>	<b>Q&amp;A</b>	<b>Q&amp;A</b>
3:00-3:30 PM	<b>Coffee Break</b>		
3:30-3:50 PM	<b>Ebola Virus Disease Survivors Care Program in West Africa: Experience from Guinea, 2016</b> <i>Presenter: Dr. Mory Keita</i>	<b>Immune responses up to Day 360 in African healthy volunteers receiving monovalent Ebola Zaire heterologous prime-boost vaccines, combining Ad26.ZEBOV and MVA-BN-Filo</b> <i>Presenter: Dr. Valerie Oriol Mathieu</i>	<b>Ethnography and Ethics in an Ebola Trial: Towards a Grounded Ethics of Research</b> <i>Presenter: Dr. Mike Callaghan</i>



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<p><b>3:50-4:10 PM</b></p>	<p><b>Connaissances, attitudes et pratiques des soignants du CHU de Conakry et de l'INSE sur la maladie à virus Ebola après l'épidémie</b> <i>Presenter: Dr. Mouctar Bayo</i></p>	<p><b>A review of Participant retention methods in an emergency clinical research response setting: The PREVAIL I Experience</b> <i>Presenter: Sarah Browne</i></p>	<p><b>Getting in touch with communities within a clinical trial through m-health: The CommCare experience and the PREVAC study</b> <i>Presenter: Dr. Alex Quach</i></p>
<p><b>4:10-4:30 PM</b></p>	<p><b>Tertiary care provision for Ebola survivors in Sierra Leone</b> <i>Presenter: Dr. Fenella Siegel</i></p>	<p><b>Enrolling study personnel in Ebola Vaccine trials: From Guidelines to practice in a non-epidemic context</b> <i>Presenter: Dr. Edouard Lhomme</i></p>	<p><b>Strengthening the Malian health system through graduate training in public health: the University of Bamako experience</b> <i>Presenter: Dr. Moctar Tounkara</i></p>
<p><b>4:30-5:00 PM</b></p>	<p><b>Q&amp;A and Closing Comments</b></p>	<p><b>Q&amp;A and Closing Comments</b></p>	<p><b>Q&amp;A and Closing Comments</b></p>
<p><b>SIDE MEETING ON DATA SHARING PLATFORM</b></p>			
<p><b>5:30-7:00 PM</b></p>	<p><b>Main Conference Hall</b></p>	<p><b>West African Consortium on Data Sharing Platform</b></p>	<p><b>Laura Merson Oxford University</b></p>



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Conakry, Guinea



## Post-Ebola Health Challenges in West Africa

DAY 2: Friday 8 September 2017, 8AM-5PM

Venue: Main Hall, Noom Hotel

Time	Session	Speaker
8:00 – 9:00 AM	Registration	
9:00 – 9:30 AM	Opening Remarks	Dr. Moses Massaquoi Chair, WAC
9:30-10:00 AM	Towards A Sustainable Ebola Vaccine Immunogenicity: Update on Studies & Candidate Vaccines	Dr. James Neaton PREVAC / UMN
10:00 – 10:30 AM	Les Défis Sanitaires Post Ébola, Bilans et Perspectives en Guinée.	Dr. Sakoba Keita ANSS, Guinea
10:30 – 11:00 AM	Coffee Break	
11:00 – 11:30 AM	Capacity Building & Collaboration in Sub-Saharan Africa	Pr. Moses Bockarie EDCTP
11:30 – 12:00 PM	Analyse du financement de la gestion d'une menace epidemique: cas de la maladie a Virus Ebola, Cote D'Ivoire, 2014	Pr. Acray-Zengbe Petronille Cote D'Ivoire
12:00-1:00 PM	<b>Lunch</b>	



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<b>Day 2 Time</b>	<b>Room A</b> Moderators: Pr. Seydou and Pr. Foday Sahr	<b>Room B</b> Moderators: Pr. Acray-Zengbe and Dr. Mark Kieh	<b>Room C</b> Moderators: Pr. Hector Morgan and Pr. Diallo
<b>1:00-1:20 PM</b>	<b>Ebola Virus RNA persistence in the semen of male survivors- an immunomodulatory or immunoprivileged mechanism? - A Review</b> <i>Presenter: Dr. Nowiah Gorpudolo-Richmond Dennis</i>	<b>Safety of monovalent Ebola Zaire heterologous prime-boost vaccines, combining Ad26.ZEBOV and MVA-BN-Filo, assessed in a Phase III clinical trial in Sierra Leone</b> <i>Presenter: Dr. David Ishola</i>	<b>Strengthening Guinea-Mali Collaborative Training and Research Network for a Better Control of Emerging Viral Diseases</b> <i>Presenter: Dr. Bassirou Diarra</i>
<b>1:20-1:40 PM</b>	<b>Prise en charge hospitaliere des cas suspects de la maladie a virus Ebola (MVE) en Cote d'Ivoire: Experience du SMIT a Abidjan</b> <i>Presenter: Dr. Adama Doumbia</i>	<b>Boosting quality vaccine delivery with innovative mobile tracking app</b> <i>Presenter: Dr. David Vallée</i>	<b>Can we “roll back” Emerging infectious diseases (Ebola, Lassa, etc.) without empowering communities?</b> <i>Presenter: Pr. David Houeto</i>
<b>1:40-2:00 PM</b>	<b>Patterns in Distribution of Reading Glasses among Ebola Survivors in Monrovia, Liberia</b> <i>Presenter: Dr. Jennie Chuku Sackor</i>	<b>Stakes and challenges of the collaboration of health research institutions and the regulation organs in the context of public health emergency in Guinea</b> <i>Presenter: Alpha A. Diallo</i>	<b>Understanding the role of the data and safety monitoring board (DSMB) in clinical trials during an emergency</b> <i>Presenter: Gloria Mason</i>
	<b>Factors Predicting Ophthalmic Follow-up of Ebola Survivors in the PREVAIL III Longitudinal Eye Sub-Study in Monrovia, Liberia</b> <i>Presenter: Augustine Wallace</i>		<b>Stigma and other barriers to health services experienced by Ebola Survivors in Sierra Leone</b> <i>Presenter: Kwame O’Neill</i>
<b>2:00-2:30 PM</b>	<b>Q&amp;A</b>	<b>Q&amp;A</b>	<b>Q&amp;A</b>
<b>2:30-3:00 PM</b>	<b>Coffee Break</b>		



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<p><b>3:00-3:20 PM</b></p>	<p><b>Acquisition time for optical coherence tomography imaging of Ebola survivors and close contacts in Monrovia, Liberia</b>  <i>Presenter: Yassah F. Sosu</i></p>	<p><b>Laboratory preparedness for effective control of emerging and re-emerging infections in Low income countries</b>  <i>Presenter: Dr. Amadou Kone</i></p>	<p><b>Mise en place d'un modèle d'engagement communautaire dans l'essai vaccinal PREVAC en Guinée Conakry: approches, défis et leçons apprises</b>  <i>Presenter: Dr. Sylvain Faye</i></p>
<p><b>3:20-3:40 PM</b></p>	<p><b>People healed of Ebola and their psychosocial life: About 55 cases at the Donka Treatment center (Conakry)</b>  <i>Presenter: Dr. Fodé Bangaly Sako</i></p>	<p><b>Renforcement de la collaboration sur la strategie "une seule sante" (One Health) de la securite sanitaire mondiale dans la sous-region: Experience de la Cote d'Ivoire, 2017</b>  <i>Presenter: Dr Koffi Kouadio Félix</i></p>	<p><b>Enabling Community Critical Role in the PREVAIL I Ebola Vaccines Trial through Collaboration and Capacity Building in Liberia</b>  <i>Presenter: Joseph Boye Cooper</i></p>
<p><b>4:00-4:20 PM</b></p>	<p><b>Profil épidémiologique et prise en charge des patients Co-infectés par le VIH et la Tuberculose au Centre Médical Communal de Matam Conakry (Guinée)</b>  <i>Presenter: Sah Dimio Sandouno</i></p>	<p><b>Evaluation des Connaissances du Personnel Soignant sur les Virus Emergents au CHU Gabriel Touré</b>  <i>Presenter: Dr. Almoustapha Issiaka Maiga</i></p>	<p><b>Ethnomedical and ethnobotanical investigations on the response capacities of Guinean traditional health practioners in the management of outbreaks of infectious diseases: The case of the Ebola virus epidemic</b>  <i>Presenter: Mohamed Sahar Traore</i></p>
<p><b>4:20-4:40 PM</b></p>	<p><b>Indications for Clinical Follow-up Visits in PREVAIL III Eye Sub-study: First Six Months</b>  <i>Presenter: Catherine Gargu</i></p>	<p><b>INSERM (Institut National de la Santé et de la Recherche Médicale) in Guinea in the post-Ebola era: building capacity in research laboratories</b>  <i>Presenter: Daniela Fusco</i></p>	
<p><b>4:40-5:00 PM</b></p>	<p><b>Q&amp;A and Closing Comments</b></p>	<p><b>Q&amp;A and Closing Comments</b></p>	<p><b>Q&amp;A and Closing Comments</b></p>



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WEST AFRICAN TASK FORCE FOR THE CONTROL OF EMERGING & RE-EMERGING INFECTIOUS DISEASES



# 3rd West African Sub-Regional Conference

7 – 9 September 2017

Conakry, Guinea

## Post-Ebola Health Challenges in West Africa

DAY 3: Saturday 9 September 2017, 8AM-1:30PM		
Venue: Main Hall, Noom Hotel		
Closing Program		
Time	Session	Speaker
8:00 – 8:30 AM	Registration	
8:30 – 9:00 AM	Opening Remarks	
9:00-10:30 AM	Open Forum Including Presentation on Experience of West African EVD Survivors (Liberia, Sierra Leone and Guinea) in Post-Ebola Health Care Delivery System	Abu K. Kanneh and Mariatu Kargbo
10:30-11:00 AM	Coffee Break	
11:00-12:30 PM	Closing Discussion (including plenary Q&A)	
12:30-1:30 PM	<b>Lunch</b>	
1:30-7:00 PM	West African Consortium Strategic Planning (refer to separate agenda)	



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## APPENDIX 2:

### Meeting Participant List

Note: **Bold attendee** indicates that funding for travel was covered by APC Project. Guinean participants from the Conakry area were reimbursed for travel costs by APC Project at the local rate.

<b>WAC Sub-Regional Conference Participants September 7-9, 2017 in Conakry, Guinea</b>				
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152	Thia	Evelyne	TMG-GERP	-
153	Tolno	Charles	IMC	<a href="mailto:ctolno@internationalmedicalcorps.org">ctolno@internationalmedicalcorps.org</a>
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156	Touré	Fatoumatalaye	Guinea	
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# APPENDIX 3: Results of Workshop Evaluation

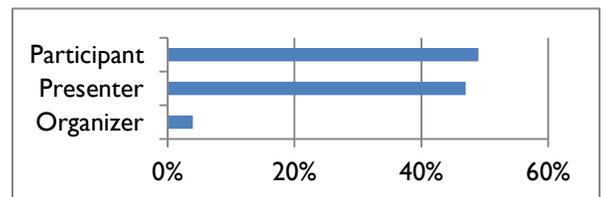
## 3<sup>rd</sup> West African Sub-Regional Conference Post-Ebola Health Challenges in West Africa Post-Conference Survey Results 30 October 2017

Out of approximately 150 who attended the workshop, 45 people completed the survey (30% completion rate). Among those who completed the survey, 40% (18) completed the French version and 60% (27) completed the English version.

### Demographics of Survey Respondents:

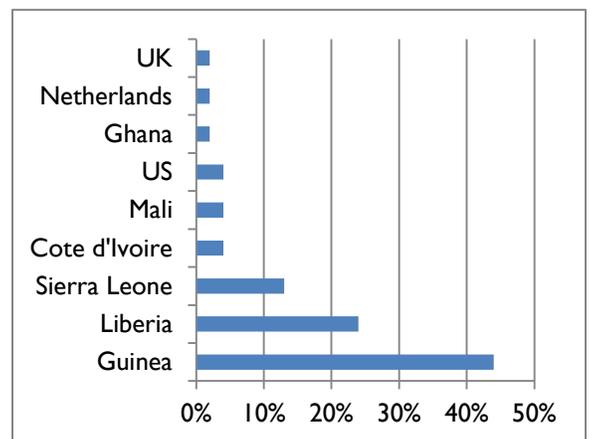
#### Roles:

- **49% Participants**
- 47% Presenters
- 4% were Organizers



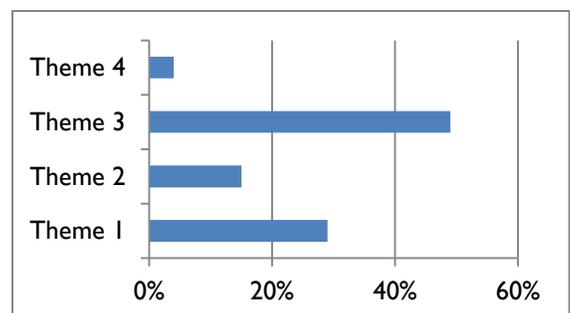
#### Nine countries were represented in the survey:

- **44% work in Guinea**
- 24% work in Liberia
- 13% work in Sierra Leone
- 4% work in Cote d'Ivoire
- 4% work in Mali
- 4% work in the US
- 2% work in Ghana
- 2% work in the Netherlands
- 2% work in the UK



### Workshop Themes:

- **49% found strengthening research collaboration, capacity building and community empowerment (Theme 3) most relevant**
- 29% found improving clinical care, addressing stigma and policy-related issues of survivors (Theme 1) most relevant



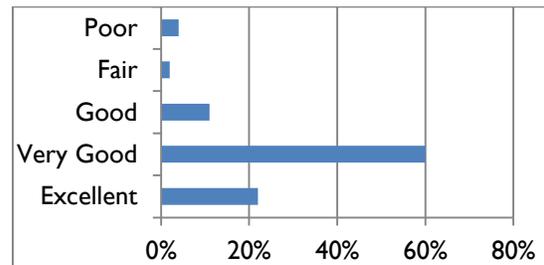
- 15% found advancing vaccines, therapeutics and diagnostics for emerging infectious diseases (Theme 2) most relevant

- 4% found strengthening collaboration on “One Health” strategy on the Global Health Security Agenda in the sub-region most relevant (Theme 4)

### Impressions of Conference:

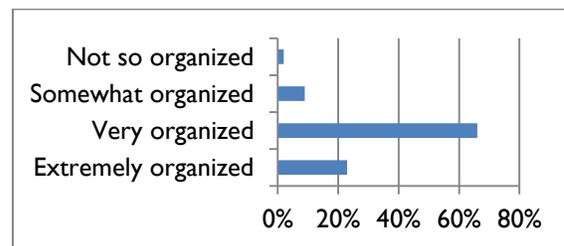
#### Overall:

- 22% rated it excellent
- **60%** rated it **very good**
- 11% rated it good
- 4% rated it poor
- 2% rated it fair



#### Organization:

- 23% rated it extremely organized
- **66%** rated it **very organized**
- 9% rated it somewhat organized
- 2% rated it not so organized



### Recurring comments from compiled feedback:

#### What did you like?

- Educational and interactive nature
- Venue, including hospitality and food
- Excellent presentations and presenters, including many young African researchers
- High profile of participants, including Guinea MOH and excellent high-level academic representation
- Overall organization of workshop
- Collaboration between countries, shared information and networking opportunities, relationship building in a multi-disciplinary crowd
- Frank exchange of ideas
- Adherence to schedule (mentioned by francophone colleagues)

#### What didn't you like?

- Poor initial organization, including during abstract selection process and in getting plenary speakers together
- Technical challenges in getting slides set up; long lines at lunch
- Several francophone presenters were not respectful of time, went over schedule
- Missing sufficient time for debate, Q&A following presentations; no feedback from smaller groups to larger group
- Not enough time for discussion between participants and presenters to pair country experiences, taking into account existing literature
- Too many presentations were offered at the same time

- Moderator didn't always stick to agenda and it was disruptive, particularly when people were in need of a break. Cultural event was announced last minute.
- Translation in some cases (English to French) could have been more concise

#### How could the conference improve?

- Improve scientific committee as well as abstract submission process, of which the selection criteria was not transparent
- Improve initial publicity, including save the date, call for abstracts, etc. to widen reach of workshop
- Provide more coaching of first time presenters in advance of the workshop
- Provide a less expensive hotel option for some participants to stay in
- Set up round tables specific to the principal themes of the workshop to facilitate exchange and north-south / south-south collaboration
- Build more time for discussion into panels, make sure final plenary sessions tie together workshop topics
- Facilitate meetings of survivors or other special groups by designating a private space and time, such as during lunch
- Increase number of days and decrease number of topics
- Provide a conference report

#### Final feedback:

- Suggestion to hold workshop during dry season for easier travel logistics
- "The organization of the workshop was exceptional."
- "The event was unique. I would like to extend many thanks and appreciation to the organizers and those who made me to be a part of such a wonderful and educative forum."
- "I would like you to create another challenge, such as asking people to propose other research items from each main topic of the conference, to continue working on before the next one."
- "Go beyond the scientific exchange and propose concrete projects to support the survivors. Take into account social science during the coming years."
- "Support young researchers in their continuous training and put all of the research results into action."



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