

# NUTRITIONAL CARE FOR PATIENTS WITH EBOLA

VIRUS DISEASE IN EBOLA TREATMENT UNITS



***PAST AND CURRENT EXPERIENCES***



U.S. Department of  
Health and Human Services  
Centers for Disease  
Control and Prevention

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*PAST AND CURRENT EXPERIENCES*

## **Final Investigation Report**

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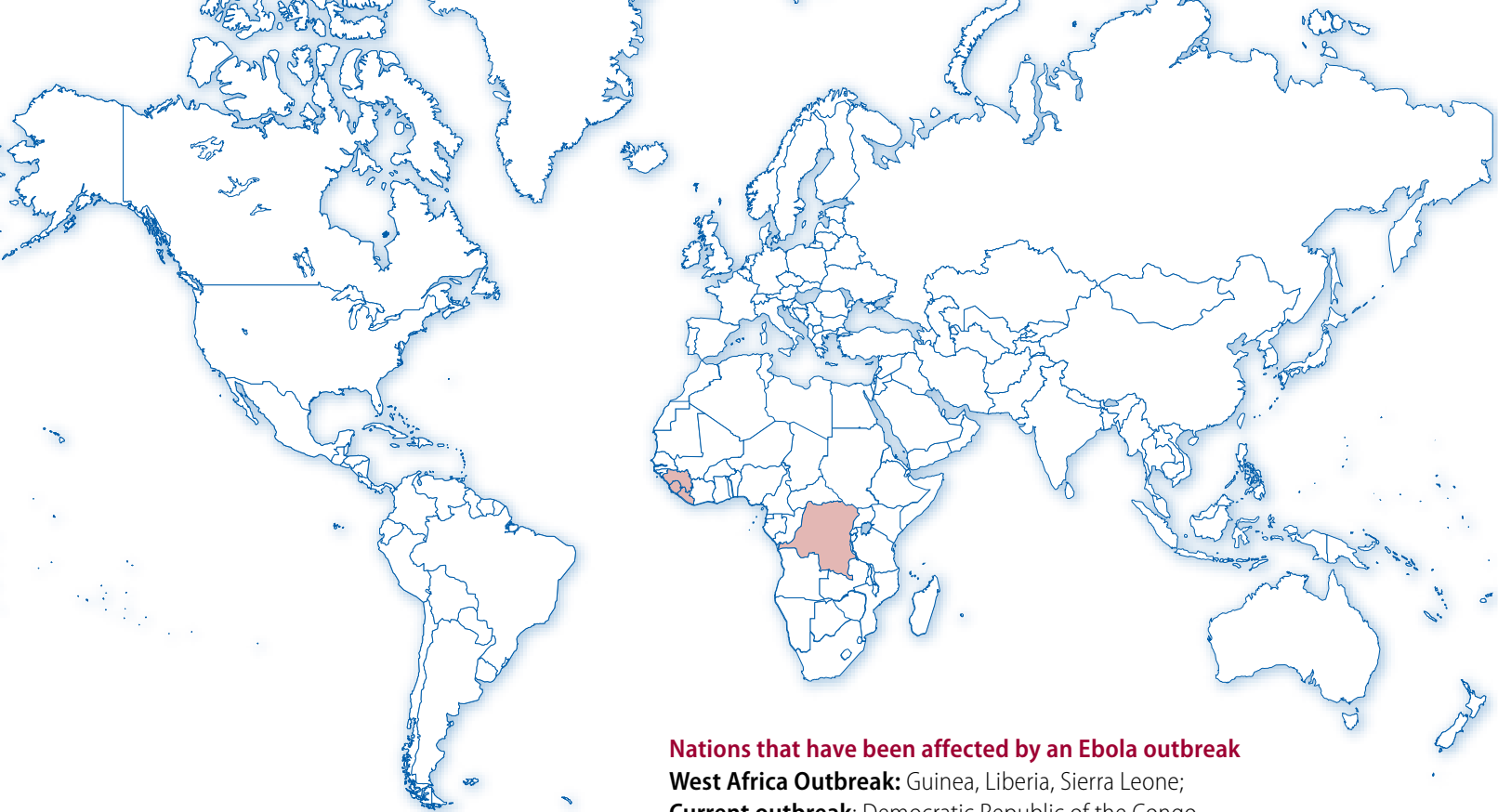
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**Nations that have been affected by an Ebola outbreak**

**West Africa Outbreak:** Guinea, Liberia, Sierra Leone;

**Current outbreak:** Democratic Republic of the Congo.

## Introduction

The World Health Organization (WHO) declared the outbreak of Ebola Virus Disease (EVD) in West Africa from March 2014 until June 2016, affecting multiple countries, in particular, Guinea, Liberia and Sierra Leone [1]. The scale of the outbreak resulted in United Nations agencies issuing new or updated guidelines on care and treatment of EVD patients. In November 2014, the WHO, in collaboration with United Nations Children’s Fund (UNICEF), and the World Food Programme (WFP), produced interim guidelines (iGL) on providing nutritional support to patients in Ebola treatment units (ETUs) [2]. These guidelines aimed to address nutritional needs and optimal nutritional care in the current Ebola crisis, with a particular focus on the practical aspects of the care within ETUs for EVD patients.

Since the onset of the 2018-2019 EVD outbreaks in the Democratic Republic of the Congo (DRC), the 2014 iGL have been translated into French and issued by the Ministry of Health, UNICEF, and WHO in adapted versions. However, to date, there is limited literature available on the impact the WHO/UNICEF/WFP iGL have had on the nutritional support and care of EVD patients.

Kodish et al. reviewed the use of three interim guidelines co-issued by WHO in Guinea. The assessed guidelines included: Nutritional Care of Children and Adults with Ebola Virus Disease in Treatment Centers, Infant Feeding

in the Context of Ebola, and Clinical Care for Survivors of Ebola Virus Disease [2-4]. Key informants from a broad group of stakeholders comprising primary care organizations involved in nutritional support, EVD survivors, family members of EVD patients, midwives, and frontline health workers were included in the review. Key informants expressed mixed opinions toward the usefulness of the guidelines, including lack of awareness of their existence and not using them. Some key informants noted that while they were theoretically useful, some of the recommended practices were difficult to implement in practice [5].

A previous literature review found a limited number of publications on specific nutritional care in ETUs that often lacked detailed descriptions of the actual nutritional care provided (Ververs/Gabra unpublished). The review emphasized the importance of reporting on practitioners’ experience to revise existing guidelines for increased applicability and acceptability. This investigation is a follow on to the previous review with the objectives to a) identify experiences and lessons learned from practitioners on the operational aspects of nutritional care and support in EVD outbreaks and b) evaluate the utilization of the 2014 iGL in the West Africa and current DRC EVD outbreak and perception of practitioners.

# Methodology

Between January and May 2019, key informant interviews (KII) were conducted to collect in-depth information on the nutritional care and support of EVD patients during the 2014-2016 West Africa outbreak and the current DRC outbreak. Initially, key informants (KIs) were purposively selected according to their position and role in organizations or institutions actively engaged in nutritional care of EVD patients. Snowball sampling was used with KIs to identify additional KIs. KIIs were conducted until information became repetitive.

KIIs were conducted following a semi-structured interview guide with three main sections: general description of the KI's background, experience with the 2014 iGL, and operational aspects of the nutritional care the KI's organization provided (Annex 1).

Interviews varied from 30 to 75 minutes and were conducted by Skype [6]. Interviews were not audio recorded, but detailed notes were taken during the interview and then analyzed using MAXQDA version 2018.2 [7]. Within MAXQDA, a coding framework was designed based on four major themes emerging from the interviews, Box 1. Through coding and interpretation of the interview transcripts, information was consolidated into experience-driven understanding of previous and current EVD outbreaks. Informed consent was sought through a verbal consent process during the KIIs. This project was reviewed in accordance with the Centers for Disease Control and Prevention human research protections procedures and was determined not to be human subjects research, and participant privacy was assured by de-identifying the project data and quotes.



## Box 1. Coding framework on **FOUR MAIN THEMES** and sub-themes

1. 2014 Interim guidelines—awareness and usefulness as perceived by the interviewed practitioners
2. Nutritional care for EVD patients in ETUs—practical experiences from the interviewed practitioners

### *Sub-themes*

- Importance of nutritional care
  - Food preparation and distribution
    - ▶ Food preparation and transport
    - ▶ Meal composition
  - Patients' dietary preferences and intake
  - Nutritional care related to EVD symptoms
  - Roles in nutritional care
  - Feeding support
  - Malnutrition—screening and treatment
  - Intake of specific nutrients
3. Lessons learned according to the interviewed practitioners
  4. Recommendations for future and ongoing EVD outbreaks according to the interviewed practitioners

# Findings

In total, 26 KIs from 12 organizations were interviewed, Tables 1 to 6. Sixteen KIs had direct contact with EVD patients in the ETUs. All KIs were international staff. The

patient load in ETUs varied between 40 - 200 patients per day, and the majority of patients were adults. There were no refusals among KIs contacted.

**Table 1. Number of key-informants listed per organizations for whom they worked at the time of the EVD response (N=26)**

Organization	Number of KIs
<b>NGOs:</b> ALIMA (2), GOAL (2), IMC (3), MSF (Belgium, Netherlands, Switzerland)(3), Partners in Health (2) Samaritan's Purse (1), Save the Children (UK, USA) (5)	18
<b>United Nations:</b> UNICEF (4)	4
<b>Red Cross Red Crescent Movement:</b> ICRC (3), IFRC (1)	4

**Table 2. Roles of key-informants during EVD outbreak (N=26)**

Role	Number of KIs
<b>Medical doctors</b>	6
<b>Nutritional advisors (nutritionists/nurses)</b>	17
<b>Health care managers in ETU (nurses)</b>	3

**Tables 3 & 4. Geographical location of key-informants during EVD outbreak (N=26)**

Number of Countries	Number of KIs
<b>Worked in one country only</b>	21
<b>Worked in 2 countries</b>	3
<b>Worked in 3 countries</b>	2

Country	Number of KIs
<b>Guinea</b>	1
<b>Liberia</b>	9
<b>Sierra Leone</b>	14
<b>DRC (current outbreak)</b>	9

**Table 5. Duration of work during EVD outbreak (N=26)**

Duration	Number of KIs
<b>Throughout the West Africa outbreak</b>	4
<b>Varied from 3 weeks to 13.5 months (average six months)</b>	19
<b>Unknown</b>	3

**Table 6. Responsibilities during work (N=26)**

Responsibility	Number of KIs
<b>Planning and implementation of nutritional care for EVD patients (protocols, feeding of patients, etc.)</b>	23
<b>Clinical care for EVD patients only</b>	3

## 2014 Interim Guidelines—awareness and usefulness as perceived by the interviewed practitioners

Almost all (n=24) KIs were familiar with the 2014 iGL issued by WHO/UNICEF/WFP. KIs actively responding to the 2014 outbreak before the release of the 2014 iGL reported developing their own guidance. Two KIs were unfamiliar with the 2014 iGL and only had knowledge of the guidelines issued in 2018 by WHO/Ministry of Health DRC/UNICEF [8].

Most organizations (8 out of 12) developed their own protocol/guidance on nutritional care during the West Africa EVD outbreak. Some aligned their protocols to the 2014 iGL upon publication. It was clear that staff were working to identify best practices on the provision of food, including the method of preparation and distribution, what to provide to patients, and how.

One-third of the KIs found the 2014 iGL not to be practical. While the technical aspects were acceptable, the feasibility was questioned as it did not provide sufficient practical applications. Protocols developed by individual

organizations were more detailed on what types of foods to provide and how to provide them. However, at least half of the KIs stated that the 2014 iGL were still useful, specifically the decision tree. KIs stated that despite the lack of evidence base for the 2014 iGL, it provided some guidance, especially in the beginning of the West Africa outbreak. Most KIs agreed it was essential to develop the guidance continuously and to contextualize it within the countries affected.

KIs noted that information was missing in the 2014 iGL that could have contributed to better organization of the nutritional care for EVD patients, Box 2. Information that would have been desirable, but was lacking included: how to use more local foods as part of the nutritional care; how to organize the food system and communication between patients and providers; the caloric needs and concrete Standard Operating Procedures (SOPs).



### Box 2. Information that was missing in the 2014 iGL according to KIs.

- How to use more local foods in the nutritional care (KIs stated there was an overemphasis on specific products, such as ready-to-use therapeutic foods (RUTF), ready-to-use supplementary foods (RUSF), fortified porridges such as Corn-Soy-Blend (CSB) and therapeutic milks)?
- How to organize a food system within an ETU, e.g., how to organize the patients' diets, the preparation, and transfer to patients, planning of supplies in relation to the number of patients, specific instructions for kitchen staff?
- How to relay nutritional information from patients to nurses and/or nutritionists?
- What are the caloric needs of patients?
- What are the concrete SOPs for nutritional care in ETUs (KIs stated that there are many on health)?
- How to organize the care in or near ETU of children who were separated from mothers, i.e., nursery care?

Some KIs questioned the recommended use of therapeutic milk in the 2014 iGL, because the local community was not regularly using milk as part of their diet. Additionally, it was questioned whether milk would aggravate diarrhea.

KIs also recognized limitations in their performance during the West Africa outbreak because of the focus on the use

of specialized products (e.g., therapeutic milks, ready-to-use therapeutic foods (RUTF), fortified porridges such as Corn-Soy-Blend (CSB)), despite the desire of patients to consume local diets:

'iGL recommended certain specific food products and local foods. Patients did not accept the porridge made from specialized products. A lot of food was wasted. Critically sick patients preferred their local food. But local foods are not fortified.'

'We asked initially support from experts who were specialized in acute malnutrition, but we should have asked experts that knew a lot about very sick patients, and not those. We needed rather advice from experts from hospital settings, e.g., perhaps protocols needed as if they were surgical patients.'



Patients did not accept the porridge made from specialized products. . . Critically sick patients preferred their local food. But local foods are not fortified.

## Nutritional care for EVD patients in ETUs—practical experiences from interviewed practitioners

### Importance of nutritional care

KIs and their colleagues perceived the importance of nutritional care in EVD patients in different ways. Although most KIs noted the importance of the

role of nutrition in patient care, some KIs mentioned that clinical staff was predominantly concerned with medical treatment:

'Nutrition wasn't such an issue in Ebola, there were a lot of other clinical issues of concern than the nutritional status of patients. The biggest risk of clinical care was heat stress for patients and staff.'

'There was no focus on food and nutrition. Nobody was checking if people had actually eaten their food.'

'As there was not much malnutrition, staff also did not prioritize nutrition.'

'Teams are under pressure, and they forget that patients need to eat.'

'We had medical doctors from country X; they said 'we are here to save lives', nutrition was not seen as important.'

'Medical doctors stated that nutrition was not important, even if they were malnourished and treated, they might still not survive. They just need to survive EVD.'



Other KIs were members of teams that acknowledged the role of nutrition in the care of the patients. It was

seen as a responsibility of the general nursing care.

‘Nutrition should go hand in hand with medical treatment; we can see what we can give to reduce vomiting or increase appetite, etc.’

‘Balanced nutrition is best for infectious disease; I don’t see why it should be different with EVD.’

‘Younger male physicians had come to “fight” Ebola. I said we fight Ebola by feeding people and supportive therapy and that was missing among younger male physicians... When in outbreak mode to think about nutrition is really hard. Most are very much focused on medication, vaccination, etc... Now we try to do more evidence-based care, but I don’t need to give you evidence of nutrition’s influence on EVD patients, it’s part of good nursing care. It is evident, just like bedsores or nutrition in HIV or TB, I don’t have to provide evidence on why bedsores need prevention!’



Younger male physicians had come to “fight” Ebola. I said we fight Ebola by feeding people and supportive therapy...

Various KIs mentioned the important role of foods for patients’ morale. They stated that this possibly contributed to patients’ recovery. One medical doctor noted it was also crucial for the morale of health workers: *‘The fact we did not look at the nutrition well had a big impact; the health staff asked us why we could not do more for the EVD patients*

*concerning foods. We did not, and this was bad for the staff’s morale as well for the patients. It was difficult for the health workers not to provide what the EVD patients wanted. The patients needed to eat, patients wanted to eat certain things, and we didn’t give that. It demotivated the staff, and also posed ethical problems for them. It was also demoralizing for patients.’*

## Food preparation and distribution

### Food preparation and transport

Half of the organizations providing food to EVD patients, prepared in onsite kitchens run by the organizations responsible for ETUs; the other half contracted local catering companies. One organization initially ran a

kitchen and then transitioned to catering, while a second organization reversed this pattern. Both options had advantages and disadvantages, see Table 7.

**Table 7. Perceptions expressed by KIs on advantages and disadvantages of using catering and onsite kitchens in preparation of foods for EVD patients in ETUs.**

Method of Food Preparation	Advantages	Disadvantages
<b>Catering—outsourced</b>	Fewer human resources to manage; easy to make culturally appropriate meals; more cost-effective; empowerment of the local community to contribute to patients’ needs	Expensive; transport to ETU not always included; lack of hygiene control; limited choice of catering companies
<b>Onsite kitchen</b>	More oversight on quality of food, preparation methods and meal times; more flexibility for meeting patients’ needs (foods as well as timing)	More staff to manage

## Most KIs had experienced challenges in the provision of foods in West Africa and DRC:

‘They were constructing the ETU. This included a kitchenette for the staff meals. When I asked about the meals for the patients, everybody remained silent. They had forgotten the issue on meals preparation for patients.’

‘Food supplies were probably a greater problem in Ministry of Health hospitals where families were normally bringing in support and resources... One hospital was not able to provide adequate support for nutrition. They mostly had doctors; many nurses had left; they had problems concerning food for patients.’

‘We found a major problem in ETUs in terms of food that was provided to patients. In the beginning, food was provided once a day. The food supply was low.’

‘Catering was the only option, ...but delivering food is not the same as nutritional care.’

‘There were food availability problems in the beginning: NGOs knew they were not feeding well. Some died maybe because they were not eating well. We knew we had to provide nutritional care.’

KIs noted that foods were transported to the patients in the ETU ward with confirmed EVD patients (Red Zone) through slides, hatches, or staff entrances. Food was primarily provided on hard plastic plates or polystyrene compartment trays. Additionally, plastic cups, sippy cups, bowls, small plastic bags, or mineral bottles were used. Spoons were typically the only utensil provided. However, KIs noted the usefulness of straws which were less frequently used. Hard plastic materials were disinfected

after use or burned, and all other materials and leftover food were disposed of as hazardous materials. Foods were individually packaged; some ETUs labeled commodities with patient numbers, patient names, or just the composition of the meal. One KI stated they would never use names because of confidentiality issues. Food was placed on tables or chairs at the bedside or in communal areas for those who could eat at a table. Various challenges were reported:

‘We had initially no idea how to get food in the Red Zone except through changing rooms. But we did not want to mix food with health staff; we had to set up a food hatch system. However, one night, a child tried to escape from the Red Zone through the hatch.’

‘Food was sitting in big bags. Nurses would give food in polystyrene trays. Soup was in a plastic bag. Adult patients were not able to untie the knot. They were not strong enough to eat with their hands. Food would just stay there. Nurses would be busy. Nobody was checking if people had actually eaten their food.’

‘For fluids, big 1-1.5 liter plastic bottles (for oral rehydration salts [ORS]) were provided, but people were too weak to pick up. Water was too hot. 40 degrees Celsius.’

Various KIs questioned whether nutritional care in ETUs was similar to nutritional care in any hospital setting or whether it required a very different setup from hospitals or stabilization centers.

### Meal composition

KIs agreed that the provision of meals and snacks evolved over time with much trial and error. Many followed the 2014 iGL, but had to adapt it to the context. There was little standardization across organizations and menus and approaches varied. Some organizations were limited on the types of foods available, which led to the use of specialized products (RUTF, High Energy Biscuits, therapeutic milks,

ready-to-use supplementary foods (RUSF), and/or CSB). The ease of use of the products by staff was also a factor in their selection. All organizations attempted to provide a balanced diet through the aid of specialized products. These specialized products were generally the recommended commodities in the 2014 iGL. KIs mentioned that the rationale behind the use of RUTF and therapeutic milks was the nutrient density of the products, easier consumption for patients with difficulty swallowing, and consumption without utensils.

Overall, three meals and 2 to 3 snacks were provided in most ETUs. Meals were provided in different consistencies: standard,

soft/semi-solid, and liquid. Typical meals were as follows:

- Breakfast: porridges (often made from CSB), RUTF, therapeutic milks, fruits/juices, bread, local doughnuts, eggs
- Lunch: often of a standard 'family' meal made from staple foods and meat/fish/chicken, sauce, beans, oil, local soup
- Dinner: similar to lunch or breakfast

Snacks included bread, fruits, biscuits, RUTF, RUSF, crisps, sweets. Some ETUs allowed snacks to be provided upon request, while others followed fixed schedules. Night-

time snacks were provided in some ETUs and consisted of RUTF or RUSF.

Liquid diets for very sick and young children were mainly therapeutic milks, soups, or RUTF diluted with water. Semi-solid/soft foods mainly consisted of mashed regular meals (listed above), RUTF, RUSF, porridges, or soups.

The caseload of ETUs had an impact on the provision of food and nutritional care. KIs reported when there were fewer patients, 20-30, it was easier to manage food, and there was greater visibility on actual consumption by patients.

“ These specialized products, patients did not eat it. This was piling up in the Red Zone, and health workers told me it was becoming a health hazard inside, and leftover food had to be burnt.

## Patients' dietary preferences and intake

The majority of adult patients in ETUS covered by the KIs did not prefer specialized products. Reasons given for the dislike of the products included the monotony of diet and lack of palatability. Similar experiences were captured in both West

Africa and DRC. This resulted in patients not consuming the supplied foods, but also significant wastage in the Red Zone, which created a health hazard. KIs mentioned numerous challenges:

'At arrival, the food systems and how they were organized were based on the use of RUTF, RUSF; Many people did not like this and wanted to have "family" meals.'

'These specialized products, patients did not eat it. This was piling up in the Red Zone, and health workers told me it was becoming a health hazard inside, and leftover food had to be burnt.'

'Patients did not accept the porridge made from specialized products. A lot of food was wasted. Critically sick patients preferred their local food. But local foods are not fortified.'

'First, we used all these ready to use products, later more comfort food. We had to let go from the typical Community Management of Acute Malnutrition (CMAM) approach, but this I found out too late...'

'Adults in critical stage got RUTF, but the feedback was not positive, so we continued with local foods.'

'Adults were not eating RUTF. But it was important for micronutrients. We let them eat local food by mixing local porridge with RUTF. That was more acceptable than giving RUTF alone.'

'Adults receiving RUTF were not happy. They wanted local food. We saw that patients weren't eating and food was rotting at the bedside. We organized more rigorous criteria for who got therapeutic milks or RUTF, the dosage, and even local food; but I still pushed for patients to eat RUTF packets.'

'In DRC we have many fruits; the nutritional care should not be with these specialized products. It works maybe well in other African countries. Some organizations insist on giving 2 RUTF sachets/day and leaving meals as secondary. This is problematic for both patient and health workers.'

Many KIs were torn between what they thought was best in the given context and the reality of the refusal of foods by adults. They attempted to improve palatability. In addition to RUTF and RUSF, CSB was used by various organizations. Adding lemon or banana improved significantly the acceptance of CSB, for more reasons than taste: *'In Liberia, we gave CSB to the patients; it reminded them of the time they were refugees and fled the country because of war-time. When they saw this CSB again, it was a bad experience for them. So I modified the taste of CSB to make it not as bad for them.'*

This experience drove some organizations to shift to a more patient-centered approach, taking into account the patients' preferences for local foods. However, other organizations continued to provide only standard meals with limited flexibility to meet patient preferences. As one KI stated: *'Not eating by patients was a big problem; that was less a problem later when we gave them what they wanted. We had to individualize care because some were not eating, and many were dying from hypoglycemia. Therefore this form of care was sought.'*

Liquid diets were problematic for some patients. This was likely a combination of the commodity (therapeutic milks) and the patients' weakness, lack of appetite, and the monotonous diet. Providing sufficient nutrition to critically ill patients was a significant issue. Nausea, vomiting, anorexia, weakness, and hiccups led to difficulty in consuming foods which resulted in weight loss in some cases. KIs stated that once patients began to recover, and their appetite returned, patients could consume large amounts of food. Many organizations allowed for double portions to meet the appetite of these patients.

The use of therapeutic milks, such as F75 and F100, as a liquid diet for adults also raised controversy over the role of secondary lactose intolerance and diarrhea. Opinions varied among KIs. One KI stated: *'F75 and F100 were given, but then patients had diarrhea, so it wasn't certain whether it was the disease or the therapeutic milk. But the local community does not use milk products'* (for adults).

The West Africa outbreak identified two local foods which were preferred and consumed by adults, including extremely ill patients: pepper soup and coconut water (Boxes 3 and 4).

### **Box 3. Pepper soup**

Pepper soup is from the English-speaking parts of West Africa and is prepared using various meats, chili peppers, and nutmeg. It is a spicy soup with a light, watery texture. It is considered to be a delicacy by some people in Western Africa. Additionally, some West Africans believe that the soup has medicinal properties [9].

In West Africa, various KIs mentioned that pepper soup was the preference of very sick patients, with fever, in a catabolic state, anorectic, and/or unwilling to eat. One KI stated: *'As they were sick, nothing worked so we changed the whole menu to pepper soup because the patients did not want anything else.'*



#### **Box 4. Coconut water**

One KI who oversaw a relatively large ETUs stated: *'It was in hospital X where it began, by accident. The hospital had a certain moment no access to potable water, they were buying water in plastic bags, but patients weren't able to hold plastic bags. One family brought coconuts and patients were able to drink the coconut water and hold the coconut. The flesh was soft and culturally accepted. We started to buy between 200-300 coconuts each day. We hired someone to cut coconuts for patients. However, coconuts were only in season until November, and we got through the urgent phase before November. By December we ran out of coconuts. Coconuts were burned (after use), the husks helped to burn the other plastics and waste. I think it had a positive impact on mortality, but I don't have enough detail to publish'...* *'We worked with one of the WHO experts on the use of coconuts and diarrhea. Coconut water as a replacement for ORS. I didn't see that it had an impact until the change in the case fatality rate. There was no way to identify the coconuts were having an impact. Self-administering of fluids was important and beneficial. Patients were taking in much more fluid, so I feel consumption of coconuts made a tangible difference. Keeping patients hydrated seemed to be having them recover quickly.'*

Another KI heard that coconuts were a success because of the potassium content. He stated: *'I started to use coconuts and soon coconuts were piling up in the Red zone. The ETU management asked me to stop. Then I looked for packaged coconut water, but there were supply limitations.'*

KIs raised the issue of taste changes as a result of EVD and/or the treatment, which might have influenced the patients' dietary intake. There was no general consensus

on the impact of taste change as an important factor in the treatment of EVD.

*'I received the vaccine and lost appetite. But there are also drugs that interfere with taste: antibiotics and analgesics, etc.'*

*'A lot of the patients just responded stating that "nothing tastes good"'*

*'It was known that patients lose their sense of taste; therefore, nutritional support (beyond pepper soup) should have been given a priority; maybe we could have worked more on the right blend of spices, we needed strong flavors.'*

## Nutritional care related to EVD symptoms

Some KIs mentioned that there was an unwritten rule that the first 7-10 days after admission to ETUs were crucial. Regarding nutritional support, one KI stated, *'If they survive the first week and especially the first few days, nutritional support is very important for survival. Exactly then we need to listen and give them what they want.'*

In the West Africa outbreak, anorexia, vomiting, and diarrhea were particularly severe [10]. As one KI indicated:

*'Symptoms of diarrhea and vomiting was what was killing them. We saw that (once the patient was admitted in the ETU) we needed to intervene earlier before the vomiting/diarrhea would start. We stopped waiting for the transition*

*phase with foods/drinks. We didn't wait until the critical stage to start with foods/drinks/fluids. Once diarrhea or vomiting is present, it is difficult to reverse it. Once the patients got critically ill, then dehydration went so fast... There were four men, still walking into the clinic but diagnosed with EVD, then the vomiting and diarrhea started, they all died at day 3... I learned to put in foods/drinks/fluids before diarrhea began. I cannot directly link to outcomes, but I felt it was working.'* KIs stated that the use of IV fluids was hotly debated. KIs had specific opinions on the use of ORS, IV fluid, and the use of foods during rehydration:

**'IV fluid provision is a double-edged sword: It helps the patient to reduce shock. But when not well nourished it is more difficult to hold on to fluids. Overall, IV fluid did not impact mortality. There were mixed results for both adults and children. IV fluid could increase and decrease mortality.'**

**'ORS and its importance are forgotten. ORS would be enough for EVD maybe, and IV fluids are overrated.'**

**'Adults who received IV fluids had little to no oral intake. Once they were off the IV they were given foods. I am convinced we can get them eating earlier if people had looked into nutrition sooner.'**

Some KIs worked diligently to improve oral fluid intake by EVD patients. As one KI stated: *'Patients would take ORS, but would come to ask for soda and coconuts (which we gave). The self-administration, acceptance, and willingness to take in fluids were important!'* Some organizations ensured that there was cold water, especially in the context of the hot climate of West Africa: *'Plastic packets of water, we stuffed the fridges full of those. We threw them over the fence for people to drink. They were nice and cold and appreciated.'* Others organized to have ice for patients with sore throats.

Most ETUs did not allow the use of nasogastric tubes (NGT) in West Africa, because of various associated risks described in the 2014 iGL [2]. Some KIs advocated to allow the use of NGTs, but to date, there is no clear consensus amongst responders.

The use of sodas was discouraged in the 2014 iGL. *'Owing to the high osmolarity of sugary carbonated beverages or juices, it is important that they are not given to patients with diarrhea. These products are low in electrolytes and nearly all essential nutrients'* [2]. However, some KIs argued that they were useful, including for patients with diarrhea,

frequently requested by patients, and helped to increase/maintain fluid intake. As one KI stated: *'Fizzy drinks were used and received well. They cheered people up.'* At least half of the organizations in this investigation reported the use of soda.

Sip feeds, designed for specific medical purposes, were included as an option for liquid diets in the 2014 iGL. Sip feeds often have a low renal solute load, low osmolarity, and come in lactose-free options. However, no KIs reported having used these products in ETUs. Some KIs stated having not tried sip feeds for the very sick might be a missed opportunity. Sip feeds, though not ideal, may be more acceptable to adult patients than therapeutic milks or RUTFs. Some clinical practitioners recommended them for critical care, especially if no other viable options were present. Various reasons of non-use were reported: unavailability in organization supply catalogs, unfamiliarity with product, substantial lead time for ordering and receipt, customs issues, the expense of product, and limited shelf life.

## Roles in nutritional care



Generally, clinical staff determined what was provided to patients, including the type and consistency of food. Most KIs noted that there was no recording of information on dietary needs or preferences, only verbal sharing of information.

In the West Africa outbreak, many organizations had nutritional staff. However, nutritionists were not always allowed in ETUs, which was perceived as an impediment to improving the nutritional care of patients. Feedback from patients and health staff to nutritional managers was minimal:

“ Nutritional care goes beyond just “providing” food. In DRC, we are now starting to learn what could be the impact of incorporating nutritional care into the response.

‘We need leadership in nutritional care for patients. We have a nutritionist and medical staff says that the nutritionist will do it and the medical team forgets to engage in nutritional care despite the fact they are most of the time with the patient, but then the patient is left alone, and the medical team is not providing feedback to the nutritionist.’

‘Clinical staff would often hear things, but keep it to themselves (not intentionally). The information wouldn’t always go back to the kitchen or nutrition advisors. Building relationships with the clinical staff was vital because they would speak up more about nutritional needs of patients.’

‘Nutritional care goes beyond just “providing” food. In DRC, we are now starting to learn what could be the impact of incorporating nutritional care into the response.’

Only two KIs stated that they were able to monitor the content and quantity of food consumed by patients through a recording chart they developed. Their system monitored improvement or decline in appetite and provided insight into patient status with regard to nutrition: ‘We knew who was deteriorating as they were

*not eating (anymore)*’. Others tried but did not have the capacity for monitoring.

Some KIs also mentioned the clinical staff’s nationality/ background resulted in different perceptions of nutritional care.

‘Western staff isn’t used to nutrition being a priority in their country as there is less malnutrition...they are wrapped up in details which made them lose sight of providing care.’

‘The perspective on nutrition is very different for Western-trained staff and national staff; Western-educated staff just refer to a dietitian in hospitals.’

Some KIs resorted to training of staff on the basics of nutritional care. However, over time in DRC, various KIs mentioned that the role and importance of nutritionists

have increased. Some KIs mentioned that nutritional care improved if some clinical staff in the ETUs were present who strongly advocated for nutritional care.

**'In many ETUs in DRC, they have now nutritionists but still no real discussion with medical teams.'**

**'We have 5-6 nutritionists working, and there is always one present who works with the medical team. It is a very different approach than in the past in the outbreak of EVD in 2012 and 2014 in DRC. Nutrition was not at all developed at the time and not well organized. We learned from experience. We want to improve and adapt treatment and improve the means around nutrition and UNICEF pushed a lot.'**

**'Nutritionists didn't enter the area where the patients are. They were NOT there to follow and see how the patients are eating. Only to help in food preparation system. Now there are discussions on how nutritionists can be more involved.'**



**The staff was overloaded, it was impossible to help everybody with feeding.**

## Feeding support

Three KIs estimated that at any time during the height of the outbreak in West Africa, an ETU would have approximately 40% severely ill, 20% moderately ill and 40% ambulatory patients. Feeding support provided to patients varied by ETU, as well as by organization. Patients in need of support were assisted by different types of staff: nutritional support staff, nutritionists, nursing aides, community members, community health workers, general infection prevention and control (IPC) staff and sometimes nurses, and doctors as they had increased access to the patients. Patients also supported each other. *'Patients helped each other with feeding support, and sometimes the patients belonged to the same family'*. Some KIs mentioned it was often a collaborative effort at the meal times. Whoever was present assisted. However, many KIs stated that in the beginning there was simply not enough staff to effectively

provide support for feeding in light of the essential tasks to run the ETU. As the response matured, EVD survivors started to play a significant role in some ETUs as feeding support 'staff', often receiving a per diem. At least six out of the 12 organizations 'employed' EVD survivors to provide feeding support. While some EVD survivors found this role to be psychologically difficult, others appreciated the opportunity to be useful while delaying their return to their communities and the associated stigma.

One KI described the construction of simple furniture, wooden triangles, which enabled patients to sit upright to help with the feeding process. Another KI stated: *'The staff was overloaded, it was impossible to help everybody with feeding. Pillows helped. We also focused on putting the patient in a seated position with sitting support furniture, like a wooden pillow.'*





## Malnutrition—screening and treatment

KIs stated that very few EVD patients were acutely malnourished upon admission. Some patients did lose weight and possibly developed malnutrition during their stay. KIs stated that though most intended to perform anthropometric measurements at admission, this was infrequently implemented because of the 'no touch policy' or lack of time. At best, weight was measured. Some organizations only screened children at discharge for referral purposes or provision of food upon discharge. One organization only measured mid-upper arm circumference

(MUAC) when children <5 years of age were suspected to be acutely malnourished. However, this was still limited by the need to sterilize tapes after each measurement. If needed, most organizations had the means to treat malnutrition as products used for the treatment of malnutrition were recommended for EVD patients in WHO's 2014 iGL.

Overall, KIs stated that malnutrition was not a significant issue; however, no prevalence data were available, as no data were collected.

'Medical doctors stated that nutrition was not important, even if they were malnourished and treated, they might still not survive. They just need to survive EVD.'

'With regard to (mal)nutrition; it might not make so much difference; it is hard enough to make them eat.'

'The high child mortality was because so many children were unaccompanied. Children did not trust anyone, and there was no encouragement to eat. And malnutrition makes a significant difference with Ebola.'

'Malnourished children were discharged to treatment centers. They did not advocate to treat severe acute malnutrition (SAM) in ETU specifically. They had a specific protocol for SAM in therapeutic centers for nutrition for ex-EVD patients/children; our understanding was that patients got wasted in ETUs as many had complications and little appetite.'

One KI questioned the use of therapeutic milks for non-malnourished children: *'In DRC, every child is prescribed F75 or F100, we don't find this is appropriate. If a child is not malnourished it can eat normal food, and they want that! ... There is no reason to give these specific products from other*

*sites where they need it, away from CMAM programmes. Therapeutic milks are still limited in availability. ... And children do not necessarily like these milks, they want real food: cassava leaves, rice, chicken/meat and fufu.*

## Intake of specific nutrients

Four KIs (3 medical doctors, 1 nurse/nutritional manager) expressed significant concerns on hypo-albuminemia

in EVD patients. The following captures the concern of practitioners:

‘EVD patients are all low in protein (hypo-albuminemia). In DRC, we have constant lab analyses; we see the biochemistry constantly and see this disaster of lack of albumin.’

‘We found that albumin is very low in EVD patients; almost no patients have normal albumin levels. We have no scientific evidence re albumin, but we know for a fact it is low (for all patients, not only the very sick) and it has a link with nutrition. And we know high energy/protein intake can help.’

‘We did not measure albumin; I guess it was low. We gave crystalline Ringer Lactate without albumin, if it was higher they could have held on better to fluids.’

‘They had low proteins, inadequate stores. IV fluid can make hypo-albuminemia worse especially because we don’t give fluids with it, such as blood.’

‘Patients have hypo-proteinemia – it will aggravate the fluid loss. We lost a few patients because they did not get the food they wanted and were not eating in a week. Many doctors want the patients to be fasting because of vomiting, diarrhea, and risk of sepsis, but if they don’t eat the drugs won’t work enough. Those doctors want the gastro-intestinal tract to be empty, then they give IV and then re-evaluate but often forget that the patients need to eat, so for one week they won’t get enough. This focus on fasting paralyzes the nutritional care and follow-up of the patient. The new slogan here is aggressive rehydration, referring to intense fluid management—so we give a lot of fluid but patients still lose water within tissues, and hypovolemia is present, capillary leak and edema exists; in fact the patient is dehydrated. Therefore the patient needs food and needs the proteins to reduce the hypo-albuminemia.’

KIs mentioned the need for specific micronutrients, such as magnesium, potassium, zinc, and vitamins A and K. One KI initially added micronutrient powders to prepared foods, but ceased as he thought it was unethical to add this without the patient’s explicit consent. The powders were subsequently directly provided in sachets to the patients,

but the staff told him that nobody used them. However, other organizations added micronutrients to centrally prepared food without explicit patient approval. Concerning the 2018-19 DRC outbreak, 2 KIs reported that laboratory analyses are increasingly assisting in determining the dietary needs of patients.

## **Lessons learned according to the interviewed practitioners**

KIs were asked what they perceived as lessons learned based on the experiences they had on nutritional care for EVD patients in ETUs. The following section describes the

most important reported lessons learned categorized by themes and sub-themes as described in Box 1.

### **Interim Guidelines WHO/UNICEF/WFP 2014**

There was a general consensus among KIs that the 2014 iGL, though initially useful for some organizations providing some kind of guidance, became less useful because of the focus on specialized products and did not evolve over time

(despite the stated need for review after six months).

Box 5 lists the lessons learned as expressed by the KIs on the nutritional care for EVD patients in ETUs.



## **Box 5. Lessons learned as expressed by the practitioners on the nutritional care for EVD patients in ETUs**

### **Importance of nutritional care**

**Nutritional care and/or its management** is everybody's responsibility and can impact treatment outcomes.

**Food helped patients to survive**, and it was important for morale and comfort. As one KI stated, *'The importance of the psychological function of food; we did not imagine how important that was at the time.'*

**The care for children with EVD** was specific and challenging, including those that were dependent on breastfeeding. Many children were scared, needed affection, psycho-social support, and encouragement to eat. Though children were in the minority, it required much additional support which was not always provided in the beginning.

### **Food preparation and distribution**

**Outsourced food preparation** through catering or kitchen had advantages and disadvantages. Regardless of the different options, it was essential to have quality control on what was prepared, how it was delivered, and adherence to high hygienic standards.

**Uneaten foods** at the patient's bedside became a health hazard in the ETUs.

### **Patients' dietary preferences and intake**

The majority of **patients in ETUs, and especially adults, did not like to eat specialized products**, such as therapeutic milks, RUTFs, fortified porridges (CSB), regardless of their state of disease.

**Local foods were preferred** and consumed over specialized products.

### **Nutritional care related to EVD symptoms (and in general)**

**Transmission of messages** related to nutritional care and general communication on nutritional needs was problematic within the ETU.

### **Roles in nutritional care**

**The turnover among clinical staff** and the limited interest and knowledge on nutrition was not conducive for the patients' care and nutritional needs (especially among foreign medical staff). There was a need for constant (re)training on nutritional care and food hygiene. It was felt that the presence of nutritionists had been essential for improved nutritional care, and those that directly accessed the patients within the ETU were able to adjust initial protocols that were inadequate. Some KIs stated that the role of strong nutritional advocates among the medical doctors paved the way for improvements in nutritional care as well as training.

### **Feeding support**

At the beginning of the West Africa outbreak, **feeding support to very sick and pediatric patients was problematic**. This improved when EVD survivors became available for feeding support and when nutritional care was seen as part of nursing care.

### **Malnutrition—screening and treatment**

**It was felt like a missed opportunity not to have collected data** on patients' nutrition, anthropometry, and patients' treatment outcomes, though the reasons were recognized as justified in the West Africa outbreak (e.g., workload of ETU staff).

### **Intake of specific nutrients**

**Hypo-albuminemia is an important problem** in many EVD patients and is/was not necessarily addressed.

In addition, many KIs expressed regret as to not having had information collected on various issues, such as:

- Evolution of nutritional status of patients in ETUs (through initial screening and monitoring)
- Link of comorbidity malnutrition/EVD and treatment outcomes
- Perceptions, experiences of patients during their stay in the ETU
- If and how nutritional support related to outcomes (mortality, morbidity)
- How EVD impacted patients' eating and preferences and what could have worked better
- How to deal with breastfeeding in the context of an ETU

The lack of this information hampered the improvements in nutritional care according to many KIs.



## Recommendations for future and ongoing outbreaks concerning nutritional care according to interviewed practitioners

KIs were asked what they would do differently in the context of ETUs and working on nutritional support for EVD patients in a subsequent outbreak. Answers were expressed as recommendations for current and future outbreaks.

KIs recommended that greater concerted action is required to work collaboratively to develop context-specific guidance

on nutritional care for EVD patients in ETUs. This guidance should address past lessons learned and include more practical guidance on implementation. Box 6 lists the main recommendations related to nutritional care for EVD patients in ETUs, according to KIs.



## Box 6. Recommendations as expressed by the practitioners on the nutritional care for EVD patients in ETUs

### Importance of nutritional care

The treatment of EVD patients should be regarded in a more holistic way where nutritional care plays an important part. Many KIs recognize the responsibility of most staff in the nutritional care plan. Doctors, nurses, and other support staff as well as nutritionists all have a role to play.

If the scale of the EVD outbreak is sufficiently large, establishing specific pediatric units should be considered. In addition to pediatric medical care, psycho-social, psycho-motor, nutritional support should be provided.

### Food preparation, distribution, and patients' dietary preferences and intake

Local foods should form the basis of all meals and snacks, and specialized products can be used, but should not be the default option. It is recommended to:

- Assess all possibilities of using local foods while taking into account local perceptions of comfort/ medicinal foods.
- Provide meals that allow adjustments for the individual patient (consistency and taste preference, as well as nutritional specific needs; e.g., increased intake of protein, potassium). It is helpful to have some kind of meal standardization to use as a base with additional adjustments and possibilities of choice.
- Attempt to have a nutritionally balanced diet via local foods. If specialized products can help and are accepted, they can be used as such or altered with taste adjustments (e.g., CSB porridge mix with local fruits).
- Ensure snacks are available any time, including nighttime, especially in hot climates.
- Ensure a participatory approach with EVD patients on nutritional care.
- Evaluate nutritional care regularly, especially in a rumor sensitive context.

### Nutritional care related to EVD symptoms (and in general)

The use of sip feeds could be considered for the very sick. However, this must be cautiously explored (taking into account palatability, acceptability by the patient, and logistical constraints).

### Roles in nutritional care

Training on nutritional care and operational aspects should be provided to new staff working in ETUs regularly.

### Feeding support

Feeding support in ETUs is an essential part of the care in ETUs. All small children and all critically ill patients need some feeding support, ideally by EVD survivors or vaccinated staff in the ETU. The use of specialized products should not replace feeding support to adults or children. Feeding support for children also provides critical psycho-social care. As one KI stated: *'EVD survivors were important for playing, affection and helping children to eat.'*

### Malnutrition—screening and treatment

Screening and monitoring of the nutritional status are essential in ETUs. This is particularly important, but not limited to children. Additional resources need to be mobilized for this activity.

### Intake of specific nutrients

If possible, continue enteral feeding during treatment and ensure protein intake orally.

Ensure timely feeding (before the patient becomes catabolic) and if possible and acceptable provide protein containing foods during rehydration with IV and/or ORS (despite diarrhea, vomiting). Efforts should be made, especially for the very sick, to provide preferred foods that also include proteins. This is particularly important to address hypo-albuminemia.

It is worthwhile to explore how metabolic conditions, such as hypoglycemia, hypo/hypercalcemia, hypo/hyperkalemia, and the use of laboratory analyses can help to refine and improve nutritional care and outcomes.

## Next steps



**Feeding support in ETUs is an essential part of the care in ETUs. All small children and all critically ill patients need some feeding support.**

The purpose of this investigation was to collate the experiences of practitioners on nutritional care in ETUs. It is the first investigation that attempted to better understand how nutritional support was managed in ETUs and the operational challenges faced by practitioners during the 2014–2016 outbreak in West Africa, as well in the current outbreak in DRC.

It is clear that the 2014 iGL served a guiding purpose. A vast amount of learning has occurred from the 2014–2016 and current EVD outbreaks for the interim guidelines to be revised. The current protocol on nutritional care for EVD patients, issued in August 2018 by WHO, the Ministry of Health of DRC and UNICEF has a heavy focus on the use of specialized products in all stages of the disease [8]. The feasibility and effectiveness of the protocol in terms of acceptability should be evaluated, taking into account the perspectives of staff and patients.

Ideally, diets should be guided by locally preferred foods and possibly additional specialized products to ensure the oral intake of proteins and micronutrients. Specialized products can have a role, however their use should be determined by the needs of and acceptability by each patient.

Without scientific evidence on how nutritional care should be provided, there is a need for continuous monitoring of practice and lessons learned. What may work in DRC may not translate to other outbreaks. However, from this investigation it is clear that some nutritional care practices are universal and relate more to the disease than the geographical locations (e.g. preference for local foods by adults, importance of feeding support).

A step for the near future would be to share the recommendations expressed by the practitioners with a wider audience and assess the support and feasibility of their implementation. Additionally, it is essential to obtain information on the perspectives of EVD patients themselves on the nutritional care they receive or have received. If future research findings are able to inform metabolically optimal nutritional care protocols, if the patients themselves do not consume what is recommended, treatment outcomes might be negatively impacted. While good nutrition cannot cure EVD, it is believed that maintaining the nutritional status of the people affected could improve their response to the treatment.

## Limitations

Limitations of this investigation included a sample size that does not allow the representation of all practitioners working in nutritional care in ETUs. However, most international organizations that have responded or are currently involved in EVD have been represented. Nevertheless, the experiences from Ministries of Health have not been documented through this investigation and therefore findings are skewed towards lessons learned

recorded from international staff. This investigation did not specifically assess the challenges around infant feeding in the EVD context in ETUs. This topic merits more in-depth studies. While findings from West Africa response outbreak cannot necessarily be extrapolated to the context in DRC, this investigation did not find striking differences in practitioners experiences between those that worked in DRC or West Africa.

## Conclusions

This investigation underscored the importance of documenting experiences of practitioners on nutritional care in emerging infectious diseases for which limited scientific evidence exists and for which interim guidelines are produced to fill in knowledge gaps. It also emphasized the importance of nutritional care in ETUs during

treatment. In the absence of rigorous scientific research on the specific role of macro- and micronutrients, documenting both patients' as well as practitioners' experiences are essential and should guide adjustments for interim guidelines and standard operational procedures for nutritional care in ETUs.

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# Annex 1. Key Informant Questionnaire: EVD and Nutritional Support

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## Introduction

Firstly, we would like to thank you for your assistance and support as a key informant for this project. Once again, the goal of the project is to determine how nutritional care and support, as it relates to EVD, has been/is currently implemented in outbreak situations and the means by which this can be improved for future outbreaks. We are eager to learn about your experiences and expertise as it may provide valuable information for this gap we are trying to fill in the literature. Before we begin, we wanted to inform you a little bit about this process:

- We will not be recording this interview; however, we will be taking notes on whatever you tell us. Is that okay with you?
  - If you choose to, we can keep the information you share with us completely anonymous
  - Following the interview, you will have the opportunity to decide whether we can acknowledge you or your organization as this information may become published
  - We're anticipating this interview to last 30 – 45 minutes
- 

## General Section

1. During EVD related work: What organization do you work for? What organization(s) did you work with?
  2. When and where did you work?
  3. In what capacity did you work? (Your background, education, training, etc.)
  4. Were you working in or near an Ebola Treatment Unit (ETU)? What was the bed capacity?
  5. Were you involved in the nutritional care and treatment support aspect of the response? If so, what specific aspect?
- 

## WHO Interim Guidelines Section

6. Have you heard of the WHO interim guidelines (iGL) for nutritional care of children and adults with Ebola Virus Disease (EVD) in treatment centers? If yes, continue. If no, move to "Operational Aspects of Nutritional Support" Section.
7. Did you become aware of the iGL prior to, during or following your response efforts in the 2014 EVD outbreak or current DRC outbreak?
8. How did you become aware? How did you find out about the guidelines?
9. Did you use the iGL?
  - ▶ If not, explain why.
  - ▶ If yes, please explain how you utilized the iGL during the 2014 EVD outbreak or current DRC outbreak.
10. Did you see other organization using the iGL and Please explain how you saw the interim guidelines being utilized during the 2014 EVD outbreak or current DRC outbreak.
11. Do you think these guidelines are useful? Are they practical? Feasible? Clear?
  - ▶ If not, why? How do you think they be adjusted?
  - ▶ If yes, please elaborate.

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## Operational Aspects of Nutritional support

12. Please provide a little insight into your experiences with the operational aspects of nutritional care and support in an EVD outbreak. (what did you do, how, why, etc) (Please share with us more specific information of what you might have seen in the Ebola treatment units. For example, types of meals provided, number of meals per day, macronutrient components, or even food preparation techniques. Examples of meal plans)
13. Please tell us a little bit about the acceptability of nutritional care and support during the 2014 Ebola outbreak or current outbreak in DRC.
14. Did you work with malnutrition in ETUs?
  - ▶ How did you care for malnourished patients if you were aware? What worked best?
  - ▶ If so, what are your opinions on malnutrition and exacerbation of EVD from your response experience(s)?
15. Were there any organizational barriers in caring for the patients concerning nutrition?
16. What are some lessons you learned, as they relate to nutritional care and support of EVD patients?
17. If you could do it over again, would you do anything differently? If so, please explain.
18. Do you think, according to your experience, that the setting or size of an ETU makes a difference in how nutritional support should be organized? If yes, please elaborate.
19. Have you developed or been part of a team that developed other guidance in nutritional support of EVD patients?
20. Do you know if the WHO iGL have ever been evaluated? If so, by who?

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## Conclusion

21. Is there anything else you would like to share?
22. In the scenario that we publish results of the interview, can we acknowledge you? The organization? Both? Neither?
23. What other organizations/people do you think we should contact?

Thank you for taking the time to spend with us today. We are very grateful for your responses and input regarding this topic.

Notes / Interviews observations:



