"We have to work together as one to stop Ebola"

A rapid qualitative study on preparedness and community perceptions

Yei River State, South Sudan

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Anthrologica Save the Children Internews Concern worldwide USAID FROM THE AMERICAN PEOPLE

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Executive Summary

Background

This research was commissioned by the EVD Preparedness Consortium comprising Save the Children, Concern Worldwide and Internews in South Sudan. It provides information on community perceptions about the Ebola outbreak and preparedness activities in Yei River State. The study was commissioned based on the recognition of the importance of integrating social sciences into Ebola outbreak and preparedness activities from the West Africa Ebola outbreak (2013-2016) and subsequent outbreaks in the Democratic Republic of Congo (DRC) in 2018 and 2019. It provides granular information about community's perceptions of activities, particularly disease surveillance, infection prevention and control (IPC), risk communication and community engagement. These details will help the EVD Preparedness Consortium to ensure a localised and agile response to the risk of Ebola in South Sudan. The formative qualitative study was conducted between August and September 2019 in Yei River State.

Methodology

This was a qualitative study using a range of methods, including key informant interviews, community mapping exercises and focus group discussions. Participatory mapping exercises were designed to elicit perspectives, experiences and suggestions from community members and leaders about health seeking behaviour, population movement and community intent in case of an Ebola outbreak. The interviews were designed to gain insights from key government officials, youth leaders, health workers, informal service providers including traditional healers and religious leaders and other members of communities. Data were collected in three research sites: Mahad, Sobe (Yei municipality, Yei Payam) and Payawa (Mugwo Payam). The study included 166 participants, of which 55% were male (N=91) and 45% were female (N=75).

Context, community stakeholders and cross-border movement

Early detection, disease surveillance and mobility. Early detection of Ebola virus is critical for control and containment. Due to the high mobility of the population, gaps and opportunities were identified that could inform future response mechanisms in Yei River State. In the porous border areas of the state, movement patterns change frequently. Population groups who move across borders include armed groups, refugees, returnees, people seeking education and healthcare services, *boda boda* drivers and (legal and illegal) traders. These populations often move covertly and try to actively avoid official borders so as not to be subjected to customs checks and associated bureaucracy (high import and export costs). By using informal routes they often bypass formal screening points. Participants who crossed the border on a frequent or daily basis reported they were "*tired of Ebola measures"* and routinely avoided screening and handwashing. Many called for "*more practical*" disease surveillance mechanisms to encourage communities to self-monitor population movement and suggested engaging with markets, schools, churches and refugee camps on both sides of the border, rather than focusing on formal border crossing points. During the study, numerous community-based stakeholders were identified as having the potential to contribute to local surveillance efforts, particularly those who frequently navigate the borders.

Knowledge and perceptions, care-seeking behaviours and provision of services

Awareness and knowledge. Participants across the study conveyed a high level of awareness about Ebola and many knew about the active outbreak in the DRC. Accuracy of knowledge was more variable across sites, however, with inaccurate explanations about the origins of Ebola frequently expressed particularly in rural areas. These included some negative statements and questioned the role of the international community. When discussing signs and symptoms of Ebola, most participants repeated information disseminated by risk communication partners and could identify at least three signs of infection (e.g., fever, vomiting and diarrhoea), although worryingly, the most frequently reported sign was bleeding from the body. Levels of knowledge about transmission pathways varied, with those in Yei City appearing more likely than those in the rural sites to give accurate descriptions. A number of respondents understood basic self-protection measures and an understanding of some of the IPC measures that had been put in place, but many requested more knowledge and greater details about transmission routes, prevention mechanisms and treatment options, in particular the availability of the Ebola vaccine. Throughout the study, participants

expressed a high level of fear about Ebola, whilst at the same time often asserting that it was not always a priority concern for them.
Health facilities, health worker perceptions and IPC. Across South Sudan, but particularly in rural areas, multiple barriers prevent equitable access to formal healthcare. These challenges were reflected in the study's findings and issues associated with direct and indirect costs were discussed, particularly the high price for consultations and drugs at private hospitals which are often the only source of care available. A number of health workers who had previously been involved in preparedness and screening efforts reported that they worked without salary and emphasised the lack of basic health infrastructure. All called for health facilities to be rebuilt and the health workforce to be trained to enable them to respond not only to Ebola but to other diseases. At the time of research, when Consortium partners were still distributing health materials to support IPC (such as handwashing buckets, gloves, soap, infrared thermometers, isolation tents and bins), health workers confirmed that it was difficult to adhere to IPC measures when they did not have access to basic protective equipment. Others requested more practical training and noted issues they had encountered in providing the most basic of services such as checking patients' temperatures or providing food. At the time of research, health workers asserted that they, like the communities they served, were fearful of Ebola, were aware of the risk of nosocomial infection and felt quite underprepared to deal with a case.

Care-seeking. Participants described seeking services from various cadres of care providers, of which some were involved in Ebola preparedness measures. Participants in urban areas would often visit formal health facilities, but also relied on homecare and local medicine when resources were limited. Those in rural areas often suggested that homecare and local, medicine were the only options available to them. Caring for the sick is normally done by female family members and many women explained that because of lack of household resources it would normally take several days for the family to collect sufficient money to attend a health facility after the onset of illness. They would often try to treat symptoms at home and if this did not work, would seek care from local healers ('*buna*'), religious healers or pharmacists. Local practitioners engaged in the study reported limited knowledge about how to implement IPC measures even though they recognised a need for protective equipment to enable them to care for their patients safely. There were numerous requests to further include local providers in preparedness activities.

Customary burial practices. Burial and funeral rites occupy an important role in South Sudanese society, with '*proper'* burials being seen as essential for both the deceased and the living. Participants from different ethnic groups reported that some customary practices such as washing, dressing and transporting the deceased's body are high-risk activities in the context of Ebola. The study highlighted that it is imperative that the introduction of safe and dignified burial practices are negotiated with community members and fully adapted to the local context.

Communication and community engagement

Information needs and misinformation. There is a pressing need for more information about the Ebola outbreak and preparedness measures to be shared with community members. Information needs change over time and were noted to be different for urban and rural populations. Across the sites there were requests for more information about the origin of Ebola, signs and symptoms of infection, its transmission routes, prevention mechanisms and treatment options. There were requests for further details about the vaccine, therapeutic treatment in health facilities and quality of care, about specific risks and how individuals should adapt their behaviour to keep safe. No detailed information about vaccination had been incorporated into broader communication efforts at the time of this study. Lack of information can be a problem, creating a vacuum in which misinformation readily circulates. Some examples of misinformation were documented, mainly related to perceptions that Ebola is airborne or spread by mosquitoes.

Trusted sources of information and preferred communication channels. When discussing who are the most trusted sources of information about Ebola, the majority of participants suggested health professionals and/or Ebola survivors. Health professionals were not universally trusted, but in general doctors were trusted more than nurses, and formal providers more than pharmacists and local healers. Survivors were trusted because they had experienced Ebola first-hand and could give a personal account. At the time of the study, a wide range of platforms was being used to provide information, but it was evident that there were significant differences in how participants from rural and urban areas accessed information. Most participants in Yei confirmed that they received Ebola awareness messages from multiple channels including local and Juba-based radio, through NGOs and/or the EVD Task Force. In contrast, those in rural areas mainly accessed information via their church and religious leaders, through community or church radio, or from radio stations broadcasting from Uganda or DRC.

Modes of communication and language. Verbal communication was strongly preferred over written materials (in particular due to low literacy levels) and issues were identified relating to the printed IEC material disseminated in Yei. Participants requested that the format or mode of communication and engagement activities be adapted from mass-mobilisation and awareness-raising to constructive two-way dialogue between Ebola preparedness actors and communities. Women suggested video as one of their preferred formats of communication, ideally in the relevant local language. Spoken language is not always comprehended in the same way as written language and it was emphasised that materials in English or Juba Arabic were often poorly understood by community members, even if they could speak those languages to some degree.

Conclusions and recommendations

The population in cross-border communities in South Sudan is facing multiple, and mutually reinforcing public health emergencies, conflict and armed violence, and natural disasters including destructive floods and related food insecurity. Its health system is severely underfunded and lacks the skilled workforce and materials to respond to the threat of Ebola and other illnesses effectively. Ebola preparedness activities should be designed accordingly, tailored with sensitivity towards the needs, priorities and vulnerabilities of communities, whilst contributing to strengthening the pillars of a functioning and resilient health system. Ideally, a holistic approach would be adopted, with serious commitment and investment for both short- and long-term priorities.

In the short-term, there are a number of priorities in order to respond to the immediate threat of an Ebola outbreak. Community-based actors will continue to have an important role, particularly in light of the ongoing insecurity and restricted movement of external response actors in areas most at risk of an outbreak. In order to have the knowledge and ability to respond to an Ebola alert, community actors will need sustained support. It will also be necessary to increase efforts that bridge gaps linking information provision, health promotion and knowledge. Again, this requires targeted efforts and investment that will build the skills of health workers engaged in the formal system as well as community actors so that they can respond together to the threat of disease.

In the long term, it is essential to look beyond the immediate threat of Ebola and there is an urgent need for greater investment to revitalise and rebuild the South Sudanese health system. This should be viewed as part of the broader transition strategy for the Consortium, as well as complementing current efforts to prevent an Ebola outbreak. In practice it means working in partnership with national institutions, linking Ebola preparedness measures to existing initiatives and platforms and contributing to building health system structures. The very challenging operational constraints in South Sudan will limit the scope of what can be achieved in a limited timeframe, however contributing to sustained health system strengthening should be integrated into the transition strategy of the Consortium.

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Acronyms

CDC	Center for Disease Control
CHW	Community Healthcare Worker
DRC	Democratic Republic of Congo
EOC	Emergency Operations Centre
EPC	Evangelical Presbyterian Church
EVD	Ebola Virus Disease
FDG	Focus Group Discussion
HIV/AIDS	Human Immunodeficiency Virus Infection / Acquired Immune Deficiency syndrome
HRW	Human Right Watch
IDPs	Internally Displaced Persons
IEC	Information, Education and Communication
IFRC	International Federation of the Red Cross
IO	In Opposition
IOM	International Organization for Migration
IPC	Infection and Prevention Control
KII	Key Informant Interview
MoH	Ministry of Health
NAS	National Salvation Front
NGO	Non-Governmental Organisation
NPA	Norwegian People's Aid
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
OFDA	Office of Foreign Disaster Assistance
PHCU	Primary Health Care Unit
PPE	Personal Protective Equipment
RCCE	Risk Communication and Community Engagement
RRT	Rapid Response Team
RSS	Republic of South Sudan
SDB	Safe and Dignified Burials
SIMEX	Simulation Exercise
SOP	Standard Operation Procedure
SPLA-IO	South Sudan's People Liberation Army – In Opposition
SRR	Surveillance and Rapid Response
SSPDF	South Sudan's People Defence Forces
STF	State Task Force
TGW	Technical Working Group
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
WASH	Water, Sanitation and Hygiene
WFP	World Food Programme
WHO	World Health Organization

Introduction

The tenth outbreak of Ebola in the Democratic Republic of Congo (DRC) was declared on 1 August 2018. As of 26 November 2019, 3,303 confirmed cases and 2,199 deaths had been reported (WHO, 2019a). Four of the nine countries that share borders with DRC have been prioritised as high risk based on proximity to areas where cases have been reported and large-scale movement across borders: Burundi, Rwanda, South Sudan and Uganda (WHO, 2019b).[1] The borders between these countries are highly porous and there are fluid movements of people, goods and services across the immediate and broader region. Between August 2018 and October 2019, 103 alerts were reported in South Sudan, of which all 49 suspected cases tested negatively for Ebola (RSS and WHO, 2019).

Preparedness activities in South Sudan

The operational context of South Sudan is highly complex. In their annual needs assessment report for South Sudan, OCHA concluded, *"The cumulative effects of years of conflict, violence and destroyed livelihoods have left more than seven million people or about two thirds of the population in dire need of some form of humanitarian assistance and protection*" (OCHA, 2019).[2] Preparedness and prevention activities in relation to Ebola must therefore be understood in the wider context of chronic conflict involving numerous non-state actors, a fragile health system, weak governance structures and deep-rooted socio-political and ethnic tensions.

Although humanitarian resources are well-established in South Sudan, at both national and sub-national levels there is little capacity to respond to a health emergency. Across the country, biomedical health services are largely provided by a patchwork of international and local non-government organisations; conflict and economic decline have continued to erode basic healthcare delivery (Elmusharaf, 2015). In 2018, OCHA estimated that each functioning primary health centre served an average of 50,000 people and in their 2019 Humanitarian Needs Overview estimated that 4,472,000 South Sudanese (close to half the population) and over 300,000 refugees did not have access to adequate health services (OCHA, 2019).

The risk of imported cases of Ebola to South Sudan comes from the direct border with DRC but also from the movement of people from DRC via Uganda into South Sudan (WHO, 2019b). In addition, the risk of a new indigenous outbreak in South Sudan cannot be fully discounted (Garside et al., 2019).

In light of the DRC outbreak, South Sudan began preparedness activities in August 2018 with the development of the first South Sudan National Ebola Preparedness Plan (August 2018 – March 2019), the formation of the National Ebola Task Force (NTF) and Technical Working Groups (TWGs). According to the Ministry of Health and WHO, between August 2018 and March 2019, 900 health care workers, frontline workers, community volunteers and military personnel in high risk states were trained on EVD surveillance (detection, alert and investigation), management of suspected and confirmed cases, laboratory safety procedures, safe and dignified burials, risk communication and social mobilisation, and infection prevention and control (IPC). An Emergency Operations Centre (EOC) was established in Juba and a free hotline to report EVD alerts (with the call-in number 6666). Twenty-eight Rapid Response Teams (RRTs) were put in place across the country and local capacity for GeneXpert testing was established.

The focus of the Second EVD Preparedness Plan (April – September 2019) shifted from initial preparedness needs to active response should a single case be confirmed. Priority activities included establishing effective mechanisms for the notification of an event, public messaging on prevention and further spread, the rapid deployment of multidisciplinary RRTs, the implementation of targeted containment measures and a coherent package of activities for the operation of isolation facilities including basic maintenance, the ability to scale up the number of staff and supplies, and streamlined local control and management in the event of patient care being launched. The Plan also emphasised the strategic prioritisation of facilities in high-risk

[1] Priority countries at risk of importing Ebola from the DRC: Angola, Burundi, Central African Republic (CAR), Republic of Congo,, Rwanda, Tanzania, South Sudan, Uganda and Zambia.

[2] South Sudan has recorded some of the worst health outcome indicators in the world. In August 2019, the WHO and the Ministry of Health and Environment reported multiple infectious disease outbreaks across the country including malaria (the leading cause of morbidity and mortality, accounting for 67% of all morbidities and 32% of all mortalities in late August 2019), measles, bloody diarrhea, rubella, hepatitis E, and other preventable communicable diseases such as pneumonia and HIV remain significant public health problems (Ministry of Health, 2019c). Together, malaria, diarrhoea and pneumonia constitute more than one third of all diagnoses for children under five. The maternal mortality rate in South Sudan remains high at 789 per 100,000 live births, with only 19.4% of live births attended by skilled personnel (WHO, 2017). Road traffic accidents are common, and mental health issues are also prevalent, particularly given vulnerabilities associated with post-traumatic stress after prolonged conflict.

states, the funding and monitoring of all RRTs' activities, and investment in a complete community-level package of Ebola preparedness to include community engagement, rumour and feedback monitoring, and community-based surveillance (Republic of South Sudan, 2019). By October 2019, 284 screening points and four isolation units had been established,[3] 2,974 frontline workers had been vaccinated, 13 safe and dignified burial teams been organised, 160 health facilities had received IPC and Water, Sanitation and Hygiene (WASH) supplies, 30,000 community "influencers" (opinion leaders, elders, religious leaders, traditional healers, local political and administrative leaders) had been engaged for EVD prevention and control and 15 Personal Protection Equipment (PPE) kits distributed (RSS, WHO and OCHA, 2019).[4]

In November 2018, WHO conducted an assessment of South Sudan's overall Ebola readiness level and rated it 17% prepared (Republic of South Sudan, 2019). A more recent assessment in March 2019 found the country was 61% prepared, indicating great progress had been made (Pendle et al., 2019). A full-scale simulation exercise to test readiness capacities in mid-August 2019 reported there to be "*Improved coordination and better performance between teams, and improved capacities for EVD readiness*", but identified a series of critical gaps that still needed to be addressed including challenges around the systematisation and implementation of Standard Operating Procedures (SOPs), inadequate linkages and information sharing between the national and sub-national levels, and the need for additional training of response workers (Ministry of Health, 2019).

The Second National EVD Preparedness Plan concluded that an additional US $12 million was required to reach the required preparedness threshold. Similarly, the WHO Regional Ebola Preparedness Response Plan (July – December 2019) highlighted prominent funding gaps and noted the risk that preparedness efforts may not extend to areas affected by ongoing conflict (WHO, 2019b).[5] A mid-term review of the Second National EVD Preparedness Plan was completed and priorities and targets reviewed. In response, the time period of the plan was extended from September to December 2019, and the financial requirement adjusted to $16.7 million. In October 2019, after the fieldwork for this study had concluded, a major new contribution from the World Bank through UNICEF and other agencies increased funding coverage to around 94% of suggested levels (RSS and WHO, 2019).

EVD Preparedness Consortium: Save the Children, Concern and Internews

To further support preparedness and readiness activities in South Sudan, the EVD Preparedness Consortium was established in July 2019 as a collaboration between Save the Children, Concern Worldwide and Internews, with funding from USAID OFDA. The Consortium's activities are being implemented in four counties across Yei River State: Yei, Morobo, Lainya, Kajo Keji. Together, the total catchment population is 201,443 people (South Sudan National Bureau of Statistics, 2008) and in line with the National Ebola Preparedness Plan, activities focus on preparing health workers, community members and other first responders regarding a potential outbreak of Ebola (RSS, 2019).

The Consortium focuses on early detection of Ebola alerts and cases and preparing cross-border communities at different levels by:

- Building the capacity of healthcare workers to conduct active EVD surveillance at their respective facilities.
- Building the capacity of Community Health Workers (CHWs) and their catchment communities so they are able to actively report alerts and cases and understand the protection and reporting mechanisms to safely handle alerts and cases.
- Raising awareness of EVD in order to support and strengthen the effectiveness of other preparedness activities. This is conducted through door-to-door awareness, health promotion in the community, radio messaging, audio messaging by loudspeakers etc.[6]

Within these focal areas, each Consortium partner maintains a particular remit: Save the Children focuses on IPC and epidemiology/surveillance; Internews on risk communication and community engagement; and Concern Worldwide on WASH and IPC. Specific activities include training healthcare workers and community health workers (CHWs) on Ebola signs and symptoms and transmission pathways, EVD

[3] At the time of writing, vaccination had stopped in South Sudan due to the depleted vaccine stock.
[4] Ebola preparedness Dashboards are published on a monthly basis by UN OCHA and can be accessed via the agency's website: https://www.humanitarianresponse.info/en/search/type/hr_infographic/locations/south-sudan/publication-date/2019?page=1.
[5] The financial requirement for South Sudan in the Regional Preparedness Plan was estimated to be $14.4 million for the period July to December 2019. The previous National Preparedness Plan (covering April 2019 to September 2019) required $16.2 million of which 82% ($13.3 million) was secured (Republic of South Sudan, 2019).
[6] These consortium activities were being rolled out during the time of the fieldwork. Trainings had already taken place in Yei and were planned for other countries.

screening and isolation, and the implementation of basic IPC and WASH measures at health facility and community levels near the DRC border.[7] Save the Children and Concern Worldwide provide specific IPC/WASH materials at the health facility level. These items include PPE, chlorine, soap, handwashing stations, waste bins and bin bags.[8] Where materials do not fulfil demand, Concern Worldwide also encourages members of the community to construct 'tippy-tap' hand washing devices out of local material. Internews works through a network of community reporters who track citizen feedback and misinformation.

Lessons learned from previous outbreaks

Lessons learned from previous Ebola outbreaks, in particular the recent outbreaks in West Africa (2014-2016) and the current outbreak in neighbouring Democratic Republic of Congo (DRC), highlight that preparedness and early response is critical (Green, 2018). Since the first reported outbreak of Ebola in DRC in 1976, most control measures have focused on a "*purely reactive response*" (rapid case identification for isolation, treatment and care, contact tracing, community engagement and mobilisation, safe and dignified burials, effective infection control; and laboratory testing) whilst "*Primary prevention through vaccination, expanding efforts to find and reach high-risk areas and groups*" is vital for stopping localised starts of epidemics, and preventing them from spiralling into global public health emergencies (Piot et al., 2019).

Strengthening health systems can help prevent, detect and facilitate a quick and efficient response to infectious disease outbreaks like Ebola. Piot and colleagues (2019) report that in order to be effective, health systems "*Must be responsive to peoples' rights and needs, addressing the everyday health problems they experience as well as emerging threats.*" This also means investing in a strong and supported health workforce, providing them with appropriate equipment and ensuring that adequate pay and protection stimulates their readiness, safety and motivation. When health workers are not well supported, they may be reluctant (due to the often very real risk for infection) or be unable to provide care (Ibid.).

Early warning and surveillance systems collect information on epidemic-prone diseases in order to trigger prompt public health interventions and are a critical tool in Ebola preparedness (Piot et al., 2019; Dickman, 2018). Surveillance, testing and if necessary, preventive contact tracing for monitoring potential transmission and introducing vaccination, often require immediate engagement and support from the affected population (Ripoll et al., 2018). Having insights into the practices and particularities of different social groups prone to infection with the Ebola virus is vital to understand their risk profiles. Reviews of surveillance systems highlight that effective surveillance and early warning activities should include affected or at risk communities at the centre of such efforts. As Dickman (2018) reported, there is a need to shift "*power to the people*" and promote a community-based one health approach, rather than solely relying on "*outside*" aid.

Effective community engagement in which communities are engaged and empowered as primary partners in preparedness mechanisms can help curtail fear and mistrust of emergency response measures (Bedford et al., 2019; Piot et al., 2019). Innovative medical technologies alone are not enough to prevent and contain epidemics without serious efforts to gain the trust of communities to understand their perceptions and better meet their needs (Nguyen, 2019). Having communities at the centre of preparedness and eventual response mechanisms will not only help with acceptance, but also with making measures more relevant, efficient and effective (Bedford et al., 2019). In order to have communities be involved in preparedness measures, information needs to be provided and knowledge built. Research in Sierra Leone showed that exposure to different types of information sources on Ebola was associated with higher knowledge and protective behaviours, even if it also gave raise to misconceptions and risk behaviour (Winters et al., 2018). Behaviour change can be effectively negotiated making use of influential and trusted members of society, and by using the most appropriate communication and community engagement tools (Ripoll et al., 2018).

Evaluations of the Ebola outbreaks in West Africa and current learning from DRC calls for social science to be included as a central component of decision-making during the conceptualisation, planning, and implementation phases of public health initiatives (Piot et al., 2019; Bardosh et al., 2019c). Social science can provide understanding about the complexity of issues, including the evolving nature of communities and dynamics within (Bedford et al., 2019; Bardosh, de Vries et al., 2019). It should do so by understanding key features of the local context and exploring how they directly influence the strategy and implementation of the overall response. This learning should then be used to tailor standard response mechanisms (like risk

[7] Due to delays in programme implementation plans, these activities had not yet started at the time of the study's fieldwork.
[8] During fieldwork in August and September 2019, the distribution of most of these items had not yet commenced (only screening tents had been set up in a select number of health facilities and some facilities in Yei had received temperature screening devices).

communication, safe burials, surveillance and facility-based IPC measures) to be acceptable and appropriate for the affected population. Pre-positioning social science knowledge and incorporating it into preparedness and response activities supports the uptake of interventions, strengthens community engagement, reduces fear and potential resistance, and ultimately contributes to preventing the transmission of the virus (Bedford et al., 2019; Ripoll et al., 2018; Bardosh et al., 2019a; 2019b).

Study rationale and approach

Although strong links with at-risk communities already exist, community engagement in the context of Ebola requires specific approaches that build on established relationships, take account of the existing psycho-social stresses in communities, and actively seek to mitigate issues of mistrust and misinformation. A number of factors that may influence the importation of an Ebola case from DRC, the subsequent response and case numbers can be predicted (including care-seeking behaviours; access to health services; local burial, funeral and mourning practices; and patterns of mobility). Such factors must be locally contextualised and it is critical to embed immediate Ebola preparedness activities in longer-term resilience strengthening and community-based surveillance (see for example, Piot, 2018; Bedford et al., 2019).

To support the work of the Consortium, Anthrologica was commissioned to undertake an anthropological study on perceptions and experiences related to Ebola and prevention measures. The research was commissioned in recognition of the importance of social science in responding to the West Africa Ebola outbreak and subsequent outbreaks in DRC. It aimed to provide granular information about the perceptions of communities and health workers in locations in Yei River State supported by the Consortium, in relation to Ebola preparedness and outbreak activities.[9] The research was designed to support a localised and agile response to the threat of Ebola in South Sudan and to directly contribute to the EVD Preparedness work of the Consortium.

The research was conducted near the start date of the Consortium, before partners had fully initiated activities. At the time of fieldwork, the Consortium had started to train a selection of health workers, community health workers and community reporters from the four target counties, to distribute screening tents and had provided a number of health facilities in Yei city with infrared thermometer devices.[10] Community engagement, communication activities, community-based IPC and WASH activities in the target areas had not yet commenced. The study focused on eliciting insights about the activities in Yei that were already being implemented and reviewed broader preparedness measures of the EVD Ebola State Task Force and partners.

The research team, in consultation with Save the Children and other key partners developed broad research questions which allowed for flexibility due to security constraints. The study focused on perceptions and experiences in Yei and Mugwo counties, providing contextual and ethnographic insights in relation to the following research questions:

1) How are key preparedness measures around IPC, surveillance, risk communication, community engagement and WASH perceived by healthcare providers and at-risk communities?
2) How can preparedness actors make critical preparedness measures more effective and relevant to the needs of the at-risk communities by operationalising feedback of these communities and health providers?

It is envisaged that the research will help preparedness actors in Yei River State to take stock of the effectiveness and relevance of (their) Ebola response mechanisms. It is intended that the findings be used by Consortium partners to inform the design of future activities, adapt existing programme strategies and/or inform the modification of activities and messaging. When possible, the research findings should serve as a platform to discuss interventions at the community level before modifications are made.

Due to security constraints it was not possible to conduct the research in all programme locations. Research was mainly conducted in Yei city, a large urban site within the catchment area of the Consortium. Data collection also took place in Mugwo county, a more rural area in which some research activities were cancelled due to insecurity in the area. There was also a limit to the extent the research could assess perceptions of the Consortium's preparedness mechanisms due to delays in initiating many activities. At the time of data collection most activities had not started yet, and the study was not designed to be an evaluation of the activities that had started. Where activities had been implemented, perceptions of the

[9] Community in this research is defined as: "*a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings*" (MacQueen et al., 2001).
[10] This activity was halted during the fieldwork due to security incidents in and around Yei.

activities were sought if relevant to the overall research questions. These perceptions were fed back to the Consortium so that real-time changes could be made where applicable.

Study methodology

The study was granted ethical clearance and the relevant local permissions by the Ministry of Health in Yei River State. It was conducted in four phases between July and October 2019 and included two periods of work in South Sudan. The ethical clearance process was managed locally by Save the Children staff in Yei River State.

The following methodology was used:

Phase 1: Document review

At the start of the consultation process, a rapid desk review was completed to provide the foundation for the work. It sourced material published in peer-reviewed journals and grey literature including programmatic documents and drew on previous work conducted by Anthrologica regarding Ebola preparedness initiatives in South Sudan and the region.

Phase 2: Design of research tools

Based upon the rapid document review, a topic guide of key themes was developed focusing on community leadership structures; infrastructure and service mapping; on-going issues (i.e., challenges other than Ebola); population movement patterns; gender and vulnerability; health and care-seeking behaviour; knowledge and awareness about Ebola; IPC; communication and language; burial rites; and community solutions. This formed the basis for the design of a series of research tools: semi-structured in-depth interviews and focus group discussion frameworks, participatory community mapping exercises and creative methods including drawing and theatre.[11] Appropriate methods were used engage different stakeholder groups including illiterate participants. The key themes were addressed in each interview, focus group discussion and participatory exercise, allowing for the analysis of themes across participant groups and field sites and to triangulate information. Specific questions and probes were reviewed and refined during the study.

Phase 3: Preliminary trip to South Sudan

During the preliminary trip to South Sudan in August 2019, the lead researcher conducted a series of exploratory meetings with preparedness actors from Concern Worldwide, Internews, IOM, Save the Children, UNICEF and WHO in Yei and in Juba. The study was presented to the Ministry of Health in Yei River State and relevant ethical permissions and security clearances were obtained. The national research assistant was recruited and trained, and the study sites and methodology were agreed with Save the Children Humanitarian Managers in Yei and Juba. Logistical arrangements for data collection commenced. A short mission report detailing this trip was submitted to Save the Children in August 2019.

Phase 4: Substantive trip to South Sudan, including data collection

All data collection was undertaken by the lead researcher with support from a national research assistant who translated between English and local languages (Dinka, Kakwa, Juba Arabic, Pojulu, Peri) as appropriate.

Study sites: The sites were selected by Save the Children in Yei River State in coordination with the Ministry of Health in South Sudan and in consultation with the lead researcher. Initially, sites were selected in four counties (Lainya, Morobo, Kajo Keji and Mugwo) based on their vulnerabilities to an imported case of Ebola and the presence of mobile communities (internally displaced peoples (IDPs), refugees and returnees, traders, *boda boda* (motorbike taxi) drivers and hunters). Due to ongoing security issues and delays in programme implementation, however, not all areas could be included in the final study. To adapt to the

[11] Save the Children had oversight of the tools prior to their finalisation and implementation, and the full portfolio of tools (including the study's consent form) will be shared at the end of the consultation.

shifting situation and in line with security oversight from the Government's Security Department, Ministry of Health, and Save the Children, study sites were finally selected in Yei municipality (Mahad, Sobe and Yei City); and Mugwo (Payawa and Mugwo town). Due to further incidents around Mugwo, and related government restrictions on travel, much of the data collection was conducted in urban areas in Yei city. The more urban focus provided specific insights into risks related to Ebola transmission in these settlements. Both communities in Yei were served by the Evangelical Presbyterian Church (EPC) Clinic, a private hospital in Sobe supported by Save the Children through the OFDA-USAID EVD Preparedness Grant. During the course of the fieldwork, the hospital and centre were provided with key equipment including screening tents and thermometers, and key staff were trained on Ebola IPC. Table 1 below outlines key characteristics of the research sites.

Table 1 – Characteristics of research sites

					Land typology		Major livelihood					
Payam	**City**	**Area**	**Ethnic Groups**	**Rural/urban**	Urban	Mountainous	Agriculture	Livestock	Hunting	Trading	Armed forces	Other informal
Yei	Yei city	Mahad	Kakwa, Peri, Pojulu, Dinka, Nuer	Urban	•		•	•	•	•	•	•
		Sobe	Aqua, Pojulu, Mongo	Urban	•		•			•	•	•
Mugwo	Payawa	-	Kakwa, Pojulu, Dinka, Nuer	Rural		•	•		•	•	•	•
	Mugwo town	-	Kakwa, Pojulu	Rural		•	•		•	•	•	•

Participants and recruitment: Study participants were selected using purposive, non-probability sampling. Participants for the focus group discussions were recruited by the research assistant and local community leaders in each study site according to three stakeholder groups: community leadership (included traditional leaders, government officials and religious leaders); health workers from formal healthcare facilities (including nurses, doctors, midwives, pharmacists, lab technicians and cleaners); and community members drawn from the larger study population and identified by their community leaders as being of greater risk of coming into contact with Ebola (including market women, hunters, small- and large-scale traders, IDPs, refugees and those with family members across the border).[12] The community mapping exercises were completed by community leaders in each site, and additional in-depth interviews were conducted with key government officials, youth leaders and other service providers including traditional healers and religious leaders. In total, 166 participants were included in the study (55% were male (n=91) and 45% were female (n=75)). Table 2 below presents the final research sample in Mugwo and Yei.

Consent: When possible, written informed consent was obtained from all participants prior to commencing each data collection activity. Verbal informed consent was obtained from those participants who asked not to provide written consent. The research lead provided a full explanation of the study in English and emphasised the optional, voluntary, confidential and anonymous nature of participation. The study explanation and consent form was translated into local languages (Kakwa, Dinka, Juba Arabic, Peri, Pojulu), and a copy was provided to the participant. It was made clear that participation would not affect any future services and/or community benefits needed or received. All participants were given the opportunity to ask questions and request further explanation. The study's consent form was presented, explained in detail and read aloud for illiterate participants. The contact details of the Save the Children's national focal point for the research was included on each consent form and provided to community leaders. A copy of the consent form was provided to participants upon request.

Data management: Detailed notes were taken by the lead researcher during all data collection activities. When possible, recordings of data collection activities were made, but most participants asked not to be recorded. Soft copies of the study's completed consent forms and all materials produced during data collection sessions including drawings, community maps and photographs of participatory activities were

[12] Sample size and sample framework were not stipulated and due to security and movement restrictions, a convenience sample was agreed. The sample framework was agreed with the MEAL manager from Save the Children Juba and other relevant local staff in Yei River State. Previous versions of the research framework that were agreed prior to the security situation deterioration were also shared and discussed with Save the Children.

Table 2 – Research sample summarising the conducted activities in Yei River State

		Yei			Mugwo	
Tool used	**Stakeholder group**	**Sobe**	**Mahad**	**Yei city**	**Payawa**	**Mugwo city**
FDGs	Women	-	10	-	-	-
	Men	10	10	-	-	-
	Community leaders	12	12	-	-	10
	Traders	-	-	10	-	-
	Boda Boda	-	-	12	-	-
	Healthcare workers	-	-	11	-	-
Total tools	**Number of FDGs (9)**	**2**	**3**	**3**	**0**	**1**
Community mapping	Community leaders	5	5	-	-	5
Total tools	**Number of mappings (3)**	**1**	**1**	**-**	**-**	**1**
Interviews	Government officials	1	-	5	-	3
	Traders and transport actors	-	-	6	-	1
	Refugees and IDPs	1	-	2	-	3
	Radio leaders	-	-	2	-	
	Church leaders	1	-	2	-	1
	Healthcare workers	-	-	4	1	3
	Alternative healers	-	-	1	-	1
	Youth and women leaders	-	-	3	-	3
Total tools	**Number of interviews (44)**	**3**	**-**	**25**	**1**	**15**
	Total participants (166)	**40**	**37**	**58**	**1**	**30**

retained by Anthrologica. Hard copies of the materials were given to Save the Children's Humanitarian Manager in Juba.

Phase 5: Analysis and reporting

Preliminary analysis was conducted throughout the data collection process. At the conclusion of the fieldwork, the lead researcher led a series of roundtable workshops in Yei and Juba to present initial findings to CDC, Concern Worldwide, Internews, OCHA, the Red Cross, UNICEF and USAID. Findings were also shared during a training session for CHWs organised by Concern International in Yei and at the Communication and Community Engagement Technical Working Group in Juba (which included participants from Internews, OCHA, UNHCR and WFP). Feedback and immediate reactions to the presentation were positive and key operational partners reported that the findings were useful in reformulating EVD preparedness programme implementation strategies in Yei River State and other border-areas in DRC.

The full analysis of all qualitative data was conducted by the lead researcher using thematic analysis. Dominant themes were identified through the systematic review of interviews, FGDs, materials generated through participatory exercises and observation notes. Salient concepts were coded and their occurrence and reoccurrence labelled by hand. The emerging trends were critically analysed according to the study's objectives. The analytic process was systematic and transparent, and all raw data were available to Save the Children should they wish to access it.

The draft report was shared with Save the Children for feedback and comments were incorporated as appropriate prior to finalisation.

Methodological limitations

As mentioned above, insecurity issues meant the study and research team had to be agile and rapidly adapt to changing situations on the ground. Throughout the research, the team sought to mitigate the impact of the study's limited resources by employing a carefully developed pragmatic methodology and by using the available resources efficiently. The maximum possible number of interviews, FGDs and participatory exercises were conducted at each field site given the time and operational constraints. Having community leaders assist in the selection of participants may have resulted in some sampling bias (e.g., if leaders favoured people from their own clan or tribe to "benefit" from the soft drinks and water provided to participants). The research team mitigated this by working closely with the community leaders involved in the selection of the participants to ensure fair representation. In qualitative research, there is always a risk associated with misinterpretation and the possibility that participants provide what they perceive to be socially-correct responses, or withhold sensitive information. Attempts were made address this by the research team working closely together to plan translation styles in advance and decide how to best capture colloquialisms, idiomatic expressions and jargon. Careful phraseology was used when posing questions.

Sections of narrative were repeated to the participant to confirm or clarify statements. In addition, the research team was not known to the communities or individual respondents in advance, and through the careful consent process, a 'safe-space' for sharing ideas was created. Participants were encouraged to speak openly and the research team did not feel that socially-correct answers biased the findings. Interview and discussion frameworks allowed similar questions to be asked in multiple ways in order to triangulate responses across relevant stakeholders. Finally, the study focused primarily on urban areas in Yei River State, and as such findings are not necessarily generalisable for more rural areas in the state, or transferable to other states. While the findings of this study are designed to be of operational use by Consortium partners in adapting their activities, the study was not a formal evaluation of activities implemented.

Report structure

This report explores community and health worker perceptions, preferences and solutions in relation to Ebola and key preparedness measures. It also documents other relevant contextual details that should be taken into account when designing and implementing EVD preparedness activities in conflict-affected South Sudan, particularly Yei River State. The findings highlight a number of key factors that could influence the introduction and spread of Ebola in South Sudan including: patterns of mobility; care-seeking behaviours; barriers to health services; and customary burial practices. The report records existing communication and engagement platforms, structures and potential entry points for programme interventions that would ensure communities are at the centre of preparedness activities.

For ease of reference, the findings are structured in three chapters, and include references to recent research and literature where relevant. Chapter 1 details the context of Yei River State, community stakeholders and cross-border movement. Chapter 2 explores knowledge and perceptions, care-seeking behaviours and the provision of services. Chapter 3 focuses on communication and community engagement. Each chapter concludes with a set of key recommendations that draw on feedback and requests from the wide range of study participants. The final chapter summarises the report's conclusions and key considerations.

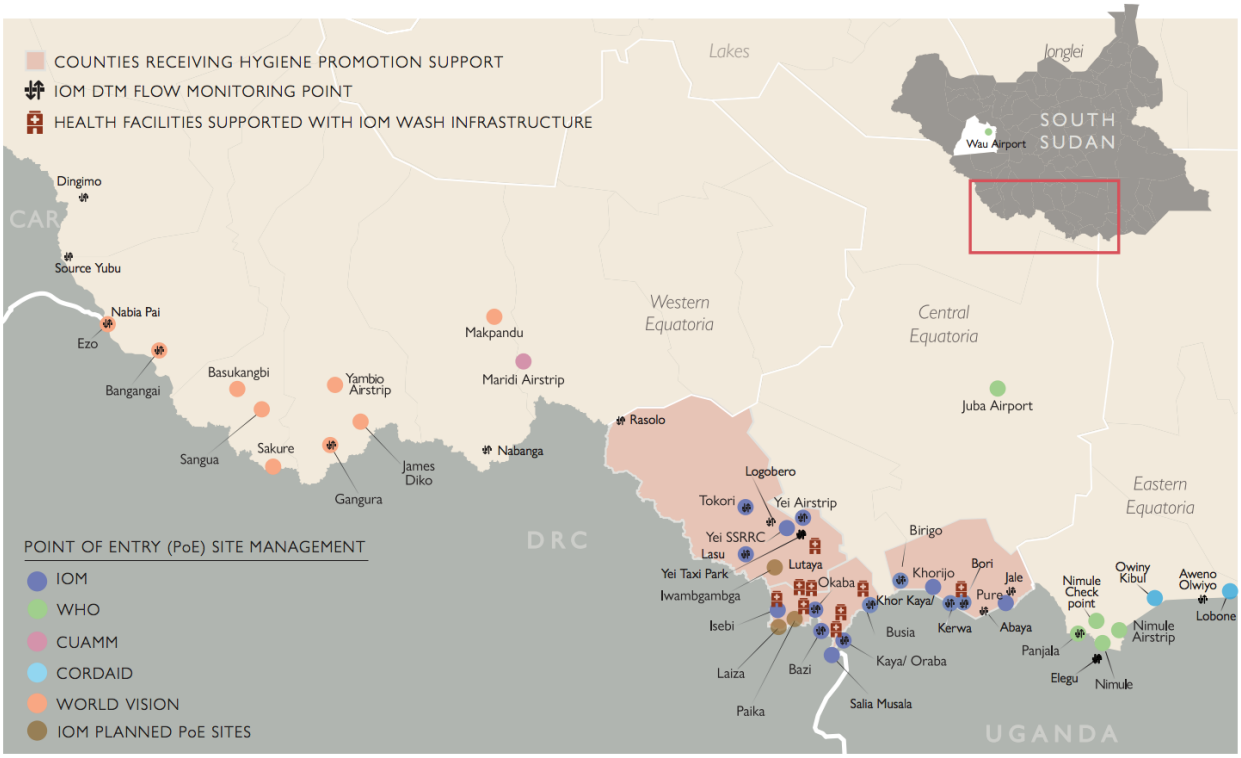
Chapter 1 – Yei River State: context, community stakeholders and cross-border movement

Yei River State, a province in the South of South Sudan, is an important commercial hub with important trade links to the capital Juba and other cities both in South Sudan and neighbouring countries including Kampala and Arua in Uganda. The province borders Ituri Province in DRC where, at the time of writing, active transmission of Ebola was continuing (IOM, 2019). In July 2019, for example, there was a confirmed case of Ebola in Ariwara (Ituri Province), another trading hub approximately 70 kilometres from the border with Yei River State, and to which many participants of the study reported to travel to frequently. The case was contained and a swift response prevented further spread of the virus but indicated the risk of cross-border transmission.

Yei River State is home to a diverse and inherently mobile population that frequently cross-national borders for trade, family networks, education and other services such as healthcare, and to search for safety from ongoing insecurity. Preparedness and prevention activities must therefore be understood against the contextual backdrop of Yei River State in which government soldiers continue to conduct active counter-insurgency operations against 'rebel' forces in certain areas (HRW, 2019). This conflict has added to the existing deep-rooted socio-political and ethnic tensions and violence has significantly hampered preparedness activities. For example, the death of three IOM staff in Morobo County, Yei River State, earlier in 2019 resulted in the temporary cessation of Ebola preparedness measures (HRW, 2019).

The complex operating environment of Yei River State means that in addition to providing routine health services and addressing other health emergencies (at the time of the study, multiple malaria outbreaks and active measles outbreaks were reported in Lainya and Kajo-Keji), it is difficult for the already stressed health system to fully respond to the threat of Ebola. Ongoing insecurity and underdevelopment across the state have hampered preparedness activities including health worker training and prophylactic vaccination of selected frontline workers (due to a shortage in vaccines, not all healthcare workers operating in the area have been vaccinated). Despite such challenges, the on-going humanitarian crises and chronic underfunding, key preparedness structures have been established however. In Yei city, an isolation unit has been set up next to the Norwegian People's Aid (NPA) hospital and a rapid response team based in Yei trained to follow-up and safely manage Ebola alerts.

Map 1 - Official Points of Entry in Yei River State (source: IOM - September 2019)



In response to the risk of imported cases across its national borders, South Sudan's EVD State Task Force and key partners in Yei River State established formal screening at points of entry and points of crossing along the official border. Between September 2018 and September 2019 more than 802,993 travellers were screened (IOM, 2019) but due to the border's porous nature, formal screening efforts face considerable challenges. As one government advisor in Yei emphasised, "*There are too many roads from Congo – Ebola can come into South Sudan so easily".* A senior level official at the Ministry of Health in Yei agreed, "*The issue of the Panya roads, that one we really do not have under control".* '*Panya*' roads (the direct translation being 'rat' roads) are informal paths hidden by thick vegetation and often used by traders to avoid detection by border authorities. The paths change frequently and are often only known to those who use them, primarily traders, *boda boda* drivers, refugees, IDPs and community members living in the borderlands.

Lessons learned from previous outbreaks

Infection with a filovirus, such as Ebola, is unlikely except through direct contact with an infected person (or certain animals) during the acute stages of illness. Transmission through indirect contact has been reported but is uncommon (Brainard et al., 2015). Reviews from previous outbreaks indicate the likelihood of infection involves a wide range of dynamics (Ripoll et al., 2018; Brainard et al., 2015). Vulnerability to infection is shaped by gender, age, profession and social position as these determine responsibilities relating to the care of the sick, burial practices, movement patterns and so on. Vulnerability may manifest itself differently in different contexts, so it is important to rapidly identify those groups most at risk of infection and to provide them with knowledge and resources for their self protection. Routine and robust surveillance systems should be designed to detect early signs of an outbreak, take into account local context and be quickly scaled up during epidemics (Gates, 2015).

Ebola is known to spread undetected and at a more rapid pace in areas characterised by limited health care and wildlife monitoring systems which can delay the identification of illnesses and unusual morbidities and mortalities in humans (and animals). In areas where formal healthcare is unavailable and inaccessible, identification is not only made by formal healthcare professionals but also by other members of the community including chiefs and other local leaders (Ripoll et al., 2018; Parker et al., 2019). Collaboration with local actors to prevent Ebola through community-based surveillance and early warning systems is critical, particularly where trust in the state is low (Bedford et al., 2019). Ensuring community members have some level of responsibility for early detection and preventive surveillance can help the response gain legitimacy and trust (Bedford et al., 2019). This is particularly important in conflict-affected and politically unstable contexts in which distrust of 'outsiders', government and other international agencies can quickly deteriorate.

Mapping patterns of population movements to trace and prepare for transmission can support preparedness efforts (Ripoll et al., 2018), and should be done at the most local level. Human patters of movement are complex, as social groups, kinship, ethnic, inter-ethnic, political and trade networks exist across administrative and country borders and (Ripoll et al., 2018; Sweet, 2019). It is also important that any tracking of population movement of refugees or armed groups be done sensitively and diplomatically, stressing the common goal of stopping Ebola and maintaining the appearance of non-partisan neutrality. Trade and travel restrictions applied in previous outbreaks have had long-term economic consequences, and are strongly discouraged (Burki, 2016).

Boda boda drivers

Because of the itinerant nature of their work, *boda boda* drivers are vulnerable to Ebola exposure. Drivers who participated in the study in Yei explained that they, "*Transport the sick and the dead from Congo and Uganda",* and expressed concern about the risk they faced when transporting patients who "*Have not been tested at a screening centre".* Although a number of drivers suggested that they wanted more information on how to transport a patient and how to protect themselves, many expressed an interest in playing a greater role in Ebola preparedness activities.[13] *Boda boda* drivers have access to (informal) information that is of use to preparedness efforts (such as the location of the *panya* routes, who travel on them, and when) but which formal response partners, including the Ministry of Health, may not be party to. A number of drivers who participated in the study confirmed that they would be willing to share information about the

[13] In both West Africa and DRC, taxi drivers and *boda boda* drivers have been positively involved in the Ebola response. In the West Africa outbreak, they worked to deliver laboratory testing in Sierra Leone and Liberia (CDC, 2017) and helped raise awareness on key signs and symptoms. At the start of the outbreak they also helped transport sick patients to health facilities, at great risk to their own safety (Richards, 2016).

location of *panya* roads if their anonymity could be guaranteed by partners, as "*This information is not for the government to have".* Others suggested that they were in a strong position to disseminate information to their passengers, "*We could play them Ebola messages on the radio".* It was also noted by *boda-boda* drivers that they could convey critical information to Ebola response partners about cases of sickness, misinformation and other relevant local information. Image 1 was drawn by *boda boda* drivers who participated in the study in Yei to depict the numerous crossing border crossing points they routinely used and highlights their intimate knowledge of the borderland and its communities.

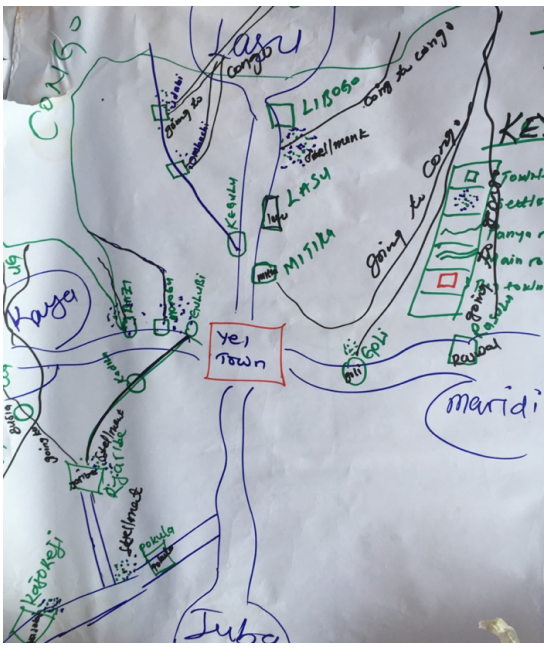


Image 1 – Map of *Panya* roads leading into DRC and other neighbouring drawn by *boda boda* drivers in Yei city. This map details the various ways that "*Ebola could come in rapidly without you noticing it*").

Traders

Informal and formal traders, both small- and large-scale, should also be seen as potential community-based partners. Traders cover large areas and frequently cross borders into neighbouring countries via routes from Yei through Kaya to Ariwara (DRC), Arua (Uganda) and onwards to Kampala. Many reported to actively avoid official borders so as not to be subjected to customs checks and associated bureaucracy (high import and export prices and bribery), and by using informal routes they bypassed ("*dodged*") screening points. One trader from Yei City who participated in the study reported that he frequently visited Ariwara city to purchase *kitenge* cloth and second-hand clothes.[14] He explained that he often avoided cross-border checkpoints, preferring to use a *panya* road, balancing his wares on the back of a *boda boda* motorbike before switching to a car in Kaya. Another trader asserted, "*I was discriminated for coming from Congo and had to undergo screening, which delayed my travel and time is money*." As a result, he began to take a *panya* road to avoid the screening centre. Similarly, other traders confirmed that they did not enter the voluntary Ebola screening centre located on the round-about next to the Traffic Police in Yei city.

Women traders usually sell agricultural produce at cross-border markets, travelling from city to city on an almost daily basis and using taxis filled with as many people and wares as possible.[15] Such markets have become increasingly accessible due to the fragile peace between Riek Marchar's SPLA-IO and Salva Kiir's Sudan People's Liberation Army (SPLA). Women from Yei travel to numerous markets that are also frequented by women from DRC and borderland communities. Yei has a daily market and Mugwo has a market each Saturday and Wednesday. Lasu and Ombachi have markets on Tuesdays and Saturdays whilst the market in Morobo is held on different days.[16] Market days are popular for social networking and exchanging information, as well as for trading, and are therefore important locations for preparedness activities. However, on particular roads (such as the road from Yei to Kaya) market days are also risky, with frequent robberies and armed violence. Insecurity may prevent Ebola preparedness actors from reaching markets. Like *boda boda* riders, traders are an important stakeholder group to provide with information about preventing Ebola to lower their risk profile, but are also an important source of local information. In addition, many women traders are also mothers responsible for their family's health and can affect local / household infection prevention control measures. Most of those engaged as part of the study, however, had no formal education, could not speak English (see Chapter 3) and reported to believe in alternative explanations for Ebola suggesting, for example, "*It comes from God"* and *"They say the devil cursed Congo".*

Illegal traders and poachers operate between Garamba and Lantoto national park and across other porous border areas. Such traders are known to cross illegally into DRC to obtain gold, diamonds and other valuable natural resources. This is particularly important given the Ebola hotspots in the Biakato Mines area in neighbouring Ituri, DRC (WHO, 2019c). During the study, several instances of illegal trade were reported although not verified. As one Somali oil trader suggested, "*The only reason to go to DRC is to bring back some gold or diamonds*".

[14] These clothes are widely available in Yei city and are colloquially called "*Ariwara*" after the city in the DRC where they come from.
[15] Relatively high fatality rates have been consistently recorded for women in most Ebola outbreaks. Women's increased exposure can be attributed to time spent at home and their responsibility for caring for the sick.
[16] In Mugwo, for example, the city is very quiet during non-market days as people stay on their farms. Yet during market day, people from more than five *payams* would travel to the city (the county's capital), including all the chiefs. A *payam* is the second-lowest administrative division in South Sudan with a minimum population of 25,000.

Family and social networks

Kakwa, Avokaya and Mongo ethnic groups straddle the South Sudan-DRC border and families have settled across the borderlands linked by ethnic ties, histories of displacement and economic opportunities. Family members travel back and forth regularly, often for social activities including celebrations and burials, and study participants emphasised that most do not cross at formal border points or require a visa. Some people travel beyond the immediate borderlands to visit family in refugee camps or host-communities in and around Arua and Kampala; and Congolese refugees reported visiting family in Iturbi. Other participants described having houses and relatives in Arua, and preferring to visit health facilities in Uganda rather than South Sudan. Traders from Yei reported to visit their families in Juba, Congo (Aba), Uganda and some travelled as far as Somalia, Ethiopia and Eritrea. In addition, returnees from Uganda and DRC have been reported to travel back to areas in Yei River State, in light of the pending peace.

Education

Younger people in Yei confirmed that many attended school or university in Arua, whilst participants on the DRC-side of the border reported that children frequently crossed from South Sudan to attend school.[17] Several participants highlighted specific concerns related to school attendance. Teachers from Yei Day Secondary School, which boasted over 2,000 students, described their school as being "*Left behind at risk"* due to the lack of IPC measures and no access to infrared thermometers. They emphasised that preparedness measures were not in place and were concerned about the risks associated with students returning to school after holidays spent visiting family members in DRC. Teachers were unsure of what to do in the event of a child presenting with signs and symptoms of Ebola and noted that there was no isolation centre on site and insufficient chlorine.

Refugees and IDPs

The conflict in South Sudan has displaced over four million people and has been characterised by UNHCR as the fastest growing and largest refugee situation on the African continent (UNHCR, 2017). There is, therefore, a long-established practice of people moving internally within Yei River State due to insecurity issues and crossing the South Sudan-DRC-Uganda borders to find safety. Study participants described many cases of displaced communities fleeing to Yei City and its surrounding areas, most using routes unknown to authorities. A recently displaced elder from the city of Logo in South Sudan that was under siege by the government, recounted how he had travelled through the thick bush of Lainya to Yei city, "*We moved on foot, by night so the soldiers could not find us… The army and rebel forces can accuse you, they can say you are spying on them".* With other members of his village, he sought refuge in a Catholic Church compound in Yei known for providing shelter and food to IDPs. Refugees fleeing violence in Ituri, DRC, were also reported to travel to Yei and Kaya and to cross from refugee camps close to the border with DRC. Once in Yei, refugees made their way to specific IDP areas. Some would register with UNHCR whilst others asked community leaders for housing in local neighbourhoods. An alternative healer from DRC who practised in Yei confirmed that he often treated patients crossing from refugee camps in DRC.

Armed groups

A peace agreement, signed in Addis Ababa on September 2018, built on the peace accord signed in 2005 and the Independence Agreement of 2011 was, in November 2019, extended for another 100 days. The Agreement resulted in a cessation of open hostilities between the national army, the South Sudan People's Defence Forces (SSPDF), the Sudan People's Liberation Army In Opposition (SPLA-IO) and other smaller militia groups. Whilst a tentative peace is kept in some areas of the country, in late 2019 Yei River state remained the location of fighting between the SSPDF and other militias, for example in Lainya and around Kajo-Keji. The army monitors the peace from barracks in and around Yei (including in Panyume and Mugwo). In areas with armed militias who have not signed the peace agreement (for example, forces from Thomas Cirillo's National Salvation Front (NAS) believed to be operating in Mukaya and Lainya), the national army continues to fight the '*rebellion'.* Armed militias move frequently, both within Yei River State and across borders, often using covert crossing points and both militia and army soldiers cross into the DRC via Lantoto and Garamba National Park and move freely to refugee camps in Uganda.

[17] UNESCO (no date) reported that in South Sudan, every third school has been damaged, destroyed, occupied or closed since 2013, and more than 70% of children who should be attending school have not received an education.

Recommendations

- Although vertical interventions are necessary in some situations, preparedness efforts should be embedded within broader strengthening of the health system to the greatest degree possible and focus not only on Ebola but also other dangerous infectious diseases (see for example, Kieny et al., 2014; Kouadio et al., 2016). The high level of investment currently being made in Ebola preparedness must be designed to provide rapid prevention returns and longer-term integrated benefit. Effective local health systems delivering an integrated set of health services are essential for prevention. According to the Global Preparedness and Monitoring Board this would "*Yield multiple benefits beyond preparedness, including infectious disease prevention and control, better health outcomes and increased community trust, as well as surge response capacity*" (GPMB Board, 2019).

- Participants who crossed the border on a frequent or daily basis reported they were "*Tired of Ebola measures"* and routinely avoided screening and handwashing. Many called for "*more practical*" disease surveillance mechanisms that encouraged communities to self-monitor population movements and to engage with markets, schools, churches and refugee camps on both sides of the border, rather than focusing on formal border crossings. Efforts to include community-based mobilisers in surveillance systems could be critical in ensuring effective monitoring (Bedford et al., 2019).

- Participants also suggested that preparedness efforts should maximise existing cross-border links and local leadership structures to ensure that activities were locally owned rather than been seen as top-down directives from Juba or Kinshasa and to prevent "*Politics from getting in the way*".

- Given the porous nature of the border areas around Yei River State and the associated challenges of formal screening measures, setting up community-based surveillance systems is a critical component of preparedness activities. Communities across disease outbreaks have been successfully supported to establish community-based early warning systems and surveillance (Bedford et al., 2019). During the study, numerous community-based stakeholders were identified as having the potential to contribute to local surveillance efforts, particularly those who frequently navigated the borders at both informal and formal crossing points. Participants suggested that Ebola preparedness actors should perceive their high degree of mobility as an opportunity to help "*Prevent the Ebola disease from coming into South Sudan*". Investment should continue to be made in building the capacity of local actors to collect and convey information pertinent to response efforts and to ensure mechanisms are in place for such reporting to be analysed and validated. The localisation of preparedness initiatives will likely increase the acceptance and commitment of local communities (Ibid.). Health officials in Yei confirmed that they have developed strategic partnerships with at-risk communities, particularly those along the border and in areas formerly controlled by the SPLA-IO and acknowledged "*We really need support of the communities there*".

- Community-level stakeholders who had a higher risk profile such as *boda boda* drivers asked for greater training about how to protect themselves and what to do if they encountered a suspected case ("*We need training and support on what to do when we are transporting a case*").[18] A number of drivers suggested that if they were to report information, they would need "*A good way to communicate as most areas don't have* [mobile phone] *network*". Local solutions should continue to be explored together with drivers, with a critical eye towards insecurity dynamics. If they were to be incorporated into preparedness and response efforts more formally, drivers also requested that they '*Be given identifiers like T-shirts or caps*".

- Collaboration with trading associations should continue to be strengthened. Trading associations have offices in many border areas and beyond and provide a ready network for communicating with traders (cascading information, encouraging the adoption of personal protection measures and self-reporting etc.), and acting as a conduit for information to flow from traders to response partners in a coordinated manner.

- Communication materials and engagement efforts must be tailored not only to specific stakeholder groups, but also through a lens of gender sensitivity (also see, Smith, 2019; Ambramowitz et al., 2015). Many women, both at household level and those working in markets and as traders, have low literacy rates and suggested direct inter-personal communication methods and dialogue in preferred local languages would be beneficial.

[18] At the time of the research, Internews had not yet started implementing planned activities with *boda boda* riders.

- Participants emphasised that rather than trying to reach IDPs and refugees in transit, they could be reached most effectively in their destination areas by chiefs, community and religious leaders and other key service providers. Key providers who interact with new arrivals include personnel offering education, health and psychosocial services such as teachers, doctors, nurses and church leaders. Collaborating with these actors at destination points requires detailed, localised mapping of population movements (e.g., the Displacement Tracking Monitoring (DTM) Participatory Mapping of IOM and REACH) and coordinated information exchange between agencies offering services across borders.

- A participant connected with the army in Yei suggested that military doctors embedded with the armed forces should be trained in prevention, preparedness and case detection so "*We can deal with it on our own and be our own teachers".* It was reported that armed forces in Yei City had received training from the IFRC on Ebola signs and symptoms and transmission pathways and that a select number of officers had been trained on IPC measures and Safe and Dignified Burial (SDB) protocols. In contrast, community members living in areas that were formerly strongholds of the SPLA-IO asserted that opposition forces were not often included in awareness raising activities or engaged directly in preparedness efforts. Participants reported that armed actors should not be used to 'track down' suspected Ebola cases or be involved in contract tracing efforts, particularly in territory formerly held by the SPLA-IO or other militias, this is in line with findings from the outbreak in DRC (Bardosh et al., 2019a; 2019b). As learning from DRC showcased, the involvement of armed actors could undermine community trust and elevate concerns (as in the DRC) that Ebola is a 'weapon of war' and used by the government to coerce, control and monitor affected populations (Ibid.). It was notable, however, that several participants who identified themselves as having links to the army appeared willing and interested to be involved in stopping Ebola and in enabling safe passage for Ebola response actors. As one confirmed, "*We should see Ebola as the common enemy"* and "*To fight Ebola we should be allies".* Collaborating with armed personnel (both militia and state forces) in preparedness efforts must be considered with caution and further detailed assessment is needed about how best to collaborate with armed actors in relation to Ebola preparedness and response (see also Pendle et al., 2019).[19]

[19] At the time of writing, the EVD Preparedness Consortium had started to work in areas with strong military presence (such as Geri) through community mobilisers (speaking local languages) who reach both military and civilian residents.

Chapter 2 – Knowledge and perceptions, care-seeking behaviours and services

Key findings are presented regarding levels of knowledge, awareness and perceptions about Ebola, care-seeking behaviours (both 'normally' and in the context of Ebola), the provision of services including infection prevention control and burial rites. When relevant, findings have been disaggregated between stakeholder groups, particularly in terms of different community members and health workers.

Experience from previous outbreaks highlights the need to reinforce basic public health systems (Gates, 2015) to be able to respond to Ebola outbreaks, other infectious diseases and more systematic health challenges, while taking into account contextual factors. Nosocomial transmission rates have been high in previous outbreaks (including in the current DRC outbreak) due to insufficient prevention measures, poor IPC practices and limited training and resources for health workers. Nurses and doctors often find early detection challenging, and additional training is needed, as initial symptoms are often non-specific (such as high fever, muscle and joint pain) and can easily be confused with other common illnesses (Ripoll et al., 2019).

Beyond a health facility setting, however, transmission risk is high for those caring for the sick, particularly in a home environment (Brainard et al., 2015; Richards, 2016). Funeral and burial-related events are also well-recognised as elevating the risk of transmission (Tiffany et al. 2017). Efforts to persuade local populations to change funeral traditions during outbreaks can be met with misunderstanding and (at least initial) resistance. As Parker et al., (2016) noted, in Sierra Leone households and communities were highly articulate about their need for practical information about risk factors for Ebola transmission, how to reduce risks when caring for the sick and burying the dead, and material resources necessary to put this advice into practice.

Awareness and knowledge of Ebola

In general, participants across the study conveyed a high level of awareness about Ebola. Many confirmed that there was an active outbreak in the DRC but several participants remained sceptical, "*They say Ebola is here, but I have not seen it with my own eyes*".[20] Alternative explanations about the origins of Ebola were frequently expressed during the study particularly in rural areas, and included negative statements questioning the role of the international community ("*They say the Whites bring the illness"*) and the circulation of '*Ebola-money*'.[21] Knowledge levels appeared to be more variable across field sites. A UNICEF representative commented, "*In Yei city, people have really become like Ebola specialists… the questions they ask are challenging*", whereas in discussing more rural areas, a government official suggested, "*I am not really sure if the information has really reached the people*".

In discussing signs and symptoms, most participants repeated information disseminated by risk communication partners (see also Chapter 3) and could identify at least three signs of infection (e.g., fever, vomiting and diarrhoea), although worryingly the most frequently reported sign was "*Bleeding from body openings*". Different levels of knowledge about transmission pathways were also evident across the research sites, with participants in Yei City appearing more likely than those in the rural sites to describe key infection routes including "*Through the body fluids of sick people from DRC*" such as blood, vomit, urine, sweat and faeces (no participant mentioned semen). There was a strong link made between Ebola and bushmeat. In attributing the spread of Ebola to "*Eating the animals from the bush*", some participants attributed less significance to human-to-human transmission and given that they had "*Eaten bushmeat since forever*" were sceptical about messaging that warned against consuming bushmeat and, by extension, about the agenda of preparedness efforts (see also Garside et al., 2019).[22]

There was a degree of understanding about some IPC measures that had been put in place by the Ebola State Task Force. In Sobe, for example, women who participated in the creative focus groups drew images of hand-washing stations and through acting short scenes, demonstrated that when a person dies from Ebola, doctors have to wear special equipment to care for the deceased (see Image 2 below). This level of knowledge was not evident for other measures however, such as isolation units and temperature screening

[20] This finding was also reflected in the knowledge attitudes and practices (KAP) study led by UNICEF which reported that whilst most respondents in Yei (89%) had heard of Ebola, only 50% believed that EVD could be transported from DRC to South Sudan.
[21] Around the time of the study, youth in Juba frustrated by the lack of employment opportunities and job security, accused white aid workers of "*taking critical jobs away from South Sudanese*". If there was an outbreak of Ebola in South Sudan, it is likely that it some would interpret it in these terms, as has been the case in DRC.
[22] Misinformation about transmission routes was also recorded in the KAP survey led by UNICEF: 37% of respondents claimed Ebola could be transmitted through mosquito bites; and 15% suggested Ebola could be spread through the air (was airborne).

at health facilities. Questions such as "*Why do they have that tent there?*" and "*Why do they try to shoot you with this gun*?" were common.

Image 2: "*Doctors should wear this when they touch a patient*".

A number of participants reported basic self-protection measures such as "*To stop Ebola you need to not touch*", but other protection behaviours were not often reported. Some participants in Yei described washing their hands when entering a market, NGO or hospital compound, although several recounted instances of bystanders making fun of people washing their hands publicly, calling out "*Ebola is not here, it is in Congo"*. Others discussed what action to take in light of a suspected case, "*If you get blood from your nose, go to the health workers*" or "*Call the Ebola hotline 6666*". Concerns were expressed about how to implement the advice provided by the Ministry of Health, particularly in relation to notifying health workers or telephoning the Ebola hotline, "*What would I do when I don't have reception on my phone?*" and "*What if they don't pick up, what do I do then*?" Several participants also highlighted suspicions about the Ebola hotline as they associated the number 6666 with "*The devil and illuminati.*"

Many, particularly those with higher levels of education, living in urban settlements, and those who had been exposed to Ebola information for a longer time, requested more knowledge and greater details about transmission routes, prevention mechanisms and treatment options. Frequently asked questions included, "*Does Ebola survive for long outside the body?*"; "*If you touched Ebola and then washed your hands quickly with chlorine, would you kill it*?"; "*Why is it that health workers get the vaccine and we, the people, do not?*"; and "*Will there be treatment for Ebola, or will I for sure die*?"

Perceptions and fear

Across the study, participants expressed a high level of fear about Ebola. Sentiments of fear cut across all stakeholder groups regardless of social class, age, ethnicity and gender. Messages embedded in communication materials and radio messaging such as "*Ebola is a severe and often deadly disease",* or "*Ebola is dangerous as it can kill quick" had* been rapidly absorbed by communities and contributed to generating fear and at times panic (see Image 3).

Several messages that were meant to motivate the population and health workers in the '*fight against Ebola*' were found to cause increased anxiety, particularly when they used analogies with war and conflict. Statements by the Ministry of Health officials such as "*We should be fighting the Ebola virus like rebels*" and "*Instead of a gun, you* [health workers] *have your gloves* [personal protection equipment]" were also echoed by participants who readily described Ebola as "*The rebel in the bush*". In their creative focus group, women in Sobe explained, "*When people come bleeding from their eyes, nose and other bodily openings* [i.e., if they saw a suspected Ebola case] *then we all run. We run like we do from the rebels*" (see Image 4). In depicting the level of fear associated with Ebola, a male participant in Sobe marked an empty space on his paper with the caption "*This area has Ebola, there is nobody in it*" (see Image 5). Several participants suggested that the rebels were easier to manage than Ebola because "*You can hide from them, whilst against Ebola you are defenceless*", whilst others suggested, "*Ebola does not discriminate. It does not know your political affiliation; it is not a joke*". Government officials also acknowledged the high degree of fear in communities, and as one stakeholder concluded, "*I pray Ebola does not come here, we are not prepared, many will run*"). Unfortunately, certain components of the response exacerbated levels of fear as when the Ministry of Health and response partners organised a simulation exercise in Yei during which health workers were dressed in PPE. It was not communicated to the wider population that this was a preparedness and training exercise, and people responded violently by threatening to burn down a clinic in Yei.

Image 3 – IEC material outside a health facility in Mugwo county.

Image 4 – A drawing by women in Mahad illustrates the more dramatic elements of the disease, which causes people to "*run from Ebola like we run from the rebels*".

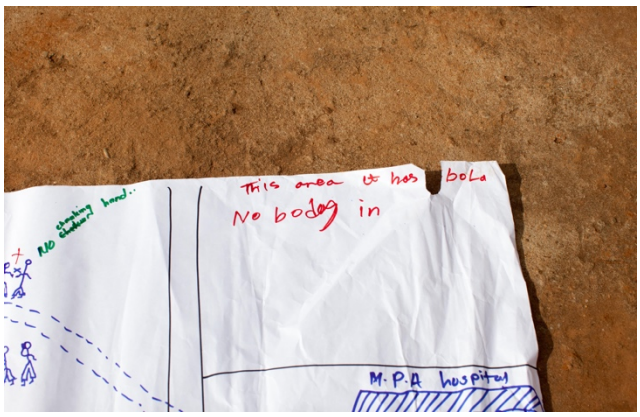


Image 5 – "*This area has Ebola. Nobody in [it]". Drawing my male participant, Sobe.*

Care-seeking behaviours

In light of the ongoing challenges faced in their daily lives, many participants asserted that Ebola was not a priority for them. iIn relation to the near collapse of the state health system and its extremely constrained resources, participants questioned, "*Why are you all working for Ebola, yet it is not here*?" In an operational context such as Yei, preparedness efforts can often appear to be a luxury in the face of numerous immediate challenges. Participants called for response partners to reprioritise their aid, primarily to strengthen the health system. As one community member explained, "*People are dying already and you don't help them*", the implication being that resources are overly focused on Ebola.

Caring for the sick is normally done by female family members with support from friends and neighbours (see Image 6). Many women who participated in the study explained that because of lack of household resources, it would normally take several days for the family to collect sufficient money to attend a health facility after the onset of an illness. Community members believe that they will have to pay for EVD related care, as they would for healthcare services in a normal situation. In the meantime, they would often try to treat symptoms at home with painkillers or with local herbs ("*When there is no money, we just take the medicine from the bush*") and if these did not work, would seek care from local healers ('*buna*'), religious healers or if they had money, from pharmacists in the city or at cross-border markets. These different cadres of care providers play an important role in the health-seeking practices of the population in Yei and in some rural areas, as in Payawa, Mugwo, participants suggested that homecare and traditional medicine were the only options available to them.

Given the communities' tendency to rely on local care practitioners (as discussed above) and the fact that many practitioners in the border areas treat patients from both DRC and South Sudan, it was notable that many of the local practitioners who participated in the study had limited knowledge about how to implement IPC measures even though they emphasised their need for protective equipment, particularly gloves, to enable them to care for their patients safely. UNICEF representatives confirmed that traditional healers had been engaged in Ebola awareness activities in Yei as part of preparedness work conducted in partnership with the Ministry of Health, but no practitioner who participated in this study had been included in such a training. Some had been engaged by risk communication teams raising awareness, but all felt they needed further training on prevention mechanisms and be supplied with protective equipment. Many expressed willingness to support the response and asked for recognition of the work they did as at-risk frontline providers. This was clearly outlined in the following narrative:

"My name is Rose and am 33 years old. I am Kakwa and originally from Ingbokolo in the DRC. I work with local medicine and am known as a 'buni'. I use the bark of trees that have healing power and cook them into a medicine which I give to my patients. I used wood and the tarpaulin given to me by UNHCR to make my hospital room. I have medicine for

Image 6 – "*When someone is ill, everyone comes to help….*"

vomiting, diarrhoea and fever. People come across the border to see me when they are sick and I travel back and forth to see my patients. My skills came to me in a dream. I also dreamt about how to treat Ebola and I made the medicine which is here with me now. I healed four people from the Meri refugee camp in Aba [Haut-Uélé province, DRC] *when they were sick with the virus. I think Ebola is from God, but I can cure its symptoms. I would like to support the Ebola response, but I do not have any money to buy the things recommended by the Ministry of Health, things like gloves. I also fear the illness and would be happy to refer any sick patients to the hospital".*

Religious leaders were also identified by participants as important sources of care, particularly for the critically ill and dying. As one community member noted, "*If nothing else works, we bring the patient to the church*". When asked during the creative focus groups to describe the most important avenues of care, several participants drew churches, explaining that praying for the sick is especially important when the cause of illness is spiritual or a curse. Women market traders in Mugwo suggested that Ebola was a "*Curse from God*", and it is therefore possible that religious healers will be sought by community members to resolve suspected Ebola.

Participants who had links to the armed forces described unique challenges they faced when accessing formal healthcare.[23] Soldiers in rural areas reported that local doctors would often not treat them, '*When they see a military brother, they get scared and they flee the health centre*". Military personnel stationed in Yei city reported to have access to the hospital located inside the army barracks but noted that it often lacked equipment and resources resulting in them having to attend other public facilities such as the NPA hospital.

As discussed above, there was a strong narrative of 'running away' when community participants described what they would do if they encountered a suspected Ebola case. In describing what action they would take if they or their own child were sick, most suggested that they would try traditional medicine and home care, and then if they suspected Ebola (because of severe symptoms such as bleeding) would present at a health facility and and/or call the Ebola hotline.

Health facilities, health worker perceptions and IPC

Across South Sudan, but particularly in rural areas, multiple barriers prevent equitable access to formal healthcare. Many health facilities have been destroyed during years of conflict (REACH, 2018); surviving health facilities have limited water and sanitation and lack in-patient capacity; health workers have often fled their facilities or are absent having not been paid for months; insecurity prevents the population from travelling to health facilities; there is a chronic lack of medical equipment and essential drugs; and low quality care. Such challenges were raised by participants across the study sites in addition to issues associated with direct and indirect costs, particularly the high price for consultations and drugs at private hospitals which are often the only source of care available. According to the recent joint rapid assessment conducted by Save the Children, Internews and Concern Worldwide, only 16 health facilities in Yei, five in Morobo, 10 in Kajo Keji and 20 in Lainya counties were reported to be operational (EVD Preparedness Consortium Internal Assessment Report, unpublished). Similarly, during a health sector meeting organised by the Ministry of Health and Environment in Yei in August 2019, it was reported that only 50% of health facilities were mapped and just 20% of those were currently supported by NGO partners. A number of health workers who had previously been involved in preparedness and screening efforts reported that they worked without salary due to the Ministry of Health's depleted budget. Others emphasised the lack of basic health infrastructure and called for health facilities to be rebuilt and the health workforce trained to enable them to respond, "*Not just to Ebola but also for other deadly diseases*".

At the time of the study, health workers in Yei had been trained on Ebola prevention, IPC and WASH, but many of those who participated in the research still reported having questions about the virus, the functionality of IPC measures and practical solutions applicable to their own daily practice and place of work.[24] All implementing partners and participants reported the need for refresher and follow-up training. Many health workers confirmed that "*All precautions should be taken before touching the patient*" but

[23] A more detailed mapping of armed actors in Yei River State is provided by Pendle and Marko, 2019.

[24] Save the Children implemented a three-day training that included a selection of formal healthcare providers. The training focused on EVD transmission, personal protection and handwashing, donning and doffing, case management of suspected Ebola patients, triage, contact tracing, community engagement and chlorine mixing. It included a practical simulation element, and taught participants how to manage dead bodies. Concern International provided a two-day training focusing on hand hygiene, PPE donning and doffing and waste management, and (briefly) community perceptions on Ebola. It targeted community health volunteers and primary healthcare providers. Some overlap in participants in the two trainings was reported. Not all healthcare providers involved in the study had yet been trained by the Consortium.

asserted that it was difficult to adhere to these measures when they did not have access to basic protective equipment, including gloves. Others requested more practical training ("*How should I isolate a patient"*; "*How should I mix the chlorine?*") and noted issues they had encountered in providing the most basic of services such as checking patients' temperatures ("*It was a hot day, everyone we tested had a temperature, even me and I am not ill….so I let them all through*"). Nurses also expressed concern about how to feed patients who were admitted as health facilities do not normally have sufficient resources to provide food and depend on a patient's family to provide such care.

Many health workers asserted that they, like the communities they serve, were fearful of Ebola, felt underprepared to deal with a case and were aware of the risk of nosocomial infection. As one health worker at a private clinic in Yei city confirmed, "*If Ebola comes and I don't have the PPE, I will also run*". In their participatory focus groups, several health workers depicted themselves and other frontline providers fleeing from facilities (see Image 7) and suggested that their underlying fear, limited training and lack of equipment could cause them to make mistakes and not fully adhere to rigorous IPC measures.

Image 7 – "*This is the guard at the facility, he is running as he is not confident*".

Customary burial practices

Burial and funeral rites occupy an important role in South Sudanese society, with 'proper' burials being seen as essential for both the deceased and the living (Idris, 2017). Some customary practices such as washing, dressing and transporting the deceased's body to their natal village are high-risk activities in the context of Ebola given the high viral load and danger of transmission. At the time of the study, Safe and Dignified Burial (SDB) teams from the Ministry of Health with support from the South Sudan Red Cross and Red Crescent, had been trained to not touch the deceased, to bury the body in a designated area and to ensure family members do not come too close to the body.

Although response partners will implement SDB protocols, it is imperative that these are negotiated with community members and fully adapted to the local context. Some participants, including several community leaders, suggested that "*What they are proposing to do would not be appreciated here*", whilst others appeared willing to adapt burial rites if this would protect them and their communities from infection. Most compared the adaptation of burial rites in the context of Ebola to changes previously experienced during periods of conflict, and as one female participant in Sobe concluded, changing burial practices because of Ebola "*Will be like losing your child in the bush when you run from the rebels".*

Recommendations

- There were repeated requests from different stakeholder groups including healthcare workers, community members and leaders, traditional healers and religious leaders across the study sites for response partners to share more detailed information about Ebola, its signs, symptoms, transmission pathways, how to prevent and protect against infection, what to do if a case is suspected, where to seek treatment, and about the treatment itself and vaccination. They also reported the need for more training and more general IPC supplies to be able to respond to other diseases "*that kill now".*

- Analogies between Ebola and conflict may be understandable given the long-term insecurity in South Sudan, but the use of militarised language and the drawing of direct comparisons between 'fighting the virus' and 'fighting the rebel groups' is unhelpful and escalates existing tensions and fear. Response personnel, including those from the Ministry of Health, should avoid using such tropes in their communication efforts. The importance of language used was also noted in the Ebola outbreak in DRC, where social scientists reported that making "alerts" in case of an Ebola case was compared with alerting the police when something was wrong (instead of "calling a doctor"). Community members associated the term with being "picked up" by the security services, which was inherently negative (Bardosh et al., 2019a).

- Key messaging should be re-orientated away from '*Ebola is a deadly and dangerous disease*' towards reaffirming positive messaging that focuses on the high chance of survival if a patient presents quickly for early treatment.

- Because of the multiple sources of care, it is vital that local healers, religious leaders, pharmacists and other local frontline providers be trained on Ebola and IPC measures (this is in line with findings of Hewlett and Amola, 2003, following the Gulu outbreak in Uganda, and outbreaks in West Africa and DRC, see, for example, Ripoll et al., 2018; Sweet, 2019). Although it is understood that engaging such stakeholders has been done to some extent in Yei, further investment is required, particularly if they are to contribute to community-based surveillance efforts and referral of cases.

- Given the systemic weaknesses in the health system, finding the best available local solutions to the challenges of IPC and access to basic care should be done collaboratively at the community level and with health workers. Communities often have pragmatic solutions for overcoming barriers during an emergency situation, and these should be developed and supported, see for example how communities supported the care for children orphaned by the Ebola outbreak or provided insights on how best to manage feeding to those in quarantine (Abramowitz et.al., 2015). Similarly, health workers are well placed to find solutions within their daily practice through dialogue, refresher and practical training, although key resources (gloves, chlorine etc.) must be provided at the point of service delivery.

- As women are usually the primary carers at the household level and may therefore be at greater risk of exposure to illnesses, including Ebola (see, for example, Smith, 2019; Ambramowitz et al., 2015) specific efforts should be made in providing them with training and support, particularly in terms of IPC for homecare, identification of symptoms, rapid alert to health workers or via the Ebola hotline, and early presentation at a health facility.

- As part of their training, health workers and other frontline providers should be taught negotiation skills and have tools to address the fear communities feel in relation to Ebola and other illnesses constructively. They must also be better equipped with self-coping mechanisms for their own fear and stress.[25]

- It is imperative that safe and dignified burial protocols are negotiated with community members and fully adapted to the local context (for example, see Fairhead, 2014 and 2016; Hewlett and Hewlett, 2017; and Bedford et al., 2018). Such adaptations can have significant psychosocial impacts on the family of the deceased as well as the burial team and must be dealt with sensitively by skilled facilitators trained in psychosocial support. Involving the army or other state security actors during SDB must be avoided at all times as this would bring additional negative connotations, fears of coercion and would likely weaken the fragile trust that must develop between SDB teams and the community.

[25] As part of the trainings that Concern International conducted with health workers and community healthcare workers, sessions on community misperceptions and "*how fear can harm*" (based on data made available by Anthrologica) was provided. In addition, community mobilisers address community-based misinformation during community mobiliser trainings.

Chapter 3 – Communication and community engagement

Exposure to information sources in previous outbreaks has been associated with higher knowledge and protective behaviours, yet this exposure was also significantly associated with misconceptions and risk behaviour (Winters et al., 2019). Even though having knowledge appears to be beneficial for adopting protective behaviours, misconceptions also affect risk behaviour. Communication channels should be considered within the broader context, acknowledging the complex interactions among societal, community, and individual features which influence knowledge and behaviour. A high prevalence of misconceptions has, in past outbreaks, led to the rejection of interventions (Vink et al., 2019; Winters et al., 2019) whilst localised communication interventions have been found to effectively change behaviour and its determinants (Figueroa, 2017).

It was well noted amongst response partners as well as community-based participants that providing information did not always result in corresponding behaviour change, and that the mode of communication and the use of trusted channels were often as important as the substantive content of tailored messaging. It was clear that the information needs of participants had changed over time and as secondary school teachers who participated in the study in Yei emphasised, "*It takes time to change people's behaviour. Malaria took time. So did HIV/AIDS, so your Ebola will also take time*".

At the time of the study, a large number of risk communication and community engagement (RCCE) actors were operating in Yei River State and providing key information services to communities at risk. Since the Ebola outbreak in DRC, messages about the virus have circulated on local and national radio stations, via churches, through social mobilisation efforts by community-based volunteers and on posters displayed on public billboards. At times, mass mobilisation efforts have been reinforced with house-to-house visits by volunteers to discuss key signs and symptoms, making use of Information Education Communication (IEC) materials distributed by the Ministry of Health with support from UNICEF and the South Sudan Red Cross and Red Crescent.

Participants across the field sites frequently requested that "*NGOs answer our questions"*. This indicates that the information needs of different populations were not being fully addressed. As highlighted in Chapter 2, participants demanded more information about the origin of the Ebola, signs and symptoms of infection, its transmission routes, prevention mechanisms and treatment options. Specifically, participants asked for further details about the vaccine, treatment options and quality of care, about the risks that different stakeholders face and how they should adapt their behaviour to keep safe. It was noted during interviews with UNICEF and other partners that no detailed information about vaccination had been incorporated into broader communication efforts. This is problematic as it creates a vacuum of knowledge in which misinformation readily circulates. That demand for the vaccine is high should be interpreted positively. In a UNICEF-led KAP survey, 95% of respondents in Yei River State confirmed that they would accept the Ebola vaccine if it were available to them (UNICEF, 2019).

The circulation of misinformation was also seen to be problematic for preparedness activities as it had the potential to undermine key messaging and reduce the level of trust between community members and response workers. Tracing misinformation and modifying key messages to directly target and respond to misinformation is an important component of agile communication.[26]

Trusted sources of information and communication channels

In discussing who participants regarded as the most trusted sources of information about Ebola, the majority suggested health professionals and/or Ebola survivors. Health professionals were not universally trusted, but in general doctors were trusted more than nurses, and formal providers more than pharmacists and local healers. Survivors were trusted because they had experienced Ebola first-hand and could give a personal account. This was reinforced by the notion that "*seeing is believing"* (also discussed in relation to modes of communication below). In addition to survivors, participants asserted, "*We want to hear from those who have seen an outbreak in DRC or South Sudan before*". This presents interesting opportunities for engagement and suggests that past outbreaks actively shape the way the current and future outbreaks and preparedness activities in South Sudan may be perceived.

[26] At the time of fieldwork, Internews was training a community correspondent and at the time of writing, Internews Community Correspondents were deployed in the four countries. They were deployed during daily field missions to hard-to-reach areas to gain a more in-depth understanding of the communication needs of communities and to mitigate misinformation.

At the time of the study, a wide range of existing platforms were being used to reach audiences, but it was evident that there were significant differences in how participants from rural and urban areas accessed Ebola related information. Most participants in Yei confirmed that they received Ebola awareness messages from multiple channels including local radio, radio Miraya broadcast from Juba or through NGOs or local partners awareness-raising activities.[27] A very small number reported that they sourced information from social and online media either through their own devices (mobile phones) or at internet cafes (including across the border in Uganda). In contrast, participants in rural areas suggested that they mainly accessed information via their church and religious leader, through local community or church radio, or from radio stations broadcasting from Uganda or DRC. It is well understood that church networks have extensive coverage and reach, extending even into the most remote communities, and as one government stakeholder confirmed, "*Spreading messages through the church in rural areas makes total sense as they are directly in touch with people every day*". Church radio stations usually broadcast in multiple languages (see below), and many had already completed audience mapping in rural areas that would be useful for preparedness actors.

Participants also suggested market days as good opportunities to engage people from more rural areas, and during the study, the research team observed multiple organisations attempting to convey information on a variety of topics (Ebola, gender-based violence, child abuse) to market goers in Mugwo. Unfortunately, this uncoordinated approach and jostling to give information meant that it was unlikely that key messages had been well understood or absorbed.

Modes of communication and engagement

Across the field sites, verbal communication was strongly preferred over written materials and several participants mentioned issues related to printed IEC material disseminated in Yei. For many, *"The pictures are not enough"* and it was repeatedly noted that, "*The language is not right"* (discussed further below). Participants therefore requested that the format or mode of communication and engagement activities be adapted from mass-mobilisation and awareness-raising to constructive two-way dialogue between Ebola preparedness actors and communities. As a teacher from a secondary school in Yei emphasised, "*We don't like it when you just speak to us… we want the opportunity to ask you questions".* Several participants described mass mobilisation sessions to be counterproductive as they were "*Chaotic and no one can hear"*. There was a perception that NGOs and response partners "*Prefer mass mobilisation efforts because then they get more people*", but broad consensus amongst participants in both urban and rural sites that interpersonal communication would be more effective and efficient, particularly if community members were provided with sufficient time and opportunities to ask questions. A number of participants wanted to 'test' (e.g. validate) their knowledge with technically skilled health workers as this would make them feel more confident in their own ability to protect themselves, their family and communities.

Study participants, particularly women, suggested video as one of their preferred formats of communication. After decades of conflict and minimal investment in the education system, South Sudan continues to report some of the lowest literacy rates in sub-Saharan Africa and many of the female participants in the study had limited literacy levels. They emphasised that, '*People need to see something moveable… if you cannot see it, then the problem seems far away*". Women traders in the Dar Es Salam market in Yei suggested that Ebola preparedness actors should put up big screens to project films about Ebola because *"Seeing is believing…we want to see what they* [Ebola preparedness actors] *are talking about".* Participants asked to see footage of *"Real people in DRC who are sick, those who are getting treatment and those that have survived the disease".* A catholic bishop who oversees a popular radio station in Yei confirmed, '*People function like that, they need to see the evidence*".

Language

South Sudan has considerable linguistic diversity, and this creates some operational challenges for effective communication at the community level. As part of the study, participants were asked what their preferred language(s) were. The graph below illustrates the most commonly spoken languages amongst participants, including Kakwa, Pojulu and Peri; there are different dialects in a language group that are sometimes mutually comprehensible. It was noted that Juba Arabic is often used as a common language when members of different ethnic groups mix and whilst other languages (Lingala, Dinka, Amharic) were spoken by different stakeholder groups across the study areas including traders, refugees and IDPs who preferred

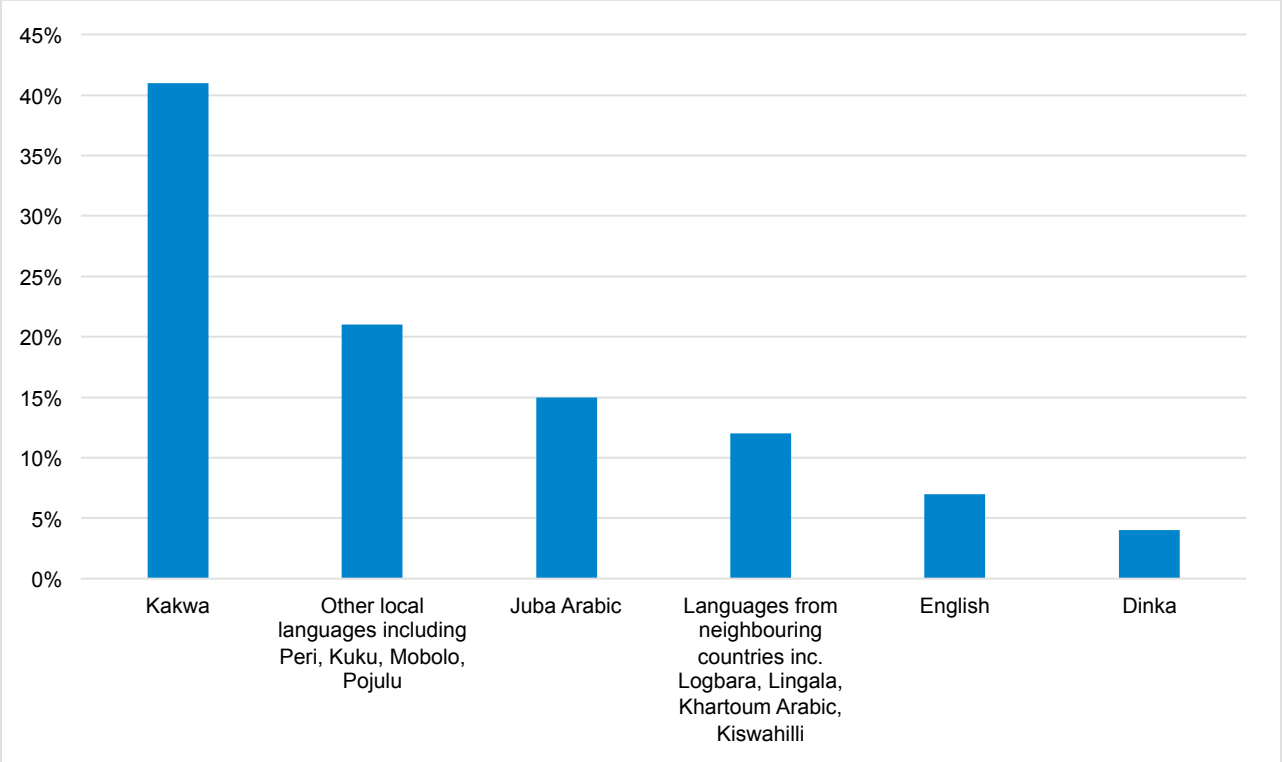
[27] In the UNICEF-led KAP survey, frequently consulted sources of information were reported to include radio (mentioned by 76% of respondents) and health workers (mentioned by 74% of respondents).

to speak their mother-tongue, most were able to communicate with the wider population through Kiswahili (the most common trading language in the region) and sometimes English. In their official capacities, government representatives most often converse in English, whilst members of the armed forces were reported to speak Dinka, Nuer or Peri, and "*Their own military language*".

Spoken language is not always comprehended in the same way as written language and participants emphasised that materials in English or Juba Arabic were often poorly understood by community members, even if they could speak those languages to some degree. Participants in Mahad and Sobe confirmed that they had limited understanding of Juba Arabic and whilst some community and religious leaders were able to converse in English, all expressed a strong preference for using their local language(s).

As a secondary school teacher in Yei city confirmed, "*The posters are in English, but the people here only speak the Kakwa… it would be better if they use our own language"*. Several participants explained that friends would rapidly translate messages and information between languages, for example, "*When we hear things on the radio, my friends translate it to Kakwa for me*" but this raises obvious concerns about the quality of translation and the transference of information.

Graph 1 – Languages spoken as self-reported by study participants (n=166)



Recommendations

- Further assessment of modes of communication, trusted channels, the substantive content of messages and languages used would provide a stronger evidence base for the development of nuanced and targeted communication and engagement initiatives rather than blanket information campaigns. This is also important as messages that seem logical from a biomedical, disease prevention perspective may not always be interpreted as such by affected communities (for example, see Chandler, 2014; and Allgaier, 2015). To complement this, more granular analyses of knowledge about Ebola across stakeholder groups and in different areas of Yei River State is urgently needed, particularly in rural and difficult to access communities. This will help target resources for greatest impact which, as preparedness activities continue, will be increasingly important.

- Although mass one-way communication is necessary to push basic messages about signs and symptoms, prevention behaviours and to raise awareness at the start of preparedness activities (or an active response), in Yei River State this must now be supplemented by dialogue and interpersonal

communication supported by creative and stimulating formats such as video and theatre.[28] Many participants called for dialogue with preparedness actors so that they had the opportunity to ask questions and raise their key concerns. Evidence from previous outbreaks and other situations has shown that two-way engagement increases learning and knowledge uptake, supports the transference of knowledge into positive action, creates a sense of trust and shared ownership, and can combat misinformation (Bedford et al., 2019). However, it is important that messages are locally relevant (Allgaier and Scalastog, 2015) and comprehension is tested with the affected community (Kinsman et al., 2017).

- Messaging and IEC materials should be updated to address the population's changing information needs and to respond to misinformation circulating in communities. Participants asked for more detailed information about IPC measures, transmission routes, specific risks that different stakeholder groups face and how they should adapt their behaviour to keep safe, treatment options and quality of care, and about vaccination particularly its inclusion / exclusion criteria (this is in line with earlier information requests from Ebola affected communities in DRC, see for example Bardosh et al., 2019a; 2019b).[29]

- All communication should be evidence-based and convey the most up-to-date information. Communication actors should therefore collaborate closely with medical teams to ensure messaging is as accurate as possible. Similarly, medical teams should align the way risk communication and community mobilisers communicate with patients so that there is consistency in the ways Ebola is presented and discussed. Key messaging about Ebola could also be integrated into broader health communication initiatives, and investment during an Ebola outbreak could bring about longer-term uses of these platforms (see Bedford et al., 2017).

- Given the wide range of languages spoken across Yei River State, and the high level of illiteracy, there is need for further assessment and mapping of the most appropriate and relevant languages to use when engaging different target groups and when using various modes of engagement. The importance of providing information in the right language during preparedness and response is further discussed by Berger and Perret (2019).

- Cross-border communication should be mapped and strengthened so there is consistency in messaging and to ensure that mobile populations are similarly engaged in South Sudan, DRC and Uganda.

[28] At the time of writing, the EVD Consortium reported to make more use of poems, songs and theatre to focus on the transmission, control and prevention of EVD.
[29] At the time of writing, Concern community mobilisers have been deployed at 18 out of 20 health facilities and use UNICEF and custom IEC material focused on EVD, WASH and other key IPC behaviours.

Conclusion and summary recommendations

The population in cross-border communities in South Sudan is facing multiple, and mutually reinforcing public health emergencies, conflict and armed violence, and natural disasters including destructive floods and related food insecurity. Its health system is severely underfunded and lacks the skilled workforce and materials to respond to the threat of Ebola and other illnesses effectively. Ebola preparedness activities should be designed accordingly, tailored with sensitivity towards the needs, priorities and vulnerabilities of communities, whilst contributing to strengthening the pillars of a functioning and resilient health system. Ideally, a holistic approach would be adopted, with serious commitment and investment for both short- and long-term priorities.

In the short-term, there are a number of priorities in order to respond to the immediate threat of an Ebola outbreak. Community-based actors will continue to have an important role, particularly in light of the ongoing insecurity and restricted movement of external response actors in areas most at risk of an outbreak. In order to have the knowledge and ability to respond to an Ebola alert, community actors will need sustained support. It will also be necessary to increase efforts that bridge gaps linking information provision, health promotion and knowledge. Again, this requires targeted efforts and investment that will build the skills of health workers engaged in the formal system as well as community actors so that they can respond together to the threat of disease. The Consortium is already making substantial contributions to these activities, and the specific recommendations set out throughout this report highlight ways in which those contributions may be enhanced.

In the long term, it is essential to look beyond the immediate threat of Ebola and there is an urgent need for greater investment to revitalise and rebuild the South Sudanese health system. This should be viewed as part of the broader transition strategy for the Consortium, as well as complementing current efforts to prevent an Ebola outbreak. It is an enormous task, and whilst it is recognised that it falls outside the current scope of work of the Consortium, as a bare minimum the Consortium's activities should fit into the broad principles of the 2005 Paris Declaration on aid effectiveness.[30] In practice this means working in partnership with national institutions, linking Ebola preparedness measures to existing initiatives and platforms and contributing to building health system structures. The very challenging operational constraints in South Sudan will limit the scope of what can be achieved in a limited timeframe, however contributing to sustained health system strengthening should be integrated into the transition strategy of the Consortium. Linking Ebola preparedness activities with longer-term health communication activities, and training health workers on critical concepts of hygiene as part of training on Ebola IPC measures, all in coordination with broader structures, are some of the practical ways this can be achieved.

Building on learning from Yei River State

The research highlighted areas in which specific Ebola preparedness activities of the Consortium could be built upon in Yei River State. The detailed recommendations set out at the end of each chapter in this report can be summarised under the following three themes:

- **Ensure ongoing training and supervision for healthcare workers.**

Invest in refresher training and continued supportive supervision for healthcare workers to address their underlying concerns and constraints. These efforts should address the needs identified by study participants to provide detailed information about Ebola, its signs, symptoms, transmission pathways, how to prevent and protect against infection, what to do if a case is suspected, where to seek treatment, treatment available and vaccination. Stress and fear may otherwise prevent front line providers from responding rapidly and appropriately when faced with an alert, suspected or confirmed Ebola case. Messaging should be positive and avoid language that fosters fear.

- **Ensure activities continue to adapt to local challenges.**

Where formal care is less accessible, explore 'best available' local solutions to the challenges. This should take into account the challenges in distributing sufficient IPC supplies, delivering basic care, movement of populations and local customs such as burial practices. It should be done collaboratively with the full range

[30] As set out by the OECD: "Aid Effectiveness 2005-10: Progress in implementing the Paris Declaration", OECD Publishing, Paris, 2011.

of formal healthcare workers, informal providers and other community actors identified. This is particularly important in rural and insecure areas and could facilitate early detection and necessary rapid response.

- **Put communities at the centre of the response.**

Address the fear and concerns of communities and continue to build knowledge on Ebola and prevention measures whilst promoting early presentation at health facilities. Community dialogue, specific activities addressing women and mobile populations and community-based surveillance plans will help facilitate early detection and positive response. Attention to the appropriate modes of communication, specificity of the content of messages and use of language(s) according to target audience will be more effective than blanket information campaigns. Continuous mapping and attention to cross-border communications will be essential to ensure that mobile populations are similarly engaged in South Sudan, DRC and Uganda.

Post-script

At the time of writing, the EVD Preparedness Consortium reported to have completed the following activities. Some of these were adapted during and since the time of fieldwork, whilst others were modified based on participant feedback collected and presented during the implementation of the research study.

- Community mobilisers and community-based surveillance teams have been embedded within communities and provide surveillance at the community level. These community mobilisers are nominated by the communities themselves and work in the communities they are from to help ensure a sense of community ownership of the programme.
- Community mobilisers work in local languages and have been provided with IEC materials that do not require literacy, for example, photographs are often used to convey the information. Community mobilisers work across their entire catchment area, ensuring that community events, places of worship, markets, schools, etc. are all directly included in EVD and IPC/WASH activities. Events such as Global Handwashing Day in Morobo provided a community platform for knowledge sharing. Poems, songs, and theatre were used to focus on transmission, control, and prevention of EVD.
- Whenever possible, community mobilisers work in teams of two (one female, one male) to encourage gender balance and to ensure that women, regardless of their level of literacy, are receiving training and support at the community level.
- In areas of implementation where there is a strong military presence (Geri), the Consortium has deployed community mobilisers to engage both military and civilian residents. Community mobilisers are specifically recruited to match the needs of the community they serve. For example, in IO areas, Nuer speaking mobilisers are recruited to reflect the linguistic landscape of the catchment area.
- Community mobilisers have been trained about Ebola, routes of transmission and prevention strategies, with supervision of medical personnel from the Ministry of Health, WHO and Save the Children. Supportive supervision ensures that accurate and responsive information continues to be be shared with communities over time.
- The Consortium has provided specific IPC/WASH materials at the health facility level. These include PPE, chlorine, soap, handwashing stations, waste bins, and bin bags. Community mobilisers also encourage members of the community to enter the "*hygiene ladder*" by engaging in practices like constructing tippy-taps, when no handwashing station is present.
- All Concern trainings include sessions on community rumors and misperceptions, based on the data presented by Anthrologica. During health worker and CHW trainings, a full session is dedicated to "*how fear can harm*". Community misinformation (rumours) which may cause fear, are also addressed during community mobiliser trainings.
- Internews Community Correspondents are deployed during daily field missions, including in difficult and hard to reach areas, in order to gain a stronger understanding of the communication needs of communities.
- The Consortium's overall focus on WASH acknowledges and accounts for the fact that Ebola is "*not always there*", but that other health issues are. By strengthening the capacity of frontline health workers and the community to better undertake best practice IPC/WASH measures, the Consortium is working towards longer term benefits.

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