# Social Science in Humanitarian Action

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## Cross-border dynamics and healthcare in West Nile, Uganda

Since the start of the Ebola outbreak in the Democratic Republic of Congo (DRC) in August 2018, one single episode of Ebola has been reported within Uganda. A family travelled from Uganda to Mabalako Health Zone in North Kivu, DRC, to attend the funeral of their grandfather on 1 June 2019 (who was confirmed as having Ebola, on 2 June). They crossed back from DRC into Kasese District on 10 June, through the Bwera border post and sought medical care at Kagando hospital. The five-year-old grandson was symptomatic and, suspected of having Ebola, was transferred to Bwera Ebola Treatment Unit (ETU). The Uganda Virus Research Institute (UVRI) confirmed that he had Ebola on 11 June, along with two other family members, his 50-year-old grandmother and three-year-old brother who were both also admitted to Bwera ETU. All three died. As of 26 June, 108 exposed contacts had been identified and were monitored daily. With no new cases or deaths reported, Uganda successfully completed its first 21-day follow-up period on 3 July 2019.<sup>1</sup>

On 30 June 2019, a case (mother of five children infected with Ebola, two of whom had already died) was confirmed in Ariwara Health Zone, Ituri Province, having travelled overland from Beni (460km south of Ariwara). This was the first confirmed case in this health zone. At the time of writing (5 July 2019), 177 family contacts had been listed, and 40 had already been vaccinated. Ariwara is less than 10km from the border with Arua, Uganda, and is the site of a large weekly market that is a major hub for local traders from West Nile, DRC and South Sudan.<sup>2</sup> Preparedness efforts were rapidly scaled-up in the border areas of Arua, Maracha and Yumbe. The Arua District Task Force mobilised on 2 July and the Uganda Ministry of Health deployed the National Rapid Response Team to conduct a needs assessment. A vaccination team from Kasese was also deployed to Arua District on 3 July to vaccinate frontline health workers.<sup>3</sup>

Against the backdrop of on-going preparedness work in Uganda as related to the outbreak of Ebola in DRC, this brief summarises key considerations concerning cross-border dynamics and health structures and behaviours in the West Nile sub-region of north-west Uganda. It builds upon the SSHAP brief 'Uganda-DRC: cross-border dynamics' (published December 2018). Following the case in Ariwara, the research team connected with a number of key informants in Arua who had been involved in previous research and confirmed that, in general, local communities were more concerned (perceived greater risk) about this case than the previous case in Kasese due its close geographic proximity to West Nile, and because cross-border movement (e.g., to the market in Ariwara) is a critical part of everyday life.

This brief was drafted by Elizabeth Storer (the London School of Economics and Political Science) and Georgina Pearson (St George's, University of London), with support from Ingrid Gercama, Theresa Jones and Juliet Bedford (Anthrologica). It builds on long-term ethnographic research on issues related to health and healing conducted in Adjumani, Arua, Maracha and Moyo districts of Uganda between 2009-2018. Earlier field experience was updated with a review of recent published and grey literature, informal discussions with colleagues in Kampala, Arua, Adjumani and Moyo and a rapid assessment within Arua Town (March 2019) and further follow up in July 2019. Additional information was contributed by Dr. David Kaawa-Mafigiri (Makerere University, seconded to UNICEF Uganda). Prior to finalisation, it was reviewed by expert advisors from Anthrologica, University of Durham, Gulu University, London School of Hygiene and Tropical Medicine, Makerere University, UNICEF Eastern and Southern Africa Regional Office. Responsibility for the brief lies with the Social Science in Humanitarian Action Platform (SSHAP).

## Key considerations and recommendations

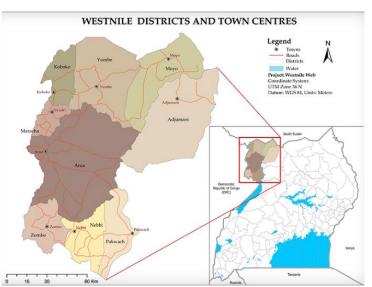
- Language and communication: West Nile is a multi-linguistic zone, the dominant languages being Lugbara, Ma'di, Kakwa, Aringa, Alur and Kinubi. It is also necessary to identify specific languages and dialects of the refugee communities as well as the host communities, and for effective communication, the most appropriate language must be established and used in both oral and written materials. Inter-personal communication and radio broadcasts are well received, and popular radio stations with good coverage provide services in multiple local languages (e.g., Radio Pacis, a radio station of the Catholic church based in Ediofe, Arua; Voice of Life, an Anglican church radio station; Arua One FM; and Paidha FM which covers five districts in West Nile).
- Local authorities: It is critical that community engagement initiatives go through and ideally be led by the Local Councillor (LC) system that functions from the district to the village level. Although collaboration with LCs will need to be sensitively tailored to the local context, their participation will foster local ownership, help to ensure appropriate remuneration for local response actors and effectively cascade information between administrative levels. Similarly, working with elders and clan structures is important given their role in local and cross-border governance and the influence they can bring to bear in both creating and overcoming concerns about biomedical care, as well as the introduction of by-laws associated with public health measures. There are strong religious foundations across West Nile (Catholics, Anglicans and Muslims) and religious leaders also offer significant ways to engage different community groups. Key Catholic leaders can be reached through focal points in Ediofe diocese, Lodonga Basilica, Bethany Charismatic Renewal Centre, and Anglican parishes through the central Madi-West Nile diocese in Arua Town. Collaboration with different local associations is also important. Most association chairmen are contactable via mobile phone and can be accessed locally.
- Support and remuneration: Evidence from previous fieldwork suggests that biomedicine is well regarded, but that trust in the
  provision of services reduces when public health messaging is unclear, resources are limited and delivery is inconsistent. Local
  governance structures and networks are in place which have been effectively operationalised during previous disease outbreaks,
  including the LCs and Village Health Teams (VHTs). It must be stressed, however, that these are normally unpaid positions. Any
  additional responsibilities and expectations of work must be locally agreed, appropriately supported and remunerated (the lack of
  support for VHTs is often cited as one of the main challenges for neglected tropical disease drug distribution programmes in the

region). In early July 2019, the Ministry of Health issued a circular stipulating the rates of remuneration for VHTs and other volunteers engaged in EVD activities. The modalities for payment remain challenging, however.

- Burial and funeral practices: Customary practices can be modified in response to specific situations, and communities are highly pragmatic in finding acceptable ways to bury and mourn respectfully, whilst ensuring they are safe. These negotiations must be resolved at the community level as the disruption of customary burial practices and mourning, particularly if done by 'outsiders' has the potential to elevate tensions and result in violence. There are important precedents for adapting 'normal' burial practices, for example, during the initial years of the HIV/AIDS epidemic, and more recently in relation to Hepatitis. During the rapid assessment in Arua in March 2019, key informants suggested three acceptable modifications to local funeral rites: a) if a person was suspected to have died from Ebola, then the family (or clan) would engage government medical personnel or response partners to help safely prepare the body; b) mourners would not stay for extended periods of time and food would not be prepared or shared amongst those who gathered; and c) objects belonging to the deceased would be included in the casket (as in previous times), particularly if they were perceived to carry a risk of further infection. It was also emphasised that response partners must appreciate the sensitivities associated with asking questions about the cause of death and the condition of the deceased's body (as well as questions associated with contact tracing and community-based surveillance), and receive appropriate training to navigate such conversations diplomatically.
- Rapid research: Further rapid research is needed to better interpret how communities perceived the imported cases in Kasese and the related return of suspected cases to DRC from Uganda. In addition, further detailed community-based information is required in terms of scaling preparedness activities in areas, such as West Nile, that were previously classified as medium- (rather than high-) risk districts. Ten months into the DRC outbreak, there is general fatigue associated with preparedness activities. This may foster complacency in the borderlands (particularly those located far from areas affected by or at risk from recent cases), and amongst communities for whom Ebola is not a priority concern.

### **Cross-border dynamics in West-Nile**

West Nile: Uganda is divided into ten sub-regions. West Nile sub-region is one of three regions in Northern Uganda, lying mainly to the West of the River Nile. It is comprised of nine districts: Arua, Adjumani, Koboko, Maracha, Moyo, Pakwach, Nebbi, Yumbe and Zombo. The largest urban centre in the sub-region is Arua Town (420 kilometers from Kampala) where the Regional Referral Hospital is located. In the most recent national census (2014), the total population across West Nile's nine districts was reported to be 2,660,667.5 West-Nile is the second poorest sub-region in the country. According to a 2017 poverty index, 85% of the West Nile population were multi-dimensionally poor, and 59% lived in severe poverty (compared to 70% and 38% nationally).<sup>6</sup> The majority of the population is not educated beyond primary level and subsistence agriculture is the main livelihood. Staple crops include cassava, beans, groundnuts, sesame, maize, potatoes and sorghum and many households sell agricultural surplus to supplement their income. Along the banks of the River Nile agriculture is supplemented by fishing, but there have been periods of drought and famine in the region, particularly during the dry season, from December to April.



https://www.westnileweb.com/the-region

- Cross-border trade and crossings: Although a recently completed tarmac road connects Pakwach Nebbi Arua (in Uganda) with Kaya (South Sudan border), and the road from Gulu - Atiak - Bibia (in Uganda) to Juba (South Sudan) is also tarmac, vast swathes of the region remain poorly connected and are serviced by unpaved murram roads, some of which are impassable in the rainy season. Along the Uganda/South Sudan border there are official road crossings at Elegu/Nimule and Moyo/Kajo Keji, plus a river crossing at Panyanga/Nimule (where there is a large market). There are also Uganda National Roads Authority (UNRA) ferry points at Omi-Laropi, and Maaji-Obongi with registration check points. UNHCR refugee entry points are located at Busia, Kaya, Logu, Kerwa, Afoji and Elegu, which service refugee settlements across Yumbe, Arua, Moyo and Adjumani districts.8 Uganda/DRC border there are customs posts at Goli, Vurra, and Ondramacacu. Whilst these are official crossing points, there are a multitude of informal crossing points along the entire highly-porous border. Young men continue to be involved in informal trade in particular, and often cross the border at night via panya roads (small, unmonitored roads) to avoid the taxation and bribes incurred at official border crossings which reduces the profitability of their trade. Respondents in Arua suggested that Congolese pass more easily over the border and expressed concern about being caught using panya roads by Congolese authorities whom they associated with violence, imprisonment and fines (which were also reported to be given by the Ugandan Revenue Authority). The dynamics of cross-border trade fluctuate and recent instability in South Sudan has presented heightened security concerns, particularly for those involved in small-scale trade. However, the ethnic interconnections between the Lugbara of north-western Uganda and north-eastern DRC and the Kakwa who live across the tripartite border maintain "pre-colonial trading patterns" which are a significant "indigenous form of development that allows the population in the peripheral border areas to 'fend for themselves".
- Family and social ties: Everyday life in the borderlands of West Nile is shaped by historical and contemporary socio-economic dynamics: clans and their associated social networks continue to be influential. Typically, small clans operate as extended family units of three to four generations including an elder, their sons and their families. In rural areas, most people continue to live in settlement patterns dictated by the clan, although members may have migrated to Arua (and beyond). Such affiliations are less pronounced in villages that encompass trading centres. In Arua and its urban peripheries, most people have purchased or rent a

plot of land as a single family unit, yet these households remain closely connected to rural relatives, and people often travel back and forth between the town and village. In cases of insecurity, it can be pragmatic for smaller clans to amalgamate to form a larger clan committee with extended reach (the role of clans in local governance is discussed further below). Such committees can straddle the border, with members crossing for impromptu meetings as well as for customary practices (including marriages and funerals) and cross-border trade.

- **Displacement**: Over recent years, communities in West Nile have experienced multiple humanitarian crises resulting in various international interventions. In the 1980s, populations across West Nile were collectively displaced to South Sudan and DRC due to civil conflict. Sporadic violence continued throughout the 1990s and areas of Adjumani and Moyo, particularly those close to the border, were affected by incursions from the Lord's Resistance Army and other rebel movements. West Nile has accepted refugee populations from South Sudan, although the rate of movement has slowed in recent years as most have already crossed to avoid the on-going conflict. Currently, the region hosts approximately 1 million biometrically registered refugees from South Sudan, and at certain times, refugee numbers in Moyo and Adjumani have exceeded the size of the local population. Many refugees (1,276,208 as of 31 May 2019)<sup>13</sup> continue to live in refugee settlements (e.g., Bidibidi in Yumbe, Palorinya in Moyo, Nyumanzi in Adjumani, and Rhino camp and Imvepi in Arua) but significant numbers were not registered and moved to live in towns amongst the host population. It is common for those registered in settlements to move between town and settlement to access resources. Humanitarian assistance continues to be provided to refugees and conflict-affected communities by multiple agencies (e.g., the provision of water and sanitation, healthcare, and programmes for severe acute malnutrition). Although refugees and host communities live together, there is a perception that the distribution of resources to refugee populations is unfair given the stress that host communities also face. Healthcare are provided to refugees to refugee populations is unfair given the stress that host communities also face.
- Languages: There are notable distinctions between the languages of West Nile and those of southern Uganda. West Nile is a multi-linguistic zone, the dominant languages being Lugbara, Ma'di, Kakwa, Aringa, Alur and Kinubi. In Arua and Maracha districts, the Lugbara language is most widely used (with the exception of Arua Municipality itself where all the above languages are spoken). In Moyo and Adjumani districts, the main language is Ma'di; in Yumbe it is Aringa; and in Nebbi and Zombo it is Alur. There is dialectical variation within linguistic groups in each district. For example, Lugbara and Ma'di languages encompass multiple dialectical variations although people can make themselves understood in conversation. Different dialects of Lugbara are spoken in Ayivu, Terego and Maracha. The Ma'di language in Moyo and Adjumani is significantly different from that of Ma'di Okollo. Most of these languages are used orally, and are not widely written or read. Except among more highly educated people, spoken English is limited across West Nile. Select military personnel, traders and Congolese refugees use Kiswahili but since this is the de-facto language of the army, its use carries connotations of force that may be inappropriate for public health messaging. It is also worth noting that there is greater affinity in languages across borders than within some of West Nile's Districts (for example, Lugbara is used in West Nile and across the border with DRC, and Ma'di is used in West Nile and across the border with South Sudan).

#### Administrative divisions and local authority

- Formal governance: In Uganda, districts are sub-divided into counties, sub-counties, parishes and villages. These divisions, derived from the British colonial system, map onto state-appointed authority. A system of chiefs operates from sub-county to parish level. Appointed by District Commissions their role is salaried and orientated around the implementation of government policies. This decentralised governance structure overlaps with the Local Councillor (LC) system and functions from the district level (LC5) to the county level (if applicable, LC4), sub-county (LC3), parish (LC2) and village level (LC1). LCs are elected by their constituents and at each level, their work is assisted by an elected council, although components of the system are often underresourced. The work of LC1s is supported by a modest stipend, although their elected council members are unpaid. It is accepted, normal practice for any intervention or response to seek permission from LC5 downwards. Securing permission and buy-in from LC1 is critical for effective mobilisation at the village level. The LC1 is the gateway to any given village and plays a unique role in addressing communities' needs from the ground to the sub-county administration level. Newcomers to a village are required to produce a letter stating their character (moral conduct) and confirming their former residence for the LC1, and most councillors keep a register of those within their village. LCs are called on to assist with 'mobilisation' (e.g. for local healthcare surveys), and often have experience of engaging in public health programmes (e.g. during Cholera or Meningitis outbreaks, and for Hepatitis B screening).
- 'Traditional' governance: A clan is formally presided over by male elders. In rural areas, clan elders continue to assert significant authority over the discipline and conduct of their descendants, and oversee customary practices including funeral proceedings. Elders often form associations at the district level, and many are familiar with supporting the work of NGOs in their areas. Examples of associations include the *Ayivu Elders Association*, *Lugbara Kari* and the *Maracha Elders Associations*. Ma'di groups have formed cultural associations referred to as the *Ma'di Futele*. Beyond these attempts to formally unite, elders maintain an important role at the household level, enforcing particular standards within homes and wider communities. Younger male members of the clan are involved in day-to-day local governance, including the issuance of by-laws. Many by-laws are associated with issues of public health significance, particularly regarding hygiene matters (including water, sanitation, the disposal of household waste etc.) with fines levied for non-compliance. There have been recent attempts to write clan by-laws across Arua and Maracha districts and some of these locally-specific laws dictate fines for clan members who fail to uphold particular health and sanitary standards within the home (such as ensuring access to a latrine, handwashing facilities, water and soap) as well as personal cleanliness. When necessary, clans coordinate efforts to deal with cross-border insecurity at the local level, including matters of theft and witchcraft, and movement across borders according to clan affiliation has been documented as a way of fleeing violence and reprisals from the state.
- Horizontal governance: Beyond forms of vertical authority based around formal administrative structures and blood / clan ties
  (traditional governance), it is common across West Nile for people to convene associations and groups as most relevant to
  everyday economic and social life. Fisherfolk and other traders have formed coalitions, and most people are involved in local
  SACCO groups (Savings and Credit Co-operatives), church groups, school committees and youth groups. Membership of
  dynamic associations is an important facet of life in West Nile, and it is important to recognise the rich local texture of these groups

and to observe the hierarchies within each association. Involving these actors is critical and will significantly increase the effectiveness of preparedness and response activities.

## Health systems, care-seeking behaviour and beliefs

- Health status: In West Nile, male and female mortality rates are among some of the highest reported in Uganda.<sup>15</sup> People across the sub-region continue to die from diseases eradicated from other parts of the country, including plague, meningitis and tuberculosis.<sup>16</sup> There remains limited safe water coverage in many areas and few sanitary latrines. The population is cogently aware of their right to health and other services vis-à-vis the state, and the perceived failure of the government to develop health infrastructure and deliver high quality care is a frustration to many communities.<sup>17</sup> The region has, however, been the focus of numerous vertical public health interventions including mass drug administration programmes for neglected tropical diseases (onchocerciasis, lymphatic filariasis, schistosomiasis and soil-transmitted helminths); insecticide-treated bed net distributions for malaria control; intermittent sleeping sickness campaigns; cholera campaigns; and Hepatitis B testing campaigns. These programmes tend to be administered by the Ugandan Ministry of Health with support from various international organisations. There are also ongoing nutrition and emergency food relief programmes supported by UN organisations and delivered through international NGOs.
- Care-seeking behaviours: Treatment pathways vary and are influenced by perceptions about the cause of illness, its severity or complexity. Decisions around when, where and from whom to seek healthcare are also determined by both financial and non-financial barriers including distance from home to the point of service provision, the availability of transport and the level of trust in treatment options and health providers. People often first engage with health facilities (either public or private) if they suspect malaria or typhoid for which they can be easily tested, or may self-diagnose and purchase a course of anti-malaria treatment or antibiotics directly from a private facility or pharmacy without testing. Families are highly influential in care-seeking decisions and behaviours. Often women provide care within the household, and it is generally expected that if a patient is admitted to a facility, their family offers support and care during this period. If symptoms persist, people frequently pursue a number of alternative / informal care practices, and may travel long distances to do so. An established biomedical diagnosis does not mean that other courses of care are not sought, and a combination of treatments (either consecutively or in parallel) are common, particularly in the case of chronic conditions and repeated episodes of sickness, or when there has been misfortune or death within a family, clan or neighbourhood. If witchcraft or poisoning are suspected, and symptoms worsen or are protracted, people tend to pursue non-biomedical therapies at the expense of returning to formal medical care.
- Health administration: State biomedical healthcare facilities are graded following the level of administrative divisions: General Hospital (District town), Health Centre IV (County), Health Centre III (sub-county), Health centre II (Parish), and Village Health Team (VHTs). The Regional Referral Hospital for West Nile is in Arua. General Hospitals at the district level provide laboratory facilities, blood transfusions, in- and out-patient services, and medical, surgical, obstetric and emergency care. At the sub-county level, Health Centre IIIs should provide essential laboratory facilities for diagnostic testing (e.g. rapid-diagnostic test for malaria, typhoid, HIV/AIDS, microscopy for intestinal helminths) and pharmaceutical treatment (e.g. tuberculosis treatment). VHTs (sometimes also referred to as Community Health Workers) offer simple analgesics such as paracetamol and anti-malaria medicine. VHTs are unpaid volunteers with minimal training who may have to travel long distances to reach households across their large catchment areas. In practice, the availability of services varies substantially across each level and can change over time. Onwards referral (e.g., from health centre to hospital) is also hindered by operational issues such as the poor road network, limited ambulance provision and high fuel costs (there is tacit agreement that patients provide a jerry can of petrol to cover their ambulance referral).
- Public facilities: A common complaint heard across all levels of the public healthcare system is that it is severely under-resourced and this negatively impacts the services and quality of care available. While the Regional Referral Hospital is in Arua, people from Adjumani tend to travel to Gulu for referral services (a three to four hour drive or longer if travelling by public transport and, depending on the condition of the road), whilst the more wealthy seek healthcare in Kampala where higher-quality care is available. Mission Hospitals are also preferred to public services, despite a small fee being charged (e.g., Lacor Mission Hospital in Gulu; Kuluva Mission Hospital in Arua; and Maracha Mission Hospital in Ovujo). It is common for Congolese citizens (particularly the family of Congolese women married into Ugandan families) to travel and stay with their extended family on the Ugandan-side of the border to access services including from Arua Referral Hospital, Bethany Charismatic Healing Centre (just outside Arua Town), and from herbalists along the border. Conversely, Ugandan citizens also cross into DRC to seek multiple forms of treatment (both formal and informal) influenced mainly by cost and issues of access. Since 2000, Uganda has adopted a policy promoting the integration of healthcare services for refugee and host populations (delivered through international organisations) into the state healthcare system.<sup>18</sup>
- Private facilities and pharmacies: Private facilities are increasingly available in towns and trading centres, with small clinics and drug shops also opening in the smaller trading areas. Private facilities offer a range of services including laboratory facilities, inpatient care and pharmaceuticals. Many people purchase medicines from private facilities or drug shops due to the frequent stock-outs at public health facilities. It is common for healthcare workers employed by the state to also provide private care to supplement their incomes, but private facilities are not necessarily run by qualified health workers, but by individuals with no formal training (many of whom may be related to health personnel). Although public and private facilities are easily distinguished, with the former being clearly marked with the logo of the Ministry of Health and a range of national health promotion slogans, communities tend to distinguish them according to cost.
- Herbalists and local practitioners: Herbalists define their practice as strictly non-spiritual and offer a pseudo-medicalised practice. Across West Nile these healers go by different names. In Lugbara, for example, a herbalist is referred to as 'ba aro nyakuni fe piri' (the person who has herbal medicine) or ojo, which can be used interchangeably to refer to practitioners including herbalists, diviners and 'witchdoctors'. Some herbalists work from small 'clinics' that can accommodate in-patients, but most operate from their compounds and acute conditions may be dealt with publicly. Herbalists often learn their trade in DRC, and people travel across the border in both directions to seek herbal treatments. The exact approach of a herbalist varies but they often treat a wide range of issues including epilepsy, wounds, ulcers, snakebites, eye problems and poisoning (also discussed below). Some use herbs administered in improvised biomedical packaging, others use intravenous drips (similar to tradi-modern)

practitioners in DRC), whilst others continue to use methods that involve cutting the skin and rubbing herbs into the incisions. In cases of illness thought to be caused by poisoning (determined by sudden deterioration, swelling of the stomach, or the analysis of social circumstance e.g. repeated misfortune, several similar deaths within a community, or the suspicion of a poisoner being nearby), the patient is likely to be taken directly to a herbalist, and if the patient presented 'too late' the herbalist may refuse to treat them. It is worth noting that traditional practitioners (particularly those referred to as 'witchdoctors') are highly stigmatised, particularly in Christian communities, and are often evicted if a community experiences multiple sudden deaths.

- Religious healers: Anglican and Catholic churches have long been involved in the provision of biomedicine, particularly in Arua and Moyo where missions maintain their headquarters and in Maracha, where the majority of the population is Christian. Since the 1990s, Charismatic Christian actors have also become involved in the management of chronic sickness and persistent misfortune, with practices including prayers and laying on of hands spreading outwards from Arua. Spiritual interventions are sought for a range of chronic physical conditions as well as for mental health complaints and (suspected) bewitching. It is notable that the Bethany Charismatic Renewal Centre, the regional (and spiritual) hub of the Charismatic Catholic Movement attracts healthseeking from across West Nile as well as the DRC and South Sudan, particularly during its popular, annual mission in January. In Yumbe, the population is majority Muslim and faith healing also plays a role amongst these communities.
- Taboos and witchcraft: Cases of sudden death, whether due to a biomedical illness, road-traffic accident or unknown cause are often explained as 'poisoning'. Whilst people describe poisoning as related to the stomach or to paralysis, in reality any sudden death (including if a medical cause was known) may be regarded as poisoning (the most extreme accusation of 'invisible power' that could be termed witchcraft). Speaking publicly about poisoning or other forms of witchcraft is deeply taboo, and an accusation generally emerges only in the context of mass crises. In general, however, asking about the cause of death or other details associated with the deceased can also be sensitive. In some circumstances, asking questions about symptoms, treatment and social responsibility is accepted, but it is never appropriate to ask about the state or condition of the body. Such questions, particularly if asked by a stranger to the community (e.g., a response team doing contact tracing) are likely to be treated with a high degree of discomfort and suspicion.
- Ebola knowledge: During rapid observational fieldwork in Arua town (March 2019), it became evident that many community members perceived Ebola to be highly contagious and transmitted through contact with infected people, and suggested that should they suspect Ebola, they would be most likely to attend the main government hospital for diagnosis and treatment. Many interlocutors regarded Ebola as an illness that 'comes from Congo'. Although other illnesses are also perceived this way (including unexplained deaths thought to be associated with witchcraft), anecdotal reports since the case in Ariwara, have suggested that some people may be actively avoiding people from Congo. During fieldwork in Arua (March 2019), people confirmed that they had heard recent communications about the Ebola outbreak in DRC and preparedness activities in Uganda, mostly through radio broadcasts, and several concluded that they already had some knowledge of Ebola from previous outbreaks (and outbreaks of other viral haemorrhagic fevers) that had occurred in northern Uganda (e.g., the Ebola outbreak in Gulu, Masindi and Mbarara, October 2000-January 2001) and in DRC (e.g., the Ebola outbreak in the neighbouring Orientale Province, June- November 2012).

#### **Funeral rites**

Funeral rites: Funerary rites are extremely important in the West Nile context and reflect customary and religious practices. Wherever death occurs, it is normal practice for the body of the deceased to be 'brought home' to be buried on clan land. For men, this is usually their natal village, whilst for married women it is normal practice for them to be buried in the village of their husband not in their own natal village. In certain cases, this involves transporting the body from outside West Nile, including from DRC, sometimes on motorbikes (boda bodas) or via public transport. Burial usually happens quickly, between two and four days after death and, as it is mandatory for anyone with a connection to the deceased to attend, funerals often involve large numbers of people who have travelled long distances. It is specifically important that family and clan members attend, and they are expected to offer a generous 'contribution' to the family of the deceased. Relatives may sit at the graveside for many days or even several weeks if the deceased was a prominent person. The family is bound to feed the large number of mourners and this can be a source of tension when people over stay. During the funeral, the casket is displayed and prayers are said. There is often an extensive and public evaluation as to the cause of death and family members will trace the medical history of the deceased to prove there was no malpractice. It is the responsibility of clan members to prepare the body for burial, prepare the gravesite and make the funeral arrangements. There are specific roles that govern the distribution of labour for these duties. Customarily, objects would be placed in the casket with the deceased (such as their spear or hoe), however it was reported that this is no longer widely observed. Graves are marked with a simple cross and gradually merge in with their direct environment and on-going life. In recent years, people in urban centres have started to purchase a plot of land and land titles for their family's burial site, but customary land tenure (where the land is owned by the clan) is the most widespread system across West Nile.

# **Contact details**

If you have a direct request concerning the response to Ebola in the DRC, regarding a brief, tools, additional technical expertise or remote analysis, or should you like to be considered for the network of advisers, please contact the Social Science in Humanitarian Action Platform by emailing Juliet Bedford (julietbedford@anthrologica.com) and Santiago Ripoll (s.ripoll@ids.ac.uk).

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#### References and notes

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- According to earlier research, Ariwara is known locally as 'Dubai' given its importance as a trading hub and abundant flow of goods that pass through it, moving between DRC, Uganda and South Sudan. The market also facilitates smuggling in the wider area. See Titeca, K. (2009). The changing cross-border trade dynamics between north-western Uganda, north-eastern Congo and southern Sudan. Crises States Research Centre, LSE. http://www.lse.ac.uk/international-development/Assets/Documents/PDFs/csrc-working-papers-phase-two/wp63.2-changing-cross-border-tradedynamics.pdf

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- Although in some areas of West Nile cash crops including tobacco were formerly grown, these activities have receded in the last decade due to the withdrawal of international companies from the area. Because of land pressures, many people acquired land away from home, either moving seasonally to harvest, or employing family members or landless laborers.

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See forthcoming SSHAP brief on DRC-South Sudan cross-border dynamics.

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