

# Community Approaches to Epidemic Management in South Sudan

RIFT VALLEY INSTITUTE

This briefing summarizes findings from the mid-point of the Community Approaches to Epidemic Management in South Sudan research project. The project is run by the Rift Valley Institute (RVI) and funded by the UK Foreign Commonwealth and Development Office (FCDO) via the East Africa Research and Innovation Hub (EARIH). The project, which began in response to the global coronavirus pandemic, is designed to document how communities across South Sudan have created systems and structures to control the spread of epidemics and infectious diseases in the country. It builds on a rapid response research study conducted by RVI in April this year: <u>Responding to COVID-19 in South Sudan: making local knowledge count.</u>

This briefing presents time-critical findings and suggestions for action. A full report will be published at the conclusion of the project that will present geographically specific evidence including detailed community methods of infectious disease management.

## Methodology

Research for the project is conducted by a team drawn from an extensive network of RVI-trained researchers.<sup>1</sup> At this point in the project, the team have conducted 82 in-depth interviews in the Yei, Juba, Wau, Malakal, Aweil West and Rubkona areas, both in-person and remotely, via telephone.<sup>2</sup> Interviewees include midwives and traditional birth attendants, male and female nurses, herbal experts, traditional healers, pharmacists, chiefs and community elders, elderly women, and local public health workers, among many others. The health and wellbeing of the team and our interviewees is the priority throughout the project.

This briefing presents preliminary analysis from these interviews and from over 430 archive files and documents from the <u>South Sudan National Archives</u> in Juba (a close RVI partner), the Sudan Open Archives and academic databases. A full report will be published later this year.

#### **Community experience**

Across South Sudan, communities have extensive indigenous knowledge of infectious diseases born from long experience. For this reason, they have developed tried and tested methods of epidemic management, isolation and hygiene. Most people have experience of multiple epidemics within their households and neighbourhoods. Many informal healthcare providers have been involved directly in organized medical responses to past epidemic outbreaks: in several areas of the country people have been involved in contact tracing and infection management since the 1970s.<sup>3</sup>

Community infectious disease management relies on symptomatic identification, the containment of potential infections through applying knowledge of infection vectors and pathologies, and creative treatment using a high level of botanical knowledge. Identifying and managing infectious diseases successfully depends on closely watching and differentiating symptoms by their local names, as clinical testing is rarely available or accessible.<sup>4</sup>

### South Sudan's healthcare system

South Sudanese communities have a realistic understanding of the limitations of the country's formal medical healthcare system. It is far from comprehensive, often misdiagnoses, is expensive or difficult to access, and does not necessarily provide the patient with reliable answers. Many medical clinics across South Sudan blanket diagnose people with typhoid and malaria when the actual problem may be something else. Community infectious disease management and treatment plans take into account the inadequacies, expense and inaccessibility of formal health facilities and drug treatments.

Formal medical institutions, based on a Western model of healthcare, are only one part of the system in South Sudan. Most people rely heavily on African plant-based medical expertise and treatment plans, which are organized primarily by local herbal experts. They may also refer to residents with some Westernized medical

knowledge but without formal employment (for example some birth attendants and men and women in the pharmaceutical trades).<sup>5</sup> This wider medical system exists partly because of the intense poverty of the majority of the population: accessing formal medical centres and drugs is expensive even if treatment is free.

## Geography and stages of medical care

In South Sudan's deep rural areas, peri-urban farms and villages, towns, cities and displacement camps, people take different paths to obtain medical care. In households this is often determined by an assessment of the severity and perceived risk level of the symptoms in question. These assessments are generally managed by women, who often have extensive symptomatic knowledge of cholera, measles, kala azar and/or sleeping sickness. They also often have experience of both herbal and medical treatment systems and what has previously worked (or not).

In different locations people follow different pathways to seek medical advice, but most often local expert women are consulted first, then family elders, traditional healers, faith leaders or herbal experts, and then the formal medical system via pharmacists or local clinics. Traditional healers and pastors can also be particularly vulnerable to infection, as they are often the first point of advice that people seek out when they become ill.

### **Community leadership in epidemics**

The people who decide what happens when an infectious disease strikes a neighbourhood are generally those who play a role in treatment pathways. These include: women running households, elderly medically-experienced women, herbal experts, local chiefs and elders, cattle camp leaders, pharmacists, faith leaders and spiritualists, depending on local societal organization.

These people have extensive experience of organizing responses to epidemics within wars and other crises. When epidemics break out, local action on epidemic control is generally decided by these key people via committee in an emergency meeting, with decisions on actions and details about the disease circulated through the community via elders, chiefs, women and students moving the information door to door.<sup>6</sup>

#### **Community epidemic management systems**

There are multiple, locally-specific methods used within communities for interrupting infection transmission and managing epidemics. For airborne diseases or infections spread through contact, people often organize houses for self-isolation, mark out separate food and water access points for households, make homemade rehydration salts, carefully manage dirty linen, bed spaces and drinking water provision to avoid cross-contamination, and use urine, hot water and ashes for disinfecting. Different communities across the country use crossed posts, rope barriers, or ash markings across paths to warn people away from sick households in quarantine. Particular care is taken to avoid transmission to high-risk residents, especially pregnant and post-partum women and young children.<sup>7</sup> Across communities, prevention measures are iteratively reassessed and improved on.

People are able to put in place these local epidemic management measures when they have detailed knowledge about disease transmission and identifiable symptoms. In our study many people emphasize the problem of diagnosis of flu-like conditions. Coughs and fevers are not marked as particularly serious symptoms, and often diagnosed as malaria or typhoid. This is one reason why COVID-19 is often not viewed as a serious illness in communities across South Sudan. Some residents suggest that COVID-19 instead should be put into the local diagnostic category of TB, which is considered much higher-risk and more infectious, prompting more immediate isolation and community control measures.

### **Suggestions for action**

**Understand and collaborate with the entire healthcare system in South Sudan.** This includes local healthcare providers like herbal experts, pharmacists and women who act as first responders for their neighbourhoods, and who have extensive experience in fighting epidemics. These informal healthcare workers are generally keen to take on scientifically backed practices, but this information must be provided through real collaboration and mutual organization of epidemic responses so that it is effectively adapted and practiced across South Sudan's diverse communities.

**Build local epidemiological knowledge about COVID-19 among this wider healthcare sector.** Across our interviews so far, men and women leaders voice frustration that they do not know the details of COVID-19's airborne transmission, symptomatic markers, the progression of serious cases, its morbidity and its terminal symptoms. They emphasize that in the absence of a comprehensive and accessible Westernized healthcare

system with adequate testing and tracing, they will need this detailed epidemiological knowledge to respond to COVID-19. Community meetings are needed for this wider healthcare sector to discuss this epidemiological information properly and then to develop concerted local responses to the pandemic.

**Place COVID-19 within community taxonomies of infectious diseases and into local languages.** This will enable people to discuss the disease with specificity and consequently take it seriously. Interviewees emphasized that a lack of knowledge creates fear, rumours and stigma; it also means that COVID-19 is seen as flu, which is not usually taken very seriously. Instead, placing COVID-19 in the context of other well-known and serious infectious diseases like TB, cholera and measles will help local leaders and communities organize to apply existing and practiced methods of transmission reduction, infection control and quarantine. These local methods are more likely to take into account the realities of everyday poverty than measures imposed from above.

**Be realistic about South Sudan's healthcare system and the usual pathways to medical help.** This is particularly important in the absence of a fully functioning or accessible Westernized medical system. Local herbal experts and informal healthcare workers are often the first point of contact and first decision-makers for people in health crises—support and training must be given to these key points of contact. Connecting with and supporting these informal healthcare workers should not just be for COVID-19 but for the full range of infectious and dangerous diseases in South Sudan (these men and women are often the first responders). This would help these local medical experts protect themselves and their communities, whilst also referring people with suspected cases of COVID-19 to the right pathways.

**Avoid concentrating solely on COVID-19.** The focus on COVID is frustrating and alienating for communities already dealing with a multitude of life-threatening health crises and other risks. This requires a coherent overall response that integrates COVID-19 actions into national public health planning, which then functions in a holistic way to the health challenges communities face.

**Devolve authority to this wider healthcare sector.** Supporting communities with the broad epidemiological and logistical skills to prepare for other epidemic outbreaks is critical. So is supporting local herbal experts and informal healthcare workers by building their collaborations and trust with the Western medical system and staff. Detailed epidemiological knowledge is vital for key local healthcare providers and advisors to be able to protect themselves, identify suspected cases, coordinate local responses, and care for sick patients effectively in the potential absence of hospital intervention. This knowledge-sharing work can only be done in consultative processes and collaborative decision-making rather than one-way information drives.

**Look beyond individual behavioural change.** Monitoring individual personal protective action does not capture community-coordinated epidemic responses. While many of the most vulnerable people across South Sudan cannot take individual protective actions—for example, avoiding crowded spaces or washing hands regularly—their safety and care is a key part of community-led organization during disease outbreaks. As the COVID-19 outbreak evolves in South Sudan, priority should be given to evaluating communities' preparedness for acting responsively and in collaboration with the formal healthcare system.

**Rethink the healthcare system.** In South Sudan, there is an opportunity for a wider reconsideration of what a sustainable, community-focused health service could look like. Organizing prevention and emergency care for COVID-19 patients must be part of a wider conversation about how a collaborative and South Sudan-specific healthcare system might work.

#### **Notes**

1 Team members are: Peter Majiek, Stephen Othur, Deng Barjok, Emmanuel Luga, Elizabeth Nyibol, Alex Miskin, Chirrilo Madut and Joseph Diing Majok.

2 Interviewees were chosen both in a targeted manner and via randomized sampling, where possible. Full details on the project's methodology will be included in the final summary report. Research locations were chosen based on the higher vulnerability assessment and the representation of ethnic groups and diverse geographies and livelihoods systems. Specific locations visited: Aweil West (Nyamlel and local market days); Marial Baai cattle camps and hospital; Gok Machar town; Nyiboli rural village and cattle camps; Malakal (town, Kodok area—rural and town); Renk town and rural areas; Wau (Marial Baai and Agok areas); Tharqueng and the Jur riverbanks; Wau town; and Rocroc Dong in Jur River county; Unity (Pakur payam in Rubkona); Rubkona town; Wichruop in Kedat payam, Guit county and Kech village; Yei (town residential areas); Lasu payam; Maridi town; and villages near Yei; Juba (Gondokoro island, New Site, Hai Referendum, Check Point, Konyokonyo and Hai Jalaba).

**3** For example, see Lasu Lauya Joja and Uzo Amaka Okoli, 'Trapping the Vector: Community Action to Curb Sleeping Sickness in Southern Sudan', *American Hournal of Public Health* (2001); M. Lamunu et al., 'Containing a haemorrhagic fever epidemic: the Ebola experience in Uganda (October 2000–January 2001)', *International Journal of Infectious Diseases* (2004); T Allen, 'Witchcraft, Sexuality and HIV/AIDS among the Azande of Sudan,' *Journal of Eastern African Studies* (2007); C. C. Jost et al., 'Participatory epidemiology in disease surveillance and research', *Rev. Sci. Tech. Off. Int. Epiz.* (2007); Abdel Ghani Bakri, 'Fighting the first Ebola virus epidemic in the World in 1976: Memoirs of a young doctor', *Sudan J. Paediatr.* (2014). For more discussion of this history of local epidemic organization, see the full report, forthcoming.

**4** The literature on sleeping sickness in particular demonstrates a reliance on people's syndromic knowledge to raise the alarm when the disease returned. Doctors emphasize that this has historically saved lives.

**5** Sometimes this incudes witchdoctors, but the consultation of witchdoctors has become less frequent in many places. For example, in Bentiu an example was given of people asking for evidence that the witchdoctor's services are effective. Communities instead are turning to herbal and Western medicine. This being said, many people with divinities or spiritual connections are also healer experts with herbal knowledge.

**6** In Aweil, old women manage the disease treatment, but decisions about what to do are taken by chiefs and imposed by gol leaders and headmen on their households. When disease breaks out in Darfur—for example, the meningitis outbreak in in 1998—chiefs monitor border areas and ask people arriving to isolate. In Yei, elders with specific knowledge of herbal medicine, transferred through apprenticing and experience, have been displaced to towns and camps, where they continue to be recognized as experts in infectious diseases, and are responsible for identifying new diseases and making attempts to treat it. Prophets and spearmasters in Luo cultures around Wau are important for declaring and protecting against epidemics; around Wau there are also many medical / health worker trainees but with no equipment or formal employment.

7 In Aweil breastfeeding women were and often still are discouraged from movement, sitting in other people's houses and engaging in greetings, particularly in times of epidemics. Traditional leaders are advocating for this today in response to COVID outbreak.

#### Credits

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