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The Rift Valley Institute works in Eastern and Central Africa to bring local knowledge to bear on social, political and economic development.

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Summary

Across South Sudan, long before the global COVID-19 pandemic emerged, communities have created systems and structures to control the spread of epidemics and infectious diseases. South Sudanese people have extensive knowledge of infectious diseases and experience of organizing responses to epidemics during wars and other crises. 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.

This research report details community infectious disease management strategies developed within the realities of South Sudan's local healthcare systems. Because the South Sudan clinical healthcare sector is overstretched and only semi-functional, the majority of South Sudanese people mostly rely on non-clinical medical advice and support from a wide field of healthcare workers and caregivers, including small private clinics and unlicenced pharmaceutical sellers, traditional herbal and surgical experts, midwives and spiritual healers.

South Sudanese community-led 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. There are multiple, locally-specific methods used by 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. Across research sites, people are already working on developing local safety measures and strategies to prevent the further spread of COVID-19 in South Sudan.

This research documents these community infectious disease management strategies, based on sustained investigative research in the Yei, Juba, Wau, Malakal, Aweil West and Rubkona areas, both in-person and remotely via telephone, from August to November 2020.[1] The health and wellbeing of the team and our interviewees was the priority

1 It builds on a rapid response research study conducted by RVI in April 2020, 'Responding to COVID-19 in South Sudan: making local knowledge count', https://riftvalley.net/publication/responding-covid-19-south-sudan-making-local-knowledge-count.

throughout the project. 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.

Recommendations for action include:

1. Collaborate with wider non-clinical health workers and caregivers, who are often first responders, including women, midwives, herbal experts and local pharmaceutical sellers. Include these workers in public health planning and clinical training.

2. Support communities with the broad epidemiological and logistical skills to prepare for COVID-19 and other epidemic outbreaks. Build sustained and detailed public health information systems to help local non-clinical and clinical workers plan locally appropriate infectious disease management strategies. More detailed and sustained information drives, in partnership with local first responders, will also build trust and counter misinformation and fatigue.

3. Localise epidemic response planning. Central planning is heavy handed and ineffective, overlooking critical local knowledge and community leadership that will make responses effective. Public health strategies should aim to build on measures people already take to try to protect themselves and their communities from multiple infectious diseases.

1. Introduction

The first case of COVID-19 was confirmed in South Sudan on 5 April 2020. As of 31 January 2021, there have been 3,961 confirmed cases of the virus and 64 deaths.[2] In April 2020, the Africa Centre for Strategic Studies assessed South Sudan as being one of the riskiest countries on earth for COVID-19 to spread. This was largely due to the fact that about half of the population are currently facing malnutrition, its clinical healthcare system is overstretched and fragmented, and conflicts continue to affect parts of the country, disrupting any coordinated public health responses.[3]

In response to the pandemic outbreak in April 2020, the South Sudan government introduced a curfew, closed its international borders, schools and religious institutions, and restricted trading in a securitized lockdown.[4] National and international agencies built a rapid messaging campaign on individual preventative measures and key symptoms of COVID-19.

This lockdown exacerbated the pre-existing economic crisis and a slower than predicted rate of infection encouraged confusion and misinformation. There is now significant uncertainty about the trajectory of the pandemic in South Sudan. With limited testing, it is likely that the number of COVID-19 cases is much higher than officially recorded.[5]

The evolution of the COVID-19 pandemic in South Sudan has raised three interconnected questions:

1. Are individual prevention methods and models of lockdown either appropriate or feasible, given the fragile state of clinical healthcare, the reliance of most people on insecure daily incomes and other labour-intensive livelihoods, and continuing local conflicts?
2. How can misinformation, rumours and messaging fatigue among a population struggling with many other immediate priorities and life-threatening risks be effectively overcome?
3. What local strategies for stopping the spread of highly infectious diseases could be adapted, or are being adapted, by residents to respond to the threat of COVID-19?

2 'Coronavirus Disease (COVID-19) tracker: South Sudan', World Health Organization. Accessed 21 December 2020, https://covid19.who.int/region/afro/country/ss.

3 'Mapping risk factors for the spread of COVID-19 in Africa', Africa Center for Strategic Studies. Accessed 3 April 2020, https://africacenter.org/spotlight/mapping-risk-factors-spread-covid-19-africa/.

4 John Peter Malish, 'COVID-19 and Fragile Peace Process in South Sudan', Juba: Institute of Social Policy and Research, 30 November 2020.

5 United Nations in South Sudan, 'COVID-19 Socio-Economic Response Plan', United Nations, October 2020. https://southsudan.un.org/en/96007-covid-19-social-economic-response-plan

Drawing on South Sudanese medical advice and a weekly rolling review by a group of healthcare practitioners involved in the pandemic response,[6] this research aims to highlight existing community strategies and systems for infectious disease management that could be integrated into effective and trusted epidemic responses now and in the future.

Methodology

The research focuses on the broad geographical areas of Yei, Juba, Wau, Malakal, Aweil West and Rubkona. These locations were identified by the South Sudan Ministry of Health COVID-19 Coordinated Response as areas of higher vulnerability to epidemic outbreaks. They were also chosen because of their diverse geographies and livelihoods systems.

The research protocol was developed collaboratively by the research team, with a particular focus on mitigating and managing the risks to conducting research safely during a pandemic. The protocol underwent external ethical review by two independent senior South Sudanese academics and was finally reviewed and approved by the South Sudan Ministry of Health Ethics Review Board.

In each area, the South Sudanese research team sought to meet as wide a range of respondents as possible, across urban centres, rural villages and settlements, and cattle camps. Respondents include young women working in homes and markets, migrant workers, older women with herbal medical expertise, traditional birth attendants, male and female military personnel, village pharmacists, cattle camp leaders, local community clinical workers, teachers, farmworkers, pastors, disabled people, clan elders and traditional authorities. Most interviewees have personal knowledge and experience of multiple infectious diseases in their own households and communities, dating back to the 1940s.

This project was conducted between August and November 2020. The research was undertaken by an 8-member South Sudanese research team via socially distanced in-person interviews and telephone interviews. The research team comprised researchers trained by the Rift Valley Institute since 2017 with experience across a range of research projects. Additional specific training tailored to this project was provided remotely by the lead researcher, particularly around telephone interviewing. Researchers had regular, weekly input from the lead researcher during the project and additional support was provided where required.

Sampling used both randomized and targeted frameworks. The randomized sampling was developed around the project's core quota sample, weighted for site-specific demographic data. For the targeted key informant interviews, community members with specific knowledge and information in relation to the topic guides were identified across key groups. These included chiefs and elders, pastoralist and cattle camp leaders, medical personal—taking a wide view of medical expertise—traders, truckers, couriers, transport workers, and

6 This group includes two male and eight female representatives from the Foreign, Commonwealth & Development Office (FCDO), Centre for Disease Control and Prevention (CDC), South Sudan Red Cross, UNICEF, REACH and Efficiencies for Clinical HIV Outcomes/United States Agency for International Development (ECHO/USAID).

other prominent decision-makers across communities such as teachers, women's associations and people with disabilities. In total, 114 interviews were conducted with 49 women and 65 men.[7]

Interviews were semi-structured, based on a topic guide updated with new questions and issues on a rolling basis. Data was collected and reviewed by the lead researcher and team leader on a weekly basis. Where there was a need for additional information or follow up questions these were also included in a revised topic guide for use in the subsequent week ensuring the integrity of the data was maintained to a high standard. Interviewees were widely supportive of the aims of the project. A former soldier now disabled and resident in Juba, notes: 'The decision to talk to communities to get their views on how they manage epidemics can allow people to work with confidence when epidemics break out. This is important because people will know how to manage diseases when there are no hospitals.'[8] An information and consent sheet, translated into relevant languages, was shared with all research participants and their agreement with this was recorded.

The health and safety of the research team and the interviewees was and continues to be of primary importance to this project. The RVI risk mitigation strategy and protection for researchers included extensive hygiene kits, social distancing protocols, private transport, comprehensive health insurance and constant review of the most up-to-date advice on COVID-19 prevention methods. The researchers were given full decision-making authority over their interview processes. They conducted telephone interviews whenever the highest standards of safety might or could not be met.[9]

Interview records were cross-referenced with more than 500 archival documents, academic papers and technical reports from the 1930s onwards focused on past epidemic responses.[10] This collective data was cross-referenced with new research on responses to the COVID- 19 pandemic in South Sudan.[11] Analysis was conducted collaboratively with research team members and using Nvivo, a programme for qualitative data analysis. The research findings and analysis, and the structure of and recommendations in this report have been iteratively reviewed by the research team and the healthcare practitioner panel.

7 The number of interviews carried out in each research location is as follows: Aweil (28), Bentiu (22), Juba (17), Malakal (20), Wau (6), Yei (21).

8 Interview with former SPLA soldier, Juba, 1 October 2020.

9 All interviews in Yei were conducted by telephone. All interviews in Unity and Malakal were conducted in- person. Interviews in Aweil West and Juba were a mix of in-person and telephone interviews.

10 The archival documents were drawn from the Sudan Open Archive (sudanarchive.net) and the South Sudan National Archive, Juba.

11 Paska Nyaboth Alfred, Amula Richard Rufino and Rajab Mohandis, 'Public Perception Survey Report on COVID-19', Juba: Organisation for Responsive Governance, 29 June 2020; Protection Cluster South Sudan and UN Office of the High Commissioner for Human Rights (OHCHR), 'Protection and Human Rights Considerations: Preparedness and Response to COVID-19 for South Sudan', Geneva: UN OHCHR, 23 March 2020; REACH, 'Population Movement and Health-Seeking in Response to COVID-19', Geneva: IMPACT Initiatives, April 2020.

2. The healthcare system in South Sudan

South Sudan has two different healthcare systems: A clinical medical system (under significant financial and practical strain); and a wider non-clinical healthcare sector working with locally devised treatments and herbal drugs. These two systems overlap and interact, and South Sudanese people rely heavily on both. International attention and support for healthcare in the country has generally focused on the clinical medical system. While this may be understandable, it is vital to take a wider view of both systems to understand how healthcare in South Sudan actually functions.

The clinical medical system

The South Sudanese clinical healthcare system is fragmented and struggling. There is roughly one doctor for every 65,000 people and one midwife for every 39,000 women.[12] NGOs and faith-based groups provide more than 70 per cent of services, with international donors financing the majority of clinical medical services. Clinical healthcare relies heavily on community health workers with basic training, and then (where available) on village-level primary healthcare units, area-level primary healthcare centres and, finally, a small number of hospitals. More than half of the nearly 12 million residents in South Sudan do not have access to primary clinical healthcare services and 75 per cent of people are more than a one-hour walk away from a clinic.[13] There is a severe shortage of trained healthcare workers, especially in rural areas, and in crucial mid-level sectors such as nursing, clinical offices and midwifery. As of early 2019, 416 of 1,893 health facilities were classed as non-functional.[14] A further 955 facilities were unable to function fully because of a lack of trained staff, supplies, delays in salaries, and the impacts of conflict and natural disasters.[15]

The national economic crisis, ongoing since 2015, has had a deep effect on the clinical healthcare sector. A lack of personal protective equipment (PPE), drugs and salaries (when paid by the state) have driven some clinical workers to leave the sector or threaten strike action.[16] High inflation has made private hospital treatment and pharmaceutical products extremely expensive and consequently unaffordable to most South

12 'Health Workforce Density', Global Health Workforce Alliance (World Health Organization). Accessed 22 December 2020, https://www.who.int/workforcealliance/countries/ssd/en/.

13 Colin Gilmartin, David Collins and Alfred Driwale, 'South Sudan Boma Health Initiative Costing and Investment Case Analysis', Arlington, VA: Management Sciences for Health, 2019, 25. As one interviewee notes, 'There are no people with qualified [clinical] medical skills in most remote rural areas in South Sudan'; interview with primary healthcare centre (PHCC) staff member, Wau, 31 August 2020.

14 Gilmartin, Collins and Driwale, 'Boma Health Initiative', 24.

15 Gilmartin, Collins and Driwale, 'Boma Health Initiative', 24.

16 Interview with retired nurse, Kodok, 2 September 2020.

Sudanese people.[17] This deters many people, including town residents, from seeking clinical healthcare in the first instance. This has further heightened a common concern that private healthcare clinics and pharmacies overprescribe drugs for profit.[18]

The South Sudan clinical healthcare sector faces the pandemic with these structural problems. In response to the threat of COVID-19, public health laboratories have been established in Nimule, Bor, Malakal and Juba to test suspected cases. The Dr John Garang Infectious Diseases Unit in Juba has a capacity to treat approximately 80 COVID-19 patients.[19]

South Sudanese residents know that these few existing clinical medical sites—from pharmacies to urban hospitals—are limited in their bed capacity, diagnostic abilities, care and treatment. Many residents blame government mismanagement. When the COVID-19 pandemic started to spread globally in early 2020, a joke circulated around the country, as follows: 'In South Sudan, there are five vice presidents, a president, nearly 40 ministers and deputies, 450 MPs and four ventilators.'[20] In these circumstances, South Sudanese people cannot necessarily rely on or even access the clinical medical system.

The non-clinical healthcare system

Given that the South Sudan clinical healthcare sector is overstretched and semi-functional, the majority of South Sudanese people mostly rely on non-clinical medical advice and support from a wide field of healthcare workers and caregivers. In the interviews conducted for this study, people often describe their healthcare access holistically: A combination of private and state-funded small clinics,[21] private pharmacies

17 Interview with female nurse in Owachi Payam PHCC, Malakal, 7 October 2020; telephone interview with daughter of herbalist in Yei Kaya, Kendire, 16 September 2020; telephone interview with traditional midwife in Yei town, 16 September 2020; interview with midwife in Bassia, Wau, 14 October 2020.

18 Interview with community elder and *gol* [clan] leader in Pacic, north-east Gok Machar, 29 August 2020.

19 'South Sudan: Improving access to COVID-19 treatment in South Sudan', World Health Organisation, 16 May 2020. Accessed 12 January 2021, https://who.africa-newsroom.com/press/improving-access-to-covid19-treatment-in-south-sudan?lang=en.

20 Interview with researcher field notes from Yirol, 28 April 2020.

21 Interview with soldier in Hai Amarat, Juba, 31 August 2020; interview with private pharmacist at Marol rural market, Aweil, 12 October 2020; interview with PHCC staff member, Aweil, 10 October 2020; interview with PHCC staff member in Wau, 31 August 2020. All these interviewees note the inconsistency of qualified staff, staff salaries and medical supplies, even at PHCCs near urban centres.

(licensed and unlicensed),[22] traditional surgical[23] and herbal experts,[24] midwives (generally without formal clinical training)[25] and spiritual healers.[26] These frontline workers, including herbalists, local midwives and healers, are generally disconnected from local clinics and hospitals, but they are critical frontline workers, especially in epidemics. First responders for advice and basic treatment are generally family members (with common herbal remedies including painkillers),[27] local knowledgeable women, herbal specialists and generally non-certified local midwives.[28]

The local geography of healthcare provision significantly determines the pathways people take to obtain advice and treatment.[29] Pathways to treatment also depend on a range of other factors, including the specific illness, family finances, the medical beliefs of those seeking care and local knowledge about which people, sites and techniques have the best chance of immediate treatment for the lowest cost and risk possible.[30] There is, therefore, no single pathway, which is often the case even for people living in the same village.[31] Similarly, these pathways are not one-directional, moving towards hospital-based clinical care: Families can return to spiritual or herbal medical workers if they do not believe that clinical medicine will be or has been effective, or if they cannot access clinical care for financial or practical reasons.[32]

22 Interview with housewife in Bentiu POC (protection of civilian site), 16 September 2020; interview with teacher in Mangok Lou rural community, Aweil, 7 October 2020; interview with housewife in Wicruop, Kedat, 7 October 2020.

23 Healthcare providers in the community are often also not full-time or titled workers (people with skills, *leert* in Nuer). Dating back into the 1900s, people obtained specialisms including obstetrics, bone setting (*atet* among the Agar Dinka) and specific skills for healing particular conditions; interview with security guard in Bentiu POC, 23 September 2020; interview with housewife in Kedat, 13 October 2020. Also see: Kaya Sarah Belknap, 'The Parameters of Post-Conflict Health Care: A Case Study in South Sudan: 1972 To 1983', Tucson, AZ: University of Arizona, May 2009.

24 Interview with chief in Wau, 7 September 2020.

25 During research, the team interviewed a total of 11 traditional and clinically trained midwives, including two men. Interview with business person in Kator, Juba, 3 September 2020.

26 Interview with housewife in Wicruop, Kedat, 7 October 2020

27 Interview with social worker in Mia Saba, Juba, 1 September 2020.

28 Interview with sports coach in Juba, 31 August 2020.

29 Interview with teacher in Rubkona, 30 September 2020.

30 Interview with social worker from Lakes State working in Tongypiny, Juba, 24 August 2020.

31 Interview with community health worker in Nasir county, 23 September 2020.

32 Interview with government worker in Juba, 1 October 2020. Herbal medicines are vital knowledge in extreme circumstances of conflict and remote health crises, especially if clinical medicine is too far away to access. Medicinal plants are not, however, in consistent supply because many are seasonal and not available in sufficient quantities for everyone. Neem trees (fast-growing trees from the mahogany family commonly used for medicinal purposes across India and Africa) are often used as a last resort, for malaria and other diseases, when other medicines are unavailable.

A mixed healthcare system

At present, most communities 'use both local and scientific medicine'.[33] Residents across the research sites make distinctions between chemical and herbal medicines but emphasize the problems involved with the knowledge and application of both. Many people remember the emergence of hospitals and their family move from herbal to drug-based treatments. As this interviewee explains, however: 'Hospitals are not [always] capable of giving appropriate treatment and many [more] people seem to die today than in the past. Every test result would come back "malaria and typhoid" when it could be other killer diseases like hepatitis and even AIDS.'[34]

Across South Sudan, communities continue to debate the relative efficacy of clinical chemical (or artificial) medicines versus traditional herbal (natural) medicines.[35] Belief in the efficacy of clinical drug-based medicine has grown significantly across the country, especially with the rise of immunization campaigns since the 1980s in particular,[36] and with localized healthcare campaigns during the 2000s and 2010s.[37] For example, kala azar[38] and cholera outbreaks in Unity State and Malakal from the 1980s onwards encouraged local faith in clinical medicine: 'When it happened in 1986 and 1998, the herbal medicines were challenged but the intervention of NGOs and government in both outbreaks made it easy to manage the infection.'[39] Residents in the six research sites who live or had lived in urban areas or in camps for internally displaced persons were more likely to seek clinical advice first or earlier, especially if they have the cash for pharmaceutical products.[40]

Seeking healing through local divinities or spiritual healers has lessened in many communities.[41] Nonetheless, many people with divinities or spiritual connections are also herbal

33 Interview with government worker in Juba, 1 October 2020.

34 Interview with disabled primary school teacher and court clerk, Nyamlel, 26 August 2020.

35 Interview with chief in Baliat County, Malakal, 2 September 2020; interview with teacher in Rubkona, 9 September 2020.

36 Interview with cattle camp leader at Kech, Guit, 9 September 2020.

37 Interview with female nurse in Owachi Payam PHCC, Malakal, 7 October 2020; interview with clinical officer in Malakal town, 30 September 2020.

38 Kala azar is a chronic and potentially fatal parasitic disease of the viscera (the internal organs, particularly the liver, spleen, bone marrow and lymph nodes) due to infection by the parasite Leishmania donovani.

39 Interview with housewife in Khalebalek village, Bentiu, 23 September 2020.

40 Interview with female nurse at Bentiu hospital, 14 October 2020. In areas with extensive experience of displacement into towns or camps such as in Malakal and Yei, this differing experience has created multiple pathways in the same community. For example, in Aboruc village at a considerable distance from Kodok town, most local residents still use traditional medicine but displaced communities coming from Malakal, Kodok and other regional peri-urban areas prioritize clinical medical car; interview with female pharmacy worker in Aboruc Settlement, Wau Shilluk, 14 October 2020.

41 Interview with chief in Nyamlel, Aweil West, 23 August 2020; interview with teacher in Rubkona town, 9 September 2020; interview with pharmacist in Rubkona, 9 September 2020; interview with driver in Bentiu POC, 16 September 2020; interview with village woman sub-chief and tea maker in Marial, Aweil, 17 September 2020.

experts, who continue to be consulted. Christian churches are still consulted for mental and some physical health problems.[42] There is also continued distrust of some new medications and belief in better herbal options, for example the use of the herbal medicine *sugur* in place of yellow fever vaccinations in the Aweil area.[43]

The expense of clinical medical care is significant.[44] Residents in all six research sites report an increase in their reliance on herbal medicine, especially since the 2015 period of hyperinflation and the civil war increasing imported drug prices.[45] From 2016 to 2020, an anti-malaria tablet has increased in price in Aweil town well above inflation: From SSP 20 to SSP 1,200 (equivalent to an increase from about USD 0.25 to USD 4) and from SSP 60 to SSP 1,500 (equivalent to an increase from about USD 0.75 to USD 5) in a rural clinic in Aweil West.[46] An anti-diarrhoea tablet increased from SSP 6 to SSP 300 in Aweil town (equivalent to an increase from about USD 0.07 to USD 1) and from SSP 10 to SSP 500 (equivalent to an increase from about USD 0.12 to USD 1.75) in Aweil West. Travel to remote clinics is financially prohibitive for most rural residents.[47] In contrast to private clinics and pharmacies, herbal medicine generally is provided without payment up front.[48]

The South Sudanese healthcare sector combines clinical and non-clinical pathways, and the routes that people take depend on access, funds, trust and the availability of treatment. International and national actors focused mostly only on clinical medical provision must take this wider view into account. This holistic overview constitutes the real healthcare system across South Sudan and underpins how people in various villages, towns, camps and rural areas will make decisions and take action as the COVID-19 pandemic develops.

42 Interview with PHCC staff member in Aweil, 10 October 2020.

43 *Sugur* is a herb used to treat yellow fever. Its root is dried and ground or pounded to make a powder, which is diluted in water and drunk. Interview with village woman sub-chief and tea maker in Marial, Aweil, 17 September 2020.

44 Interview with PHCC staff member in Wau, 31 August 2020; interview with chief in Wau, 7 September 2020.

45 Interview with PHCC staff member in Aweil, 10 October 2020; interview with private pharmacist at Marol rural market, Aweil, 12 October 2020; many other interviews.

46 In September 2016, the average exchange rate was SSP 80 to USD 1. In 2020, the exchange rate is about SSP 300 to USD 1; personal observations by the authors. Drug prices provided in December 2020 by a pharmacy supplier in Marol in Aweil west, and a pharmacy vendor in Maper, Aweil town.

47 Interview with housewife in Kech village, Guit, 9 September 2020.

48 Interview with administrative worker in Malakal town, 14 September 2020; telephone interview with daughter of herbalist in Yei Kaya, Kendire, 16 September 2020; interview with herbal expert in Marial village, Aweil, 14 September 2020.

3. Community medical knowledge and disease control

Across South Sudan, communities have extensive knowledge of local seasonal, endemic and epidemic diseases, their transmission, pathologies and symptomatic processes—both in animals and humans.[49] Communities also have tested methods of infectious disease management, isolation and hygiene practices, the interruption of surface viral transmission, triage and surveillance, adaptable during emergencies.[50] People have been involved in organized contact tracing and infection management in past outbreaks since the 1930s, and during interviews, respondents highlight what disease control methods previously have worked in their local contexts.[51]

This wide knowledge base has developed partly because the South Sudan clinical health-care system is so fragmented and contingent on external financial and logistical support. Many of these longstanding prevention and transmission interruption practices are being applied at present by local residents to try to control COVID-19. Across the six research sites in this study, community strategies for infectious disease management focus on symptomatic identification and diagnoses, patient isolation, the interruption of onward transmission and attempts at treatment, whether via clinical or herbal medicine, in that order.[52]

49 These include sleeping sickness (trypanosomiasis), meningitis (known as *Abu Farar* in many sites), trachoma, hepatitis A (jaundice), measles, malaria, cholera, river blindness (onchocerciasis), HIV, kala azar (leishmaniasis), typhoid and various forms of haemorrhagic fevers; e.g. Ebola.

50 Also see: Sharon Abramowitz et al., 'Community-Centered Responses to Ebola in Urban Liberia: The View from Below', *PLOS Neglected Tropical Diseases* 9/4 (2015).

51 P Brès, 'The Epidemic of Ebola Haemorrhagic Fever in Sudan and Zaire, 1976: Introductory Note', *Bulletin of the World Health Organization* 56/2 (1978), 1; Lasu Lauya Joja and Uzo Amaka Okoli, 'Trapping the Vector: Community Action to Curb Sleeping Sickness in Southern Sudan', *American Journal of Public Health* 91/10 (2001); T W Schillhorn van Veen, 'Sense or Nonsense? Traditional Methods of Animal Parasitic Disease Control', *Veterinary Parasitology*, Plenary Papers of the 16th International Conference of the World Association for the Advancement of Veterinary Parasitology 71/2 (31 July 1997); Georgina Pagey, 'Management of a Sleeping Sickness Epidemic in Southern Sudan', *Journal of Rural and Remote Environmental Health* 2/2 (2003); Clayton O Onyango et al., 'Yellow Fever Outbreak, Southern Sudan, 2003', *Emerging Infectious Diseases* 10/ 9 (2004); Jan H Kolaczinski et al., 'Kala-Azar Epidemiology and Control, Southern Sudan', *Emerging Infectious Diseases* 14/4 (2008); J K Tumwine et al., 'Clinical and Epidemiologic Characteristics of Nodding Syndrome in Mundri County, Southern Sudan', *African Health Sciences* 12/3 (2012); Adbel Ghani Bakri, 'Fighting the First Ebola Virus Epidemic in the World in 1976: Memoirs of a Young Doctor', *Sudanese Journal of Paediatrics* 14/2 (2014); and Vanja Kovacic et al., 'We Remember… Elders' Memories and Perceptions of Sleeping Sickness Control Interventions in West Nile, Uganda', *PLOS Neglected Tropical Diseases* 10/6 (2016).

52 Interview with teacher in Rubkona, 30 September 2020.

Symptomatic identification and diagnoses

Community medical knowledge relies on symptomatic diagnostics because there is limited clinical testing across the country; many local clinics are believed to blanket diagnose diseases such as typhoid and malaria without clinical confirmation.[53] Herbal experts and local medical staff apply their knowledge of how diseases transmit, prevent and develop to identify infectious illnesses: A herbalist in a rural area outside Aweil, emphasizes how she 'consults the patient to narrate the history of sickness'.[54] Infectious diseases and their symptoms are therefore named precisely to support this careful diagnostic process.[55] Community members note that symptoms and diseases that are not clearly named in local languages are generally those that the community does not know about in enough detail to act upon.[56]

Medical workers across the six research sites differentiate between diseases that are well-known but difficult to treat locally (yellow fever, cholera, sleeping sickness) and diseases that are new or hard to diagnose (HIV, hepatitis), and about which there is more limited symptomatic knowledge.[57] Across the research sites, traditional medical workers explain that when a new disease outbreak occurs, they 'first start by comparing the symptoms with a past disease and how that disease was treated. So they make trials for the medicines until they find the right one'.[58] While medical workers try to identify the disease, communities are generally advised to stay in their households and avoid sharing food and utensils between families.

The history of responses to sleeping sickness epidemics illustrates the importance of symptomatic knowledge among local residents. Sleeping sickness presents slowly, affecting both the body and the mind, requiring careful observation to identify the disease. In multiple epidemics since the 1940s, the alarm was raised by women identifying key overlapping symptoms: 'When identified together, the symptoms interlock as a complete disease.'[59] In multiple medical reports, doctors emphasize that this early identification saved lives.

53 Symptomatic diagnostics are used by clinical workers when tests and tools are unavailable or unreliable.

54 Interview with village woman sub-chief and tea maker in Marial, Aweil, 17 September 2020.

55 Past research into community epidemiological knowledge highlights this. See: David Adolph, Stephen Blakeway and B J Linquist, 'Ethno-Veterinary Knowledge of the Dinka and Nuer in Southern Sudan. A Study for the UNICEF Operation Lifeline Sudan / Southern Sector Livestock Programme', Nairobi: UNICEF OLS/SS, December 1996, 56.

56 Interview with researcher from Mayom now living in Juba Jebel POC, 21 August 2020.

57 Interview with clinical officer at Kuergeng PHCC, 14 October 2020.

58 Telephone interview with secondary school teacher and son of herbalist, Yei Gimunu, 9 September 2020; interview with nutrition officer at Nyieng PHCC, Guit, 14 October 2020.

59 Jennifer J Palmer, 'Sensing Sleeping Sickness: Local Symptom-Making in South Sudan', *Medical Anthropology* 39/6 (2020): 1.

Quarantine and self-isolation

Where infectious disease cases are identified or suspected, a key strategy across communities is quarantine.[60] People with tuberculosis, yellow fever, measles and cholera are commonly isolated within family compounds or in houses outside the immediate family home.[61] In Aweil, these quarantine sites used to colloquially be known as 'the coughing house'.[62] When people can still care for themselves during isolation, water, food and medicine are left at the door for collection; if they need care, a family member (generally a woman, who is often elderly) provides care, often at significant personal risk.[63]

Quarantine systems have different histories across the country. In Aweil, household quarantine methods developed to respond to *malek* (smallpox) in the 1950s, known as '*jhong akoi*' (the disease of destruction) because of its high death rate. In Aweil, poles are placed across the path to a household to signal a family quarantine. In other areas, communities use ashes to make a ring around a quarantined household. Quarantine systems are widely known and trusted. In Upper Nile, for example, 'When yellow fever and cholera broke out in 1998, we managed to get control in the shortest time possible because of experience gained from the previous kala azar outbreak management.'[64]

Social distancing and stopping surface transmission

Across the research sites, people discuss tactics for stopping surface transmission of viruses and bacteria, and fighting airborne transmission through social distancing. As a nutrition officer at Nyieng primary health care centre (PHCC) in Guit, emphasizes, 'People are trying their best by preventing themselves from catching infectious diseases like COVID-19 and others. This prevention is better than seeking treatment, which can cost a lot.'[65]

Prevention tactics such as social distancing are understood and much more practical than lockdown methods that interrupt livelihoods and access to daily resources (charcoal and food). Market workers try to re-space stalls, organize safe queuing systems at bus stations and maintain careful hygiene. A woman who works in a rural market in Aweil, explains, 'We make sure that we try hard to protect ourselves. We create distance with one another and constantly wash our hands to minimize chances of contracting COVID.'[66] In previous infectious disease outbreaks in rural and peri-urban areas across

60 Adolph, Blakeway and Linquist, 'Ethno-Veterinary Knowledge'.

61 Interview with cattle camp leader in Kech village, Guit, 9 September 2020.

62 Interview with elder in Marial Adoot village, northern Aweil, 8 September 2020.

63 Interview with tea shop worker and traditional birth attendant with herbalist expertise, Juba, 16 September 2020; interview with research, notes from Wau, 26 August 2020; interview with NGO-funded clinical officer at Boma health station in Warapei, 14 October 2020.

64 Interview with security guard in Bentiu POC, 23 September 2020.

65 Interview with nutrition officer at Nyieng PHCC, Guit, 14 October 2020.

66 Interview with village woman sub-chief and tea maker in Marial, Aweil, 17 September 2020.

the research sites, water points were allocated for groups of families or specific neighbourhoods to try to contain infections within set areas and to stop large gatherings at single sites.

Communities have extensive methods for minimizing surface transmission of viruses and bacteria. During cholera and measles outbreaks in particular, households change meal practices to avoid sharing plates and cups outside immediate family members.[67] Families have experience in carefully managing beds and linens, separating clothes for washing and changing seating layouts in compounds to provide for social distanced visits.[68] Metal plates and cups can be sterilized by being left in the sun, or plates, spoons and cups can be washed with ash.[69] In Aweil, post-partum women and their babies are assigned specific cups and utensils, and discouraged from social gatherings for a month after birth to avoid infectious diseases, especially during disease outbreaks. Other women help by delivering water to the home so post-partum women can avoid crowded water points.[70] Many of these methods are possible even during conflict. For example, in 1997 during the cholera outbreak at Kiir in Northern Bahr el-Ghazal, people organized rehydration salts, isolated infected people, buried their vomit and faeces, and used water and ash to wash people in contact with the sick.

Case identification and contact tracing

Many South Sudanese communities have experience with case identification and contact tracing, including in sleeping sickness outbreaks in Western and Central Equatoria since the 1930s, and in the meningitis outbreak in the Nuba Mountains in 1936.[71] In the 1976 Ebola outbreak in Western and Central Equatoria, a locally run district public health committee was convened that built a contact tracing and quarantine system.[72] Many people involved in the Ebola response training in the same area from 2013 to 2016, and more recently in Juba, remember this history. In past outbreaks since the 1970s, people involved in contact tracing, infection management, transport of sick people, health education and surveillance include cleaners, pharmacists and pharmacy staff, teachers and students (for example, in the 1976 Ebola outbreak), and traditional birth attendants (for example, in the 1997 sleeping sickness outbreak in Tambura).

67 Telephone interview with secondary school teacher and son of herbalist, Yei Gimunu, 9 September 2020; interview with local government worker, Bentiu town, 2 September 2020.

68 Interview with wholesale retailer from Yei working in Juba, 4 September 2020.

69 Interview with teacher in Biemruok, Bentiu, 1 September 2020. Ash is a strong alkali with a Ph ranging from 10 to 12. Because most (but not all) bacteria cannot survive in such a Ph range, ash functions as a disinfectant when used.

70 Interview with traditional birth attendant in Majak village, Aweil, 25 August 2020.

71 Major G K Maurice, 'The History of Sleeping Sickness in the Sudan', *Sudan Notes & Records Volume XIII 1930 Part 1*, Nendeln, Liechtenstein: Kraus-Thompson Organization Ltd, 1975 (Kraus reprint).

72 Abdel Ghani Bakri, 'Fighting the First Ebola Virus Epidemic in the World in 1976'.

Residents are highly aware of the risk of people acting as disease vectors. In the current pandemic, people across South Sudan are legitimately concerned about people arriving from towns, or working in offices with international staff, because of their risk perception as COVID-19 disease vectors. This echoes a wider history of tracing the movement of people as potential disease vectors between communities, including wandering children, traders and migrant workers. Chiefs and local authorities have responded both punitively and collaboratively in past pandemics. On the Aweil border with southern Darfur, and on the Yei borders with the Democratic Republic of Congo and Uganda, chiefs and local medical staff also have previously coordinated pandemic responses with counterparts across state lines, and tried to contain outbreaks to specific areas.[73]

Attempts to treat infectious diseases

South Sudanese informal medical knowledge is diverse and extensive, from bone setting, obstetrics, surgery and wound care, to medicinal plant treatments for various symptoms and conditions. South Sudanese community members are already working on careful classification of infectious disease symptoms and transmission routes, conferring on best practice and building local disease etymologies.

Different communities have specific names for key medicinal plants. In Bentiu, for example, key herbal drugs include *beb*, *modol*, *rier*, *niim*, *titil*, *pääh* and *yäw*.[74] Across communities, cattle urine is used as a powerful disinfectant. In Yei and Juba, many people grow *tereka* and *Kapakaya* (*Dekeritimelu*) in their household compounds.[75] These are used to treat general infections, especially in areas that are significant distances from clinics in Juba.[76] These herbal medicines are well-understood because they are much older and more common than drug-based medicines. They are also trusted because they often appear to work. The development of herbal treatment options is based on careful testing and observation, including seeing what works for dogs and chickens for

73 Interview with teacher in Mangok Lou rural community, Aweil, 7 October 2020; telephone Interview with engineer and teacher in Yei town, 16 September 2020.

74 Interview with local government worker, Bentiu town, 2 September 2020; interview with teacher in Biemruok, Bentiu, 1 September 2020; interview with housewife in Kech village, Guit, 9 September 2020.

75 Interview with wholesale retailer from Yei now working in Juba, 4 September 2020; telephone interview with chief in Yei, 30 August 2020

76 Interview with church worker and student in Kator, Juba, 15 September 2020; interview with wholesale retailer from Yei, working in Juba, 4 September 2020; interview with assistant pharmacist in Juba, 13 September 2020; telephone interview with chief in Yei, 30 August 2020; interview with disabled primary school teacher and court clerk, Nyamlel, 26 August 2020.

various illnesses.[77] This medical research is, however, 'trial and error', as interviewees often note.[78] Nonetheless, local herbal workers are seen to be 'trying their best'.[79]

All the local and traditional health workers who participated in this research emphasize that they know the limitations of their knowledge and practice. Local herbalists know what they can treat, including the symptoms of fevers and headaches. Many herbal workers note that they do not have cures for meningitis, *kala azar* or typhoid, among other diseases, but can treat symptoms. They emphasize that they seek to constantly improve and update their knowledge and treatment strategies, whether through clinical training or local knowledge sharing.

Many health workers also discuss past mistakes of disease identification. For example, people in Yei note that past Ebola outbreaks in the Central and Western Equatoria region initially had been treated as cholera because of symptomatic similarities, combined with a lack of understanding about inter-personal transmission. People across all research sites emphasize that leprosy was previously misunderstood as a genetic illness but is now generally understood as transmissible.[80] Health and herbal workers are keen to make similar advances in epidemiological knowledge.

Contextualizing health crises

As with national and international healthcare practitioners, local clinical and herbal medical workers across the six research sites see wider health crises such as malnutrition and food poverty as sicknesses that create vulnerabilities to other diseases.[81]

Community members and informal health workers across research sites also note that people with physical disabilities and severe mental illnesses are particularly vulnerable in epidemic outbreaks. Physically disabled people note that they often rely on urban and market environments for their welfare and daily care because of the comparative availability of food and care support in busy locations. The national lack of mental healthcare and facilities often drives families into desperate strategies during disease outbreaks in particular, including chaining up mentally unwell loved ones for their own protection.

Residents in South Sudan emphasize that the endemic but generally little-recognized mental health crisis in the country deeply affects the ability of people to take up preventative health strategies. As a cattle camp worker starkly puts it, 'There is no government. Everyone is for himself [or herself]. So why should I care about the virus? I feel death

77 Interview with mosque secretary in Riang Makuei village, 23 September 2020; interview with social worker in Juba, 24 August 2020; interview with chief in Wau area, 26 August 2020.

78 Interview with church worker and student in Kator, Juba, 15 September 2020.

79 Interview with housewife in Khalebalek, Bentiu, 23 September 2020; telephone interview with engineer and teacher in Yei town, 16 September 2020.

80 Interview with PHCC staff member in Wau, 31 August 2020.

81 Interview with housewife in the rural Akuak Ngap area of Aweil West, 10 September 2020; interview with herbal expert in Marial village, Aweil, 14 September 2020.

every day. Your coronavirus will not be the first to kill, or the last.'[82] Men and women, including this cattle keeper, note how mental illness and trauma, and the daily stress of poverty and risks of violence, all frequently induce fatalism, hopelessness and feelings of paralysis that are key barriers to self-care and healthcare.

COVID-19 medical knowledge

People across South Sudan are already having conversations about the potential best ways to manage a COVID-19 outbreak in their community.

Many people across the six research sites have experience of diseases (such as hepatitis, flu, measles and cholera)[83] that are spread via asymptomatic carriers and they recognize that this makes treatment and containment particularly difficult.[84] Market workers are alert to the risks but are unclear about the extent of the spread of the coronavirus in South Sudan. A tea stall worker and traditional birth attendant in Juba, explains: 'In the teashop where I currently work, if someone comes in and is not showing any signs of coronavirus but is weak, we immediately take precautions. But in most cases, it turns out to be malaria and typhoid.'[85] Women running households emphasize that they are adding COVID-19 to their wider disease prevention strategies at home: 'In the morning, I wash my children's hands and faces and place water outside with soap for whoever is coming to wash his [or her] hands. I am trying to protect my children not only from COVID but also from other diseases.'[86]

Formal and informal health workers across the research sites recognize the difficulties of dealing with COVID-19 in South Sudan. The symptoms are particularly difficult to differentiate from flu or other illnesses that come with fevers or coughs, such as malaria and the common cold.[87] Because COVID-19 is generally described as having flu-like symptoms, people across the research sites note that it is hard to take the virus seriously.[88] A traditional birth attendant in Aweil emphasizes that a constant cough is not generally considered a concerning symptom.[89] Another interviewee reinforces this: 'People are saying that we had diseases similar to COVID-19 symptoms and we

82 Interview with cattle camp worker, near Bor, 4 May 2020.

83 Interview with former SPLA soldier, Juba, 1 October 2020.

84 Interview with driver in Bentiu POC, 16 September 2020.

85 Interview with tea shop worker and traditional birth attendant with herbalist expertise, Juba, 16 September 2020.

86 Interview with village woman sub-chief and tea maker in Marial, Aweil, 17 September 2020; interview with elderly female herbalist in the Ariath area, Aweil, 9 September 2020.

87 Interview with student and youth leader in Wau, 20 September 2020.

88 Interview with PHCC staff member in Aweil, 10 October 2020; telephone interview with elderly resident in Yei, 3 September 2020.

89 Interview with traditional birth attendant with herbal expertise in the Aroyo area, Aweil, 1 October 2020.

have managed to deal with it.'[90] Some people argue that COVID-19 is a new version of an older disease (*tuor-tuor*, in Rumbek) that they have already had and therefore now have immunity.[91] Herbalists and elderly men and women are using hand washing and social distancing, based on their experience of past infectious diseases: 'That's how we managed whooping cough. For whooping cough, it is transmitted through the cough and shows similar symptoms to the Westerners' corona disease that they talk about now.'[92]

At the same time, people note that they do not fully understand COVID-19 transmission. If it were airborne, several Juba residents note, surely the whole of Juba would be infected by now.[93] People across the research sites emphasize that COVID-19 will only be taken seriously when communities face significant infection and death rates.[94] In the meantime, communities are discussing what treatment works for similar viruses and symptoms.[95] This includes common herbal remedies for reducing fevers[96] and for treating pulmonary and respiratory tract infections such as whooping cough.[97] Many people who were interviewed suggest that COVID-19 should be explained in similar terms as tuberculosis, which is taken very seriously across communities, with widespread knowledge about its airborne and contact transmission methods. In Yei and Malakal, tuberculosis outbreaks are taken so seriously that gatherings and collective meals are stopped.

Because of frequent epidemics and the fragility of the clinical healthcare sector, South Sudanese communities have developed their own methods of infectious disease management, isolation and hygiene practices, the interruption of surface viral transmission, triage and surveillance. These methods have been built through experience and through collaboration with healthcare teams in previous crises. In 2020, people across South Sudan are trying to work out what methods they can adapt to tackle the threat of COVID-19, based on their comparatively limited knowledge of its symptoms, transmission and progression.

90 Interview with NGO worker in Malakal, 16 September 2020.

91 Interview with female researcher, field notes from Rumbek, 7 May 2020.

92 Interview with elder in Marial Adoot village, northern Aweil, 8 September 2020.

93 Interview with tea shop worker and traditional birth attendant with herbalist expertise, Juba, 16 September 2020.

94 Interview with private pharmacist at Marol rural market in Aweil, 12 October 2020; interview with assistant pharmacist in primary healthcare centre in Aweil North, 14 October 2020; interview with female pharmacy worker, Melut, 7 October 2020; interview with female graduate and head of household in Dimtoma settlement, Melut, 13 October 2020.

95 Interview with chief in Marial South, Aweil, 16 September 2020.

96 Interview with former SPLA soldier, Juba, 1 October 2020; telephone interview with secondary school teacher and son of herbalist, Yei Gimunu, 9 September 2020; telephone interview with chief in Yei, 30 August 2020; interview with church worker and student in Kator, Juba, 15 September 2020; interview with teacher in Biemruok, Bentiu, 1 September 2020.

97 Telephone interview with chief in Yei, 12 October 2020.

4. Decision-making, collective action and trust

Across all six research sites, people emphasize that the first step in past community responses to outbreaks of dangerous diseases is a planning meeting. These meetings are generally convened by a variety of local (formal and informal) authorities.[98] Depending on the location of the outbreak, this planning meeting usually involves chiefs and committees of elders, spiritual authorities, the leading age-set committee, pastors (in some areas), local government officials, local healthcare workers, and men and women with traditional medical expertise or past epidemic experience.[99]

In particular, these meetings also include elderly women who have traditional medical or herbal expertise,[100] along with older and influential women who can support the implementation of meeting decisions about how to minimize the spread.[101] This wide pool of decision makers reflects the fact that the people who decide what happens when an infectious disease afflicts a locality are generally those who play a role in treatment pathways; for example, women running households, elderly medically experienced women, herbal experts, local chiefs and elders, cattle camp leaders, market trade union leaders, pharmacists, faith leaders and spiritualists.

These planning meetings decide on a response strategy, which includes discussion of lessons learned from previous outbreaks (for example, the 1999 cholera outbreak) and the design a plan of action.[102]

This often addresses plans for quarantine, the reorganization of market spaces, deep cleaning of crowded and rubbish dump areas, and the organization of information drives across the community. In multiple examples of past community responses to epidemics in the 1990s and 2000s, those interviewed for this study explain how individuals (both

98 These community-led planning meetings and interventions also have been vital in situations where local civil government has collapsed; for example, during in the cholera outbreak in Malakal in 2014.

99 Interview with bank manager in Juba, 28 August 2020; interview with social worker in Mia Saba, Juba, 1 September 2020; interview with teacher in Mangok Lou rural community, Aweil, 7 October 2020; interview with Medecins sans frontiers nurse in Bentiu POC, 16 September 2020; interview with PHCC staff member in Aweil, 10 October 2020; interview with private pharmacist at Marol rural market in Aweil, 12 October 2020; interview with church worker and student in Kator, Juba, 15 September 2020; interview with presidential guard soldier, Juba, 31 August 2020; interview with female graduate and head of household in Dimtoma settlement, Melut, 13 October 2020; interview with female nurse in Malakal Hospital, 2 September 2020; interview with unemployed graduate in Wau, 10 October 2020; interview with chief in Wau area, 26 August 2020; telephone interview with daughter of herbalist in Yei Kaya, Kendire, 16 September 2020; telephone interview with business person in Yei town, 30 September 2020; interview with teacher in Maridi, 29 September 2020.

100 Interview with assistant pharmacist in Aweil Civil Hospital, 7 October 2020.

101 Interview with assistant pharmacist in primary healthcare centre in Aweil North, 14 October 2020; interview with elder in Marial Adoot village, northern Aweil, 8 September 2020.

102 Interview with private pharmacy worker in Malakal POC, 30 September 2020.

men and women) were nominated to travel to water points, fishing areas, cattle camps and villages to share the decisions taken at the meeting and spread key information about the outbreak.[103]

Importantly, the strategies determined at this initial planning meeting are not fixed. The research for this study reveals many examples of outbreaks in which community strategies were revised to adjust to different infection rates and disease vectors: From water points being divided between smaller groups of users to more stringent forms of quarantine and social distancing.

Often community epidemic management planning does not order the suspension of social gatherings. Weddings and funerals are vitally important for community and family health and well-being.[104] This is particularly the case for funerals, at which the care and financial support of widows, children and vulnerable dependents are decided.[105] Instead, events are altered, including social distancing measures and smaller celebrations.[106] In the Aweil area, chicken pox or meningitis deaths are buried by a small number of men and mourning neighbours are not be allowed to mix with those who were in touch with the infected person; trees are allocated to families to sit under, to separate people from each other and minimise aerosol transmission between households.[107] In Rumbek and Juba, funerals can be kept small by killing only one goat to minimize attendance, on the promise that in future the small prayer service will be supplemented with a large memorial.[108] Small 'scientific weddings' (referred to as such because wedding ceremonies are changed to reflect scientific, clinical health advice) are organized during epidemics in Mayom, Malakal, Juba, Wau and elsewhere, with small numbers and limited ceremony in arranging the marriage and bride wealth settlements.[109] These are considered cheap but stand as a marker pending later celebrations.

103 Interview with mosque secretary in Riang Makuei village, 23 September 2020; interview with cattle camp leader at Kech, Guit, 9 September 2020; interview with village woman sub-chief and tea maker in Marial, Aweil, 17 September 2020; interview with soldier and business person, Juba, 13 September 2020; interview with trader in Bentiu, 23 September 2020; interview with social worker in Mia Saba, Juba, 1 September 2020; interview with chief in Wau area, 26 August 2020.

104 Interview with bank manager in Juba, 28 August 2020; interview with government worker in Juba, 1 October 2020.

105 Interview with elderly resident in Wau, 24 August 2020.

106 Interview with social worker in Mia Saba, Juba, 1 September 2020; telephone interview with chief in Yei, 12 October 2020; telephone interview with elderly resident in Yei, 3 September 2020.

107 Interview with disabled primary school teacher and court clerk, Nyamlel, 26 August 2020; interview with community elder and *gol* leader in Pacic, north-east Gok Machar, 29 August 2020.

108 Interview with soldier and business person, Juba, 13 September 2020; interview with business person in Kator, Juba, 3 September 2020.

109 Interview with tea shop worker and traditional birth attendant with herbalist expertise, Juba, 16 September 2020; interview with church worker and student in Kator, Juba, 15 September 2020; interview with finance officer at New Site, Juba, 25 August 2020; interview with PHCC staff member in Wau, 31 August 2020.

Funeral practices are generally only altered at times of deep crisis; for example, when funeral celebrations were suspended in Maridi during the 1976 Ebola outbreak. Funeral gatherings were suspended in Bentiu in 1998 because of yellow fever and the collective private grieving formed another way of mourning the tragedy of multiple deaths.[110] During the 1988–1994 kala azar epidemics in western Upper Nile, at moments of peak mortality, all events were suspended and villages went silent to honour the dead.[111]

Trust and leadership during epidemics

Many of the people involved in community leadership (from chiefs to traditional birth attendants and elderly women herbalists) note that this decision-making authority has shifted to clinical experts and the national ministry of health in recent years.[112] This is not generally considered in negative terms but many people express concern that preparations will not be synchronized or comprehensive enough, and that strategies imposed by state and clinical health boards will not find the same level of community response.[113] At present, this is particularly acute because of the continued absence of state and local government leadership due to ongoing national-level negotiations over the balance of power in South Sudan.

The general concern with COVID-19 epidemic decision-making led by state governments and national health committees is focused on a widespread lack of trust in high-level government actions.[114] One interviewee summarizes a frequent comment many others make: 'The government in Juba is not fit to be called "government". … Most of the corrupt so-called government officials are in the bracket that coronavirus kills fastest, so in short they are protecting themselves, not you or me.'[115]

110 Interview with housewife in Khalebalek, Bentiu, 23 September 2020; interview with female trader at Mankuay, Rubkona, 3 September 2020.

111 Interview with researcher from Mayom, Juba, 21 August 2020.

112 Interview with pharmacist in Rubkona, 9 September 2020; interview with soldier and business person, Juba, 13 September 2020; interview with housewife in Wicruop, Kedat, 7 October 2020.

113 Interview with chief in Wau area, 26 August 2020; interview with clinical officer at Kuergeng PHCC, 14 October 2020.

114 Malish, 'COVID-19 and Fragile Peace'.

115 Interview with driver, Bor town, 5 May 2020.

5. Recommendations for action

The following recommendations for action are grouped together according to the four different areas of healthcare and epidemic management strategies to which they relate. This includes: Healthcare sector actions in support of epidemic management; collaborative planning and information sharing; and governance and planning.

Support to epidemic management

1. Tap into existing community epidemic management practices and histories

Context: Neighbourhood-level planning and discussion of potential COVID-19 prevention and treatment measures is already underway in both urban and rural communities across South Sudan. Organizing COVID-19 pandemic responses without connecting to these existing planning and discussion structures, and without building on the long history of epidemic management in the country, risks pushing people towards activities that are either impossible or inappropriate for their social and economic contexts. Top-down and disconnected pandemic planning also risks exacerbating the suspicion, misinformation and alienation that many South Sudanese people already feel in relation to the COVID-19 response.

Recommendation: Learn about and build on the measures people are already taking to minimize the risks of transmission and to reorganize homes and workplaces to maximize social distancing and safeguarding of people in at-risk categories.

2. Build community epidemiological knowledge and support frontline caregivers

Context: In most instances the first people to identify an infectious illness, determine a response and provide treatment are often women, midwives, herbal experts and local pharmaceutical sellers.[116] These frontline caregivers help to plan epidemic management strategies, improvise personal protective equipment and provide care for the sick when and where the clinical system is unable to support them, despite information gaps and risks to their health.[117] These non-clinical and formally unqualified (although experienced) members of the community are not, however, generally included in national-level public health planning or clinical healthcare systems and training.[118] As such, in both South Sudan and across Africa, communities are urgently demanding more practical

116 In particular, this is because COVID-19 symptoms do not initially appear critical and fall under the category of non-serious symptoms, which is the case across all six research sites.

117 Abramowitz et al., 'Community-Centered Responses to Ebola'.

118 One local clinic worker notes that many NGO awareness-raising activities about COVID-19 move through villages 'and talk to communities without involving chiefs and even local health workers'. Interview with PHCC staff member in Aweil, 10 October 2020.

information and training on COVID-19 and other infectious diseases that builds on their existing levels of epidemiological knowledge. With a proper understanding of symptoms, disease progression and transmission risks, people can better protect themselves, identify suspected cases and care for sick patients more safely.[119]

Recommendation: Train and support these informal first responders. Herbal medicine experts are generally very open to clinical training and advice.[120] Supporting locally respected caregivers as part of the epidemic response will likely mean that the epidemic, and central epidemic management plans, will more likely be taken seriously.[121] This collaboration will also help local public health teams identify the best local tactics for interrupting transmission, for COVID-19 as well as for other infectious diseases.[122]

Collaborative planning and information sharing

1. Localize public healthcare messaging

Context: Epidemic messaging campaigns in South Sudan generally rely heavily on one-way public health communication, focused on the immediate disease risk, its symptoms and the individual case-by-case action needed. This approach, as with other pandemic messaging campaigns across Africa, has been widely criticized for unrealistic health advice that is disconnected with the lack of local services, economic circumstances and practical realities; for example, telling people to report to clinics that are not available or functioning in many cases, or to avoid markets.[123]

Recommendation: Public health campaigns need to be designed in collaboration with local communities to have better take up.[124] Local consultations that include women, chiefs, pharmacy and clinic workers, herbal experts and elderly people (especially

119 Abramowitz et al., 'Community-Centered Responses to Ebola', 14-15.

120 Steven Miles and Henry Ololo, 'Traditional Surgeons in Sub-Saharan Africa: Images from South Sudan', *International Journal of STD & AIDS* 14/8 (2003); Calvin W Schwabe and Isaac Makuet Kuojok, 'Practices and Beliefs of the Traditional Dinka Healer in Relation to Provision of Modern Medical and Veterinary Services for the Southern Sudan', *Human Organization* 40/3 (1981).

121 Building community epidemiological knowledge in this way would also likely demystify COVID-19 and therefore limit the misinterpretation of, for example, sudden deaths or case clusters as forms of poisoning or witchcraft. Narcis B Kabatereine et al., 'How to (or Not to) Integrate Vertical Programmes for the Control of Major Neglected Tropical Diseases in Sub-Saharan Africa', *PLOS Neglected Tropical Diseases* 4/6 (2010); also see M Lamunu et al., 'Containing a Haemorrhagic Fever Epidemic: The Ebola Experience in Uganda (October 2000–January 2001)', *International Journal of Infectious Diseases* 8/1 (2004).

122 This is the foundation of participatory epidemiology, a proven technique in disease surveillance and monitoring elsewhere. C C Jost et al., 'Participatory Epidemiology in Disease Surveillance and Research', *Rev Sci Tech* 26/3 (2007).

123 Abramowitz et al., 'Community-Centered Responses to Ebola'.

124 Telephone interview with housewife living at the Baka Maridi road outside Yei, 9 September 2020; interview with PHCC staff member in Aweil, 10 October 2020; interview with private pharmacist at Marol rural market in Aweil, 12 October 2020; interview with elderly traditional midwife in Maridi town, 2 September 2020.

women) would strengthen project design and better support the uptake of campaign information and actions. Localized campaign planning would also allow campaigns to incorporate community experience with disease outbreaks and epidemics, as well as include tested practices in infection interruption, into their advice.

2. Build confidence and trust through detailed and sustained information provision

Context: The COVID-19 epidemic has not followed the worst-case scenarios predicted for South Sudan in early 2020. At the same time, communities have received limited public health information, focused mainly on preventative measures and the risks of the virus, and been subject to a national lockdown. This rapid and focused public health messaging has not fully explained why a flu-like illness should be so disruptive to economic and personal life.[125] Fast-paced messaging focusing on individual risk mitigation has not addressed the reasonable doubts among many South Sudanese people that COVID-19 is only a risk for wealthy people who are able to travel and thus become infected, and that national politicians and aid workers are asking poor citizens to suffer major economic stress while breaking the regulations themselves.[126]

Localizing messaging, collaborating with frontline caregivers and building local resilience against the potential risk of wider COVID-19 outbreaks in South Sudan takes more time than is currently allowed in the centralized public health and messaging strategies.[127] Brief one-hit, one-way messaging campaigns are insufficient to address the information and planning needs that communities emphasize are critical for their ability to plan transmission minimization strategies appropriate for their local geographies, and to combat fatigue, doubt and misinformation within a sustained crisis.

Recommendation: Engage in sustained dialogue at a sub-county level that shares information about the progress of the epidemic nationally and globally, including new information on interrupting transmission and managing risk.[128] This information could be translated into statistics that have significance for family livelihoods; for example, simple statistical models that show how many people of working age are severely physically impacted by COVID-19. Being open and honest about the inequalities and systemic failures exposed by the pandemic will likely build trust in project activities rather than undermine them.[129]

125 Interview with clinical officer at Kuergeng PHCC, 14 October 2020; interview with elderly traditional midwife in Maridi town, 2 September 2020.

126 Interview with researcher, field notes from Yirol, 29 April 2020. Messaging has focused on refuting misinformation and rumours, rather than addressing the legitimate frustrations and anger that fuel misinformation and COVID-19 denialism.

127 The rapidity of awareness raising undermines its effectiveness, as evidenced in past health campaigns. Belknap, 'Parameters of Post-Conflict Health Care'.

128 Kovacic et al., 'We Remember'.

129 Abramowitz et al., 'Community-Centered Responses to Ebola'; Robert A Blair, Benjamin S Morse and Lily L Tsai, 'Public Health and Public Trust: Survey Evidence from the Ebola Virus Disease Epidemic in Liberia', *Social Science & Medicine* 172 (2017).

3. Review measurements of behavioural change

Context: Efforts by South Sudanese people to take preventative measures against COVID-19 are collective, not individualized. Measuring only individual actions such as wearing face masks, hand-washing and social distancing does not capture these efforts.

Recommendation: Monitoring and evaluation of COVID-19 preparedness should adapt to measure collective community planning and preparedness. This should include monitoring community planning for area quarantine systems, household self-isolation practices and other effective infection interruption mechanisms.

Governance and planning

1. Localize healthcare system management to take into account the mental health crisis, and economic and conflict sensitivities

Context: The administrative vacuum, systemic underfunding and the limited capacity of remaining state and county-level civil service personnel across South Sudan is undermining the COVID-19 response. Central plans are not being effectively and collaboratively localized,[130] partly because the wider field of non-clinical healthcare providers and caregivers are not included in clinically focused planning and because central plans do not recognize or incorporate local knowledge and experience.

Consequently, central epidemic planning risks authoritarian policing and surveillance methods.[131] It is also often insensitive to local security dynamics that impact infection interruption strategies. It further struggles to mitigate the gendered risks of epidemic management to women, who are first responders to possible infectious disease cases and critical frontline caregivers, and as such are at greater risk of infection, exploitation and trauma.

Recommendation: Decentralise epidemic management planning to build local strategies that reflect community organizational histories of epidemic response, and which take into account local conflict and economic sensitivities. This collaborative planning should aim to build communities of leadership with remaining civil service and state healthcare staff, traditional authorities, NGO-funded clinic workers, herbal experts and pharmaceutical workers.[132] This should prioritize the expertise and leadership of young and elderly women, who are so often primary health advisors and caregivers. Localized response planning also needs to include the self-protection strategies of disabled community members and listen to families caring for people with severe mental health

130 As emphasized during interview with village woman sub-chief and tea maker in Marial, Aweil, 17 September 2020.

131 Joe Trapido, 'Ebola: Public Trust, Intermediaries, and Rumour in the DR Congo', *The Lancet Infectious Diseases* 19/5 (2019), 457–458. All the key points made in this paragraph derive from this source.

132 Patrick Vinck et al., 'Institutional Trust and Misinformation in the Response to the 2018–19 Ebola Outbreak in North Kivu, DR Congo: A Population-Based Survey', *The Lancet Infectious Diseases* 19/5 (2019).

issues. Programmes should be open in acknowledging and attempting to address the added impact of repeated epidemic outbreaks on the mental health of community members.

2. Restructure funding frameworks

Context: Current funding models limit holistic epidemic responses by funding responses to individual diseases and supporting reactive rather than proactive epidemic action (except where vaccination campaigns are possible).[133] South Sudanese people deal with a multitude of medical issues and airborne diseases of which COVID-19 is just one more, even if it is particularly dangerous. Many people are frustrated and alienated by the specific COVID-19 emergency response because they feel that this demonstrates ignorance and contempt for the other, more pressing or as dangerous, threats to life and health that they face, which are chronically underfunded or receive no attention at all.

Recommendation: Create grant and loan models that support integrated infectious disease responses and creative reconsideration of the interconnected clinical and non-clinical healthcare systems in South Sudan.[134] Create funding models that include local leadership and community consultations to help maintain and improve local disease-preventative systems and to prepare localized plans for rapid responses to future outbreaks.

133 Kabatereine et al., 'How to (or Not to) Integrate Vertical Programmes for the Control'; Emmanuel Chanda et al., 'Integrated Vector Management: A Critical Strategy for Combating Vector-Borne Diseases in South Sudan', *Malaria Journal* 12/1 (2013): 369.

134 Gerald Amandu Matua, Dirk Mostert Van der Wal and Rozzano C Locsin, 'Ebola Hemorrhagic Fever Outbreaks: Strategies for Effective Epidemic Management, Containment and Control', *The Brazilian Journal of Infectious Diseases* 19/3 (2015); Jo E B Halliday et al., 'Driving Improvements in Emerging Disease Surveillance through Locally Relevant Capacity Strengthening', *Science* 357/6347 (2017).

Annex 1: Local methodologies by research site

Local	Past major epidemics	Health care management methods	Decision makers and local responses
Malakal (Upper Nile state)	Kala azar (Visceral leishmaniasis): 1983-1996, 2009-2012. Sleeping sickness: early 1990s in Atar area. Measles: 2013, 2019/20.	Residents in Malakal town and Upper Nile rural areas use common methods for disease prevention: • Boiling drinking water. • Ash used as a version of soap. • Restriction of movements of children and pregnant women. • Isolation of sick people and assignment of a dedicated caregiver. • Salt and sugar water provided to sick people to keep them hydrated. • Herbal medicine is usually the first line of treatment before escalation of cases to PHCCs or hospital. For respiratory illnesses like pneumonia, local treatments include: • Inhalation of herbal smoke. • Consultation of Dinka Atar woman spiritualist (tiet) with expertise in these types of sicknesses. If these options fail, clinical treatment is sought. Some communities with more experience of PHCCs and hospital health services seek clinical treatment more quickly. The majority of	While state government authorities have led on the COVID-19 response, in Nasir the Shilluk king and authorities have also imposed versions of COVID-19 directives, including restrictions on large gatherings, the organisation of small funerals, and reporting any suspected cases to chiefs. In other areas, local chiefs have imposed penalties on people breaking epidemic management measures, including fining people and organized general cleaning and waste management.

		residents seek herbal and spiritual medicine because of a lack of clinical medical access and the high price of pharmaceutical drugs.	
Aweil West (Gok Machar, Nyamlel and rural areas)	Cholera and meningitis: 1997, 2001. Malaria (during period of severe flooding): 2003. Undiagnosed haemorrhagic fever outbreak (similar to Ebola): 2016. Severe measles outbreak: 2019. Severe historical epidemics are also remembered. For example, Smallpox from 1950s – early 1970s (last outbreak 1972).	Common methods of managing infectious diseases across the Aweil area: • Restriction of funeral sizes. • Cancelation of weddings. • Allocation of wells and boreholes to different villages. • Splitting of cattle camps and moving them to remote locations. • Use of personal water cups rather than collective ones. • Adherence to system of atheek- rot (self-respect)—similar to current methods of social distancing. **Quarantine** Methods of marking quarantine include: • Placement of poles across paths leading to households with suspected or confirmed cases. Lining of paths with ashes. • Water and food shared with the quarantined households by placement at pre-agreed points for collection. • Water poured water from one container into the quarantined	• Previously executive chiefs and heads of clans: key decision-makers at summit meetings to determine community epidemic plans. Meetings also included cattle camp heads and young men and women (encouraging wider community buy-in). • Since 2010s, summit meetings replaced by government orders in determining epidemic response strategies. • Coordination between local leaders and government generally seen as ineffective.

		• container to minimise risk of transmission via surfaces. • When clinical treatment is inaccessible eg during civil war, spear-masters (beny bith) and witchdoctors (acumuk nyin) assigned individuals to care for quarantined people and determined herbal and spiritual treatments. • Movement of key individuals—clinical and spiritual workers—limited to local areas / specific villages.	
Rubkona Town and rural Unity State	Typhoid: 1986-1992. Kala azar and Cholera: 1989-94 Cholera and yellow fever: 1998. Undiagnosed haemorrhagic fever outbreak (similar to Ebola): 2016. Rift Valley fever outbreak: 2018.	There is extensive experience of epidemic response in the area, including: • Suspension of travel. • Social distancing. • Use of individual drinking cups. • Children prevented from mixing with other households. • Items not shared / borrowed with / between households. • Suspension of wedding dances. • Cattle grazing paths altered to minimise contact between different groups. **Treatments** • Herbal treatments remain a first step, although previous epidemics are recognized to have overwhelmed these.	Residents across this region say that current government-stipulated preventative measures are less closely adhered to than previous, locally determined responses. These were generally more closely followed. Residents are also aware that all of their clinical health facilities are provided by NGOs rather than by government systems, and that this raises the risk of clinical healthcare disruption if funding or security is interrupted. Many residents, including local herbal and clinical health workers, are concerned that the current lack of

		• Clinical interventions by international humanitarian orgs—Care and MSF—seen as being critically important, particularly during Cholera and Kala azar outbreaks in 1990s.	adherence to transmission prevention measures is because of widespread trauma from conflict and mass deaths resulting in nihilism and apathy about further possible risks to life.
Wau Town / peri- urban rural areas	Meningitis and river blindness: recurring over recent decades. Rubella: 2018. Measles: 2019. Ebola: early 2020. Outbreak in Mapel.	Residents note that most methods being used to control the spread of Covid- 19 are not new but have been used during previous epidemics. The use of masks and hand sanitizers is, however, a new development. Of methods used in previous epidemics, people emphasized: • Use of disinfectants, including heat, ashes and cow urine. • Avoidance of sharing clothing and bedding. • Separate eating. • Provision of food to sick people via drop-off points. • Sharing of news amongst community of houses where individuals are quarantining. Wau-specific measures: • Bloodletting • Drinking local alcohol (siko) for those with meningitis.	In Wau, community health workers have played a particularly important role in managing infectious disease outbreaks. For example, the training and organisation of community health workers in the 2006 meningitis outbreak is often noted as a key intervention that helped control the outbreak. Other key local intermediaries during epidemics include spear masters in Dinka and Luo communities, plus prophets, and herbal specialists. Many residents also noted the importance of elders and traditional authorities in disseminating and enforcing the decisions of community health workers.

Yei Town and peri- urban rural areas	Ebola (Maridi): 1976. Sleeping sickness (Yei): 1998, plus regular outbreaks dating back to 1910. Cholera (Yei): 2006. Yellow fever: early 2020.	Yei area residents have extensive experience of major epidemic interventions for cholera, sleeping sickness and Ebola. These include the organization of quarantine systems and minimising movement. Yei residents emphasize their experience of previously unknown epidemics with no real treatment pathway. For example, the 1976 Ebola outbreak was initially treated in the manner of a water-borne disease because of similarities in its early symptoms. Yei residents have experience of contact tracing systems and house-to-house epidemic response organization from the same Ebola outbreak. House-to-house mobilizers worked in close coordination with area chiefs, who link the doctors with the people and community at large. Memories of the 1976 outbreak have been reinvigorated by the 2013-16 and 2018-20 trainings of community responders, the reconfiguring of the local land survey staff into patient contact tracers, and information campaigns on Ebola's symptoms and spread.	In Yei, past epidemic management involved extensive consultation with residents, including across close national borders. Residents emphasize that, in recent decades, chiefs have sought out advice on disease identification and treatment from other communities with potential experience with the suspected illness, and from urban medical centres.

		For the ongoing Covid-19 response, Yei formed its own response that has emphasised contact tracing. There are local fears that Yei is particularly exposed to COVID-19 and other infectious diseases because it is a trade hub and refuge site for displaced people and refugees.	
Juba Town (Hai Referendum, Godele and other suburbs)	Cholera: 2014-15. Sleeping sickness (southern Juba and on the Lainya road at Kagwada). Many residents also have wide experience of epidemics from previous residence elsewhere in South Sudan and in the wider region.	Despite proximity to clinical medical services, many people across Juba rely heavily on herbal medicine, which has in their experience been effective in previous epidemics. Along with social distancing, remaining at home as much as possible, and maintaining high levels of hygiene, many Juba residents noted that they are responding to COVID-19 by ensuring a good supply of herbal medicine for fevers (particularly dekertomelo, used for malaria). Many men and women are trying to maintain social distancing, including eating separately. They note their concerns about overcrowding, particularly in poor households and cramped migrant worker bunkhouses. Residents are similarly concerned that economic pressures have undermined neighbourhood abilities to organize the isolation of infected people or houses, including the difficulty of	For Bari residents around Juba, the monye kak—the person responsible for the Bari land, whether the land of Gondokoro, Rajaf, Lobono or Jubek—is responsible for identifying and reporting the outbreak of disease to Bari authorities, although people are concerned that they are not part of the government organized response. For other communities resident in Juba, people who should be consulted on potential responses to pandemics include: • Women • Elders • Spiritual doctors • Traditional healers • Herbalists • Chiefs of the community or clans

		providing enough childcare to stop children moving between households. People from various communities recommend re-instituting charcoal or ash marking around quarantining households. The lack of a vaccine, and a common resentment towards wealthy international workers and politicians who are understood to be most at risk from COVID-19, contributes to a widespread dismissal of risk attached to COVID-19.	Some churches also provide support for accessing medication. For neighbourhoods in Juba city, block authorities were important during cholera outbreaks in the 2010s, because they organized local cleaning drives and safe reorganisation of rubbish and water points immediately, before other state interventions reached neighbourhoods.

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South Sudanese people have extensive knowledge of infectious diseases and experience of organizing responses to epidemics during wars and other crises. There are multiple, locally-specific methods used by communities for interrupting infection transmission and managing epidemics. *Community Approaches to Epidemic Management in South Sudan: Lessons from local healthcare systems in tackling COVID-19* documents these community infectious disease management strategies, based on sustained investigative research in the Yei, Juba, Wau, Malakal, Aweil West and Rubkona areas in 2020. The research encourages collaborative engagement with local knowledge and community healthcare leadership.

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