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### Changing landscapes, changing practice: Negotiating access to sleeping sickness services in a post-conflict society

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## Changing landscapes, changing practice: Negotiating access to sleeping sickness services in a post-conflict society

### Abstract

For several decades, control programmes for human African trypanosomiasis (HAT, or sleeping sickness) in South Sudan have been delivered almost entirely as humanitarian interventions: large, well-organised, externally-funded but short-term programmes with a strategic focus on active screening. When attempts to hand over these programmes to local partners fail, resident populations must actively seek and negotiate access to tests at hospitals via passive screening. However, little is known about the social impact of such humanitarian interventions or the consequences of withdrawal on access to and utilisation of remaining services by local populations. Based on qualitative and quantitative field work in Nimule, South Sudan (2008-2010), where passive screening necessarily became the predominant strategy, this paper investigates the reasons why, among two ethnic groups (Madi returnees and Dinka displaced populations), service uptake was so much higher among the latter. HAT tests were the only form of clinical care for which displaced Dinka populations could self-refer; access to all other services was negotiated through indigenous area workers. Because of the long history of conflict, these encounters were often morally and politically fraught. An open-door policy to screening supported Dinka people to 'try' HAT tests in the normal course of treatment-seeking, thereby empowering them to use HAT services more actively. This paper argues that in a context like South Sudan, where HAT control increasingly depends upon patient-led approaches to case-detection, it is imperative to understand the cultural values and political histories associated with the practice of testing and how medical humanitarian programmes shape this landscape of care, even after they have been scaled down.

**Key words:** South Sudan; human African trypanosomiasis; sleeping sickness; case detection; equity; ethnicity; displacement; medical humanitarianism

## Introduction

For over five decades, conflict in South Sudan has caused massive and continuous population displacement across ethnic boundaries. The repercussions for health system development have been dire: by 1990, 4 out of 5 health facilities in the country were shut (Salih, 1996) and the main providers of care became (and remain) international humanitarian agencies. Having only experienced formal healthcare through the punctuated cycles of emergency aid programmes, South Sudanese populations have been exposed to vastly different medical practices and cultures: from the traditional health and religious systems of neighbouring tribes, to the emergency triage systems of rebel groups on the front lines, to the many faith-based and secular humanitarian organisations intervening with their own myriad vertical programmes. This varied and highly fragmented landscape has shaped the ways populations understand and seek care.

To grapple with that legacy, this paper examines a particular example of medical care in context: screening for human African trypanosomiasis (HAT or sleeping sickness) among the displaced populations inhabiting post-conflict Nimule, South Sudan, between 2005 and 2010. The strategic location of Nimule Town and surrounding areas, where the Nile intersects the Ugandan border, has often served as a fertile mixing ground between human, tsetse and parasite populations. HAT was first identified here in 1914, but the majority of cases reported since have been associated with war-related migration, beginning with the northwards repatriation of Sudanese Madi populations from endemic areas of Uganda in the 1970s after the first civil war (M. Hutchinson, 1975), followed by displaced Ugandan Madi refugees ten years later (Harrell-Bond, 1986; Snow, 1983). As the Dinka-led rebellion of the second civil war spread south in 1989, Madi people again sought refuge beyond the border and civilians and soldiers from all areas of the country funnelled behind the Nimule frontline, rapidly enlarging the local HAT reservoir (J. A. Ruiz, 2005). A second Madi repatriation after the 2005 peace agreement amplified both ethnic tensions and epidemic risk. With each population wave to the area, modest humanitarian-led primary healthcare and nutrition programmes attempted to meet health needs, but HAT control services could never be mounted until the establishment of full-scale hospital services with the entry of Merlin, an international medical organisation, in 2005.

At the eastern edge of South Sudan's HAT transmission belt, Nimule was a late recipient of the humanitarian HAT response. Whereas by the end of the war, most humanitarian organisations in the rest of the country's hospitals were withdrawing from HAT control (Ruiz-Postigo, Franco, Lado, & Simarro, 2012), Nimule hospital was able to benefit from the substantial domestic technical and programmatic capacity created over the last decade by expert organisations such as Médecins Sans Frontières (MSF). At the encouragement of the World Health Organisation (WHO), specialist South Sudanese clinical officer, nursing and laboratory staff were recruited to Nimule from an MSF programme winding down in Kajo-keji in 2004. As the area's 1% prevalence and humanitarian best-practice dictated, these staff conducted active screening of populations in the area. With limited resources for implementation, the programme could only achieve modest population coverage of active screening but was able to institute a robust passive screening and in-patient treatment service, available to patients on-demand through the hospital lab.

By the time of our field work in 2008, a strange epidemiological pattern had emerged. Despite higher HAT prevalence levels in the local Madi population, the passive screening service was used far more often by the displaced Dinka population. This post-conflict context therefore presented an ethnographic puzzle: why would an ethnic minority displaced population be better served than a

returnee ‘host’ population by a vertical humanitarian programme led by mainly indigenous area workers? Using an ethnographic approach and a combination of qualitative and quantitative methods, we draw insight from the testing experiences and expectations of patients, as well as our observations of the evolving configuration of service delivery in this humanitarian programme, to understand: (i) why, contrary to expectations, Dinka people were more likely to test for and be detected as cases of HAT than Madi; and (ii) what influence the programme had on differential HAT treatment-seeking and case detection. By studying these behaviours in recent historical context, we consider the legacy that such humanitarian programmes create as they are passed on and scaled down.

The paper begins with a description of humanitarian HAT programmes and the wider empirical and theoretical context. After a note on method, we present data collected by Merlin and analysed by us to describe the differences in treatment-seeking behaviour in more detail. We subsequently compare the treatment-seeking contexts and logics of these Dinka and Madi populations, and provide possible interpretations of the unexpected testing behaviours. Our discussion points to ways in which these insights can inform future humanitarian practice.

## Background

Over the last three decades, medical humanitarian organisations such as MSF, have largely been credited with ‘waking up’ the global public health community to the need to control human African trypanosomiasis (HAT or sleeping sickness) (Corty, 2011; d’Alessandro, 2009; Redfield, 2012c). As one of the least researched and most deadly of the neglected tropical diseases (NTDs) (Balasegaram, Balasegaram, Malvy, & Millet, 2008; Jannin, Simarro, & Louis, 2003), HAT in many ways accommodates a humanitarian ideology of engagement based on short-term and intensive ‘relief’ (Redfield, 2010). First, HAT mainly affects poor communities in remote and conflict-affected areas of central Africa where health infrastructure and political will to respond to public health needs are weak. The lapse of chronic ‘endemic’ conditions into uncontrolled ‘epidemics’ or ‘emergencies’ (Hasker et al., 2012) can be considered an indicator of state failure, providing ideological justification for international agencies to intervene and take responsibility for the well-being of affected populations. Second, HAT is considered to be a ‘tool-deficient’ disease (MSF, 2012) or, more precisely, a disease for which the standards of treatment, surveillance and prevention are deemed too complex for use at community or primary healthcare level (Simarro, Diarra, Postigo, Franco, & Jannin, 2011; Tong, Valverde, Mahoudeau, Yun, & Chappuis, 2011).

In light of these gaps, MSF is instrumental in managing the disease globally. Known from its inception as an international organisation unique in its focus on patient care (as opposed to public health promotion only) (Bradol, 2011), MSF has treated over 50,000 cases (MSF, 2012), equivalent to 10-15% of the global reported *gambiense* burden since its first intervention in 1986 (estimated using data from (Simarro, Jannin, & Cattand, 2008; WHO, 1998, 2000, 2013)) and perhaps 20-30% of cases during the epidemic peak (Corty, 2011). In the case of HAT, MSF has ostensibly succeeded in “offering tangible proof that it is possible to do better” (Bradol, 2011, p. 217).

To address the “almost amateur situation” in which they initially found themselves (Corty, 2011, p. 136)(d’Alessandro, 2009), MSF modernised a vertical method of active screening and treatment of populations via mobile teams (Corty, 2011), an approach credited with continent-wide reductions in

HAT burden before the 1960s (Louis, Simarro, & Lucas, 2002; Simarro et al., 2008; WHO, 2000, 2013). They further developed procedures for community sensitisation, team and patient transportation, lab diagnosis via algorithms with contingency methods to reach populations off the beaten track, new treatments, detailed clinical protocols, and patient information systems that could be used to trace patients across front-lines and international borders. These systems not only allowed them to operate with relative autonomy, but also to share these innovations and influence the strategic decision making and practice of other humanitarian organisations and donors responding to HAT emergencies, thereby shaping the modern culture of HAT treatment provision.

As active screening is now practiced, statistics are kept on the populations served to provide evidence of equity in programme reach and coverage (Bouchet, Legros, & Lee, 1998), sometimes allowing analysis of relative attendance of ethnic populations in conflict, or among vulnerable groups common to insecure settings such as internally-displaced persons (IDPs) (Kaba et al., 2006). However, apart from a few notable studies from non-humanitarian groups (Mpanya et al., 2012; Robays, Bilengue, Van der Stuyft, & Boelaert, 2004; Robays et al., 2007), little attempt has been made to understand the socio-cultural dynamics that underlie HAT treatment-seeking and attendance at services in the rapidly changing, ethnically heterogeneous social environments where humanitarian HAT interventions take place. For instance, of 37 research articles on HAT authored by MSF (available at <http://fieldresearch.msf.org/msf/>), one refers to patient risk factors (Robays, Ebeja Kadima, et al., 2004) and none refer to the social context of the populations they serve. Arguably, humanitarian organisations don't need to pay attention to the particular needs and behaviours of demographic sub-groups in HAT, so long as high or 'blanket' population coverage of communities considered epidemiologically at risk is achieved. Indeed, a certain degree of ignorance about the settings where international humanitarian organisations operate has been suggested as a characteristic that preserves the position of ex-patriot managers outside of complex local alliances, thereby facilitating effective emergency response (Redfield, 2012b). While arguably necessary, this 'distance' tends to engender a homogenized view of HAT-affected people as a singular global patient community (Redfield, 2012a).

The limitations of this bird's eye perspective are mitigated by the resources uniquely available to international humanitarian medical organisations (d'Alessandro, 2009; J. Ruiz, Richer, & Meru, 2008; Simarro et al., 2011). But following successes in reducing continental disease prevalence (Simarro et al., 2008), HAT's emergency-status is becoming increasingly tenuous and resources for humanitarian-led control increasing scarce. Since the mid-2000s, HAT programs across the continent have gradually become the province of less highly-resourced government or other development partners (Jannin, Simarro, & Franco, 2011; JJ Palmer et al., 2013; Simarro et al., 2011; Tong et al., 2011; Yun, Priotto, Tong, Flevaud, & Chappuis, 2010). In many cases, an inability to conduct active screening has not prevented local health actors from maintaining passive screening services, whereby patients and referring health workers initiate presentation to central facilities. These services are routinely available to populations alongside and in between active screening campaigns but, as a method on their own, are characterised in terms of their comparative deficiencies (e.g., inaccessibility, inequity and ineffectiveness of identifying asymptomatic cases) since the onus of diagnosis rests on patients (Tong et al., 2011; WHO, 1998). Indeed, addressing the several dimensions of access (including physical, economic, informational and discriminatory) is potentially more important to ensure intervention effectiveness in humanitarian than development settings (Blanchet et al., 2013). The public transitioning from active to passive screening services may also

have important political and symbolic repercussions for a hospital or organisation's relationship with its intended service users. While the complexity of passive case detection is recognized (Bukachi, Wandibba, & Nyamongo, 2009; Hasker et al., 2011; Kegels, 1997; Odiit et al., 2004), patient and health worker perceptions of passive screening services for HAT remain relatively unexplored, as do the effects on health-seeking behaviour after a change in HAT programme strategy. We suggest that in post conflict settings, where active screening as humanitarian best practice in HAT is more difficult to achieve, programmatic exit strategies should take into account the treatment-seeking behaviours of beneficiaries and the legacy of care that their programmes leave behind.

## Methods

To understand the history and implementation of HAT control strategies in Nimule and South Sudan, we reviewed: Merlin HAT programme documents, documents from MSF given to Merlin between 2004 and 2010, and wider published and grey literature on HAT and medical service delivery during Sudan's civil wars. We augmented this literature review with unstructured interviews with Merlin hospital staff and programme managers at local, country and international levels.

Field work on Merlin's HAT programme in Nimule was undertaken by the first author (JP) during two periods over 10.5 months, September to November 2008 and April 2009 to March 2010. This fieldwork included: 33 patient case studies of HAT treatment-seeking and passive case detection, 16 focus group discussions (FGDs) with Dinka and Madi lay people, field diary notes from daily observations of passive HAT screening and treatment services, observation of active screening in 2008, 19 interviews with health workers, brief interviews with 46 non-case patients presenting for screening and statistical analysis of demographic and HAT test outcome data routinely recorded by the programme (see (Jennifer Palmer, 2012) and (JJ Palmer et al., *In press*) for further details).

Patient case studies were conducted with 16 Dinka patients, 13 Madi patients and 4 patients from other Equatorial tribes (Acholi, Lotuko, Lolubo). Observational data were recorded from the beginning of patients' contacts with the hospital using a semi-structured contact summary form and included: patient accounts recalled by lab staff; observations of patient behaviour and accounts given to medical staff during admission exams; summaries and impressions from all interviews; and patient health data. In-depth research interviews with patients and/or carers (if patients were unable to consent) were conducted after admission, in most cases on the same day, complemented by shorter follow-up interviews over the patient's stay. Interviews were also completed with a family member or friend knowledgeable about the case with the patient's consent. Contact summary forms were discussed regularly to summarise the research team's on-going impressions of the critical events that led to a patient's successful detection, to identify gaps or inconsistencies in treatment-seeking histories and to guide further data collection and analysis for the case. All case study notes and transcripts were coded line by line using NVivo qualitative analysis software (QSR International, Melbourne, Australia) and matrices that summarised and displayed data by topic were created to facilitate cross-case classification of case studies.

FGDs with natural groupings of community members (e.g. women's groups, 'youth' groups above 18 years, teachers and customary court attendees) were used to explore wider attitudes and experiences of treatment-seeking in adult Madi resident/returnee and Dinka IDP communities. FGDs were held separately for tribes (Din: Dinka, Mad: Madi, inside and outside Nimule) and genders (W:



women, M: men) with 8-10 people, lasting 45-90 minutes. They were facilitated in local languages led by a Madi or Dinka researcher trained to ask questions and probe superficial responses in a neutral way (Dawson, Manderson, & Tallo, 1993; Haaland, Molyneux, & Marsh, 2006). A second bilingual researcher took notes in English and a foreign researcher (JP) took field notes on non-verbal communication and the setting. Field notes were made by the three researchers after each FGD. FGDs were digitally recorded and fully-transcribed and translated into English for analysis in NVivo and discussion with the research team.

Almost all quotations presented from study participants are translations from local languages. In a few instances, grammar and spelling have been corrected to improve readability, while attempting to preserve the mode of expression. Only pseudonyms are used to discuss individuals in this study.

### **Ethics statement**

This study was approved by the London School of Hygiene & Tropical Medicine's ethical review committee and the Ministry of Health, Government (now Republic) of South Sudan. All study participants provided written informed consent or witnessed verbal consent if unable to write. Further approval and permission was sought from district and local authorities before interviews and discussions.

### **Passive screening equity in Nimule**

Between 2005 and 2010, Merlin staff conducted three small-scale (<30% coverage) active screening campaigns: two surveys in 2005 and 2006 (Franco, 2006; J. A. Ruiz, 2005) targeting mainly Dinka IDPs, the majority population in Nimule immediately after the war, and a third in 2008 coinciding with large-scale Madi repatriation (Figure 1). Many IDPs left Nimule in anticipation of this repatriation and therefore constituted a minority population in the area between 2008 and 2010. Community sensitisation for these campaigns typically involved meeting with local government, tribal and military authorities 2-4 weeks before a campaign to request that public announcements about the screening be made to their constituents. On the morning of a campaign, lab staff would move through villages on foot with loud speakers telegraphing the disease's symptoms, the social consequences of the disease and inviting the population to screen. Further HAT educational messages would be given as people waited in line.

Despite these small campaigns, in the first five years of the HAT programme (2005-10) passive screening was the approach responsible for screening and detecting the majority of people and cases (Table 1). Indeed, high passive rather than active screening was thought to be responsible for the reduction in prevalence suggested between the 2005 and 2006 surveys. Passive screening service utilisation rates did not, however, reflect the distribution of populations from which HAT cases would be expected to come.

Despite surveys indicating that HAT prevalence was higher in resident Madi populations than in Dinka IDPs (2006-8 survey mean 1.8% vs. 0.5%, respectively,  $p$ -value  $<0.05^1$ ), between 2008 and 2010, IDPs were around 75-times more likely to be tested for HAT at Nimule hospital, constituting the majority (93.6%) of patients passively screened in the programme (Table 1 and (Jennifer Palmer, 2012)). Throughout the programme, most Madi residents were at a geographic disadvantage in



accessing HAT screening services because of the distance they lived from the hospital, but even when these differences in distance are accounted for, Dinka IDPs were still more likely to be tested, identified and treated (Figure 2). IDPs and patients closer to the hospital were furthermore likely to be in an earlier stage of disease (52.0% of IDP cases in stage 1 vs. 25.7% of resident; 48.9% of cases from Nimule and neighbouring payams in stage 1 vs. 28.6% of cases further away, both  $p < 0.05$ ).

## Shifting places, shifting values

The flight of most Dinka IDPs to Nimule was in response to a series of attacks in late 1991 known as the Bor Massacre, one of the most violent periods of the civil war in Sudan. In these attacks, a million head of cattle were slaughtered or looted, tens of thousands of people killed or abducted and 250,000 people, amounting to 70% of the Bor Dinka population, fled the area (Jok & Hutchinson, 1999; Wheeler, 2005). In the unfolding of this violence, many Dinka people interpreted their experience as a consequence of misplaced faith in traditional religions in a modernising world. Preceded by a social-engineering programme of ‘secularisation of warfare’ led by the rebel Sudan People’s Liberation Army (SPLA) in the 1980s which stripped killing of its moral significance (S Hutchinson, 1996, 2001; SE Hutchinson, 2005), evangelical Christianity had been gaining popularity (Nikkel & Lemarquand, 2005; Wheeler, 2005). An influential Christian prophet had foretold the massacre if people did not repent their godlessness, and though traditional Dinka priests and shrine guardians sacrificed countless more bulls to the spirits (*jok*), the raids continued (Wheeler, 2005). In response, communities burned their shrines en masse and thousands were baptized such that by the end of the 1990s, as many as 90% of Bor Dinka identified themselves as Christian, mainly Episcopalian, including many of the traditional priests and diviners<sup>ii</sup>. Flight to Nimule therefore coincided with a period of radical social upheaval in which many people were seriously questioning traditional methods to cope with the insecurity surrounding them and looking to replace these with new systems of thought.

In Nimule during the period of this research, it was commonly said that, before becoming IDPs, instead of seeking treatment at hospitals, the people of Bor ‘just moved with their cattle’. There were no health clinics or medicines and if someone became sick they could be treated with local herbs. More rarely, sick patients could be taken to the hospital in Bor Town but this was characterised as an ‘Arab hospital’, built by the government in the 1980s and associated with a northern bid to assert ownership of the region, and therefore largely rejected. With the influx of humanitarian and faith-based religious organisations which deemed Nimule-based IDP needs outside of state attention and capacity, these medical programmes represented a largely new type of care attractive to Dinka people. By the 2000s, Dinka people had come to conceptualise the time before the war as a time when western medicines were denied to Dinka populations by the government. The time when services were seen as best was the short time when John Garang (the now deceased Dinka leader of the SPLA) was with them directing the battle from Nimule, his personal efforts in bringing about hospital services to Nimule through international humanitarians widely recognized:

Participant 2: we got drugs from white people through the good links made by Dr. John Garang. When Arabs mixed with us there were no drugs coming to us. [...] we have malaria, worms like tape worms, amoeba, giardia and gonorrhoea. There is lack of blood due to

improper feeding. Therefore, you the white people, come with your drugs and make a hospital and we will suffer no more.

[...]

Participant 12: This issue [of drugs] is also a big deal because it is connected to life. It is like the CPA [comprehensive peace agreement, which ended the 21 year war]. (TSNimDinM1)

A feeling of ownership over hospital services may thus be important in understanding Dinka enthusiasm for them and help to contextualise the subsequent complaints of 'tribalism' in Nimule Hospital that we observed after Madi repatriation to the area. But these appeals for western medicines, invested with a 'super-cultural' capacity (Reynolds-Whyte, 2002) associated with progressiveness, literacy, autonomy and peace, were also important for what underlay them: a feeling of insecurity from, and interest in controlling, western illnesses.

Through an evolving experience of ill health, Dinka IDPs therefore appear to have learned to define new categories of illness which reflected the diagnoses available to them in humanitarian health programs through a process of schismogenesis, by which increased consciousness about a problem creates increased demand for a solution (Nichter & Vuckovic, 1994). These diagnoses included malaria, amoeba, giardia, the HAT diagnosis available at Nimule Hospital, even 'mental illness' and malnutrition which became partly secularised and 'medicalised' (Reynolds-Whyte, 2002). In FGDs, all of these illnesses were judged to be more common since the war and they became relevant in new conceptualisations of illness, affliction and control over health:

Participant 2: [Before the war] mental illness was not common. It used to be with particular people, like those who have evil's powers [*tiet* or diviners/witch doctors], but now it has increased because of illnesses like typhoid, sleeping sickness and OV [onchocerciasis]. (TSNimDinM1)

Participant 10: In our land we ate fruits and milk which prevented illness well, but now milk has caused brucellosis. (TSNimDinW1)

From this dizzying array of possible new diagnoses, health workers and their diagnostic tests became instrumental in singling out health threats and, critically, providing effective medicines to treat them. But as people were coming to terms with how to control new diseases associated with suffering and displacement, IDPs worried about returning to their home area which they conceptualised as less developed, where access to doctors, tests and medicines for these diseases would be diminished. HAT was treated no differently from other biomedical diagnoses in being thought of as present but unrecognised in Bor before the war:

Patient's grandmother: Before when we were in Bor, we didn't have health facilities like for testing sleeping sickness, so even if somebody died of sleeping sickness, nobody would know [...] you could not know because there was no screening taking place. Even treatment of sleeping sickness wasn't there. (Dinka patient case study, HATPASS04)

These concerns would have been reinforced by the numbers of HAT patients making the minimum two-day vehicle journey to Nimule Hospital from Bor for screening and treatment in the post-war period (110 people screened, 15 cases detected in Nimule, 2005-10), because although Bor is not

considered endemic for HAT (FAO, Undated), IDPs have returned there from endemic areas with the illness and now require HAT services. Consequently, for Dinka IDPs, the risk from HAT coinciding with displacement was associated more with a new era of biomedical disease recognition than with fear of a new geographic area of endemicity. Controlling that risk to health was probably largely conceptualised more in terms of access to services, rather than in terms of moving away from areas perceived as dangerous in and of themselves.

### Trying tests in a Dinka space

Perhaps, then, successful HAT detection among the Dinka community in Nimule could be explained by patient motivation –a particularly ‘active’ form of treatment-seeking. However, critical too, was knowledge of the best places to access a variety of tests. As Dinka patients themselves explained, this led naturally to HAT diagnosis:

HATPASS22: For me I had just been after treatment in private clinics but God [...] protected me till I came here. [...] I went for a sleeping sickness test because I have done many tests, only sleeping sickness is what I have not tested.

Husband of HATPASS30: The only test that I forgot to take her for was this sleeping sickness test. It never came into my mind that I should also try this test, but recently I just thought of it.

Several factors may explain how these active treatment-seekers thought of including HAT as a diagnostic possibility. Whereas active screening aims were never achieved in the Nimule programme, the expertise and remit of the MSF-trained staff did allow the establishment of robust passive screening and treatment services within the hospital, including a renovation of the hospital lab facilities to create a separate room, door and patient waiting area dedicated to HAT screening and follow-up testing of large volumes of patients. As in the MSF programme, previously-treated patients were always allowed to come directly to the HAT area of the lab to report for their painful follow-up lumbar puncture testing so as to minimise barriers for a population already difficult to attract. Furthermore, because the specialist HAT lab staff were initially exclusively dedicated to HAT activities, when they were not conducting active surveys they could screen new patients for HAT on-demand, and encouraged HAT patients to bring their friends and neighbours for testing.

Group discussions with Dinka people suggested they commonly felt an undercurrent of discrimination at Nimule Hospital. This was especially important in the outpatient department (OPD), patients’ first point of care for most services in the hospital, since there were very few Dinka health workers that patients could easily communicate with on the hospital staff. Similarly, the language of the HAT testing service was mainly Arabic, the lingua franca between tribes of different ethnicities because Merlin could never recruit sufficiently skilled Dinka staff to serve their IDP patients, relying instead mainly on Madi, Kuku (from Kajo-keji) and Ugandan health workers. While a feeling of discrimination may have dissuaded OPD use, however, it seemed indirectly to sway Dinka people towards HAT testing:

Participant 7: You may have sleeping sickness, but when you go through OPD, you know, everything there is [tribal] injustice, everywhere. Let me say, even in the hospital and even any corner, when you go there you will be delayed and you are actually suffering! So you

need to go direct to laboratory check-up rather than delaying your time in OPD.  
(TSNimDinM2)

The policy of an open door to would-be HAT patients at the lab was therefore a welcome respite for Dinka treatment-seekers. On most mornings in the hospital there was a visible cluster of Dinka people waiting outside the HAT lab. This created a *de facto* 'Dinka space' in the outpatient areas of the hospital quickly recognisable to almost all hospital users attuned to patterns of ethnicity in the tribally-politicised context in Nimule. This attracted Dinka HAT patients such as Abraham in 2009 who had never heard of HAT before but, suffering from a chronic headache, knew that he wanted to get his blood tested at the biggest hospital he knew of, for as many diseases as he could (HATPASS27). After approaching a group of Dinka adults already knowledgeable about the rules of patient access in the hospital, they shared this useful short-cut; he joined the shorter passive screening queue rather than the long one at the OPD and screened positive that morning.

The particularities of this service were clearly monitored outside of the hospital, with, for example, Dinka people presenting for passive screening on hearing from other testers at church that CATT testing reagent was again available after a period of stock-out. Dinka health workers outside the hospital in the private sector were also playing a part: "we give health education in all these churches and say, if you are going for a journey like to Bor you can be tested [for HAT], then you go" (HCWint13). By 2009, this information exchange required no prompting from the HAT programme itself. Dinka community members had reconciled the (never formally communicated) Merlin case detection 'strategy change': "that [active screening] was sort of a sensitization to the community, so that now people know where to get a HAT test" (non-case Dinka patient presenting for passive screening, when asked why the mobile team no longer visited her village).

The story of Abraham's detection was influenced by a long series of events, and a constellation of social, political, geographical and medical factors. First, a culture supportive of testing empowered him to keep 'trying' at a bigger facility. This facility was accessible within two hours' walk but other Dinka people came from much longer distances away. Once there, it was the Dinka-friendly space that initially attracted Abraham to the HAT lab. The shorter queues were a major incentive. But he wouldn't have known about the service at all without sufficient others having learned about the service before him and come to use it –and probably the original efforts of the HAT programme staff to promote it four years earlier according to medical humanitarian best practice. In this way, HAT testing at the hospital had become sufficiently known, valued, practiced, trusted –in effect, routine– in this Dinka community that HAT detection could largely be explained by the fact that patients simply considered it the next logical test to try.

## Living without tests

In contrast to the Dinka, Madi people have had a long history of engagement with formal medical services and experience with HAT disease, both in their indigenous area of South Sudan and in areas to which they were displaced during the civil wars (Tim Allen, 1996; Harrell-Bond, 1986). Well-established Madi discourses about HAT symptomatology emphasise HAT's devastating effects on the wider community (Jennifer Palmer, 2012). Like Dinka IDPs, Madi returnees saw themselves as sicker now than before the war, but they attributed this primarily to poor health services symptomatic of a wider lack of investment in returnee welfare by government and non-governmental organisations.

For many, services were easier to access in Uganda, including for HAT where more people were typically tested via active rather than passive screening (Checchi, 2010; Hutin et al., 2004). Returnees described their feeling of neglect as being buried in ‘the bush’, that which is traditionally ‘outside’ the domestic sphere or the attention of government (T Allen, 1989):

Participant 4: What is strange for us here are the health facilities. [...] Sometimes this health unit will stay for two to three months without medicine, so if we feel sick then we just use herbs. We are staying here like we are buried. There is no good road and because of this, if you move around the village you will find a lot of graves of our children who were supposed to help us in the future. Before we were brought, the government told us that every service would be available including a health unit and a road but they are not. (TSPagMadiW1)

For returnees, the lack of testing services was representative of the type of health service development being denied to them, with tests often described as not ‘yet’ reaching their areas. Thus, for a Madi person to know if there was ‘something in the body’ he would have to travel to Nimule, a situation considered profoundly unfair since most illnesses, including HAT, were seen as more frequent or worse in the rural returnee environment.

Beyond symbolism, geographic distance from passive screening services also may have functioned as a barrier to utilisation through inhibiting the processes of information exchange which made services popular with Dinka patients. In Madi communities, as in Dinka, public announcements about passive screening services were made in churches, at returnee reception events, and during active screening in 2008. With only one active screening campaign and a drop-off in passive screening service availability precisely at the time when most Madi people were returning to Nimule (service available 201-265 days annually in 2005-7 vs. 149-152 in 2008-9), however, it is possible that returnees received a smaller ‘dose’ of communication about the service than IDPs (Figure 1). Indeed, by 2010, still the only documented cases of self-referral among Madi patients were long-term residents who had been living in Nimule at the time of the 2005/6 active screening campaigns. Unlike in 2005/6 when health workers promoted HAT services to mainly IDP populations, there was no corresponding peak in service utilisation by ‘residents’ during the second, returnee-focussed phase of service promotion in 2008 (Figure 2). During a health worker training intervention to increase HAT referrals to the hospital, transportation and opportunity costs were identified as the most important barriers to referral completion for patients living long distances from the hospital (JJ Palmer et al., *In press*). However, we could identify little convincing evidence from case studies or FGDs that self-referral for HAT was integrated into the common treatment-seeking culture in rural areas (e.g. through ‘trying tests’ or more specific HAT referral behaviours (Jennifer Palmer, 2012)). There appeared to be relatively few people knowledgeable about the service and actively seeking HAT tests who were prevented from doing so because of distance. For reasons difficult to discern, the type of medical decision-making behaviours and socio-political circumstances that could lead to Madi patient-initiated use of passive screening services instead appeared restricted to a small group of long-term residents in Nimule Town –at least for the time being.

## Discussion

In post-conflict South Sudan, donor-funded resource constraints in the Nimule Hospital HAT programme prevented full implementation of the highly-successful medical humanitarian model of

HAT service provision. Although unable to provide comprehensive active screening services, humanitarian health workers experienced in this model were able to leverage the time and physical spaces available within the hospital to offer an open-door policy of provision to any patient who wanted to be tested. Health workers communicated this information to both Madi and Dinka patient communities, but for different contextual reasons, successful treatment-seeking behaviour developed in Dinka communities and not Madi.

Examined in terms of service equity, these data suggest a serious programmatic deficiency in ensuring access to screening for all vulnerable groups in the area—a failure of medical humanitarian best practice—with Dinka IDP patients distinctly better served than Madi. In a post-conflict context when development of sustainable behaviours under new resource constraints might be the more important criteria for evaluation, this programme could alternatively be judged a partial success. While a positive effect could not be detected in rural Madi populations, there were probably no ill effects; without sufficient resources, the programme just didn't work in this setting. The programme was, however, able to create a community of Dinka test seekers who now generate demand for a service that can be provided in this new service delivery environment. This was a positive development in this setting and is arguably an encouraging, if unexpected, legacy of staff of Merlin, MSF and other humanitarian organisations that influenced current HAT control norms in South Sudan and central Africa. Interestingly, a potentially similar phenomenon was observed in the MSF Kajo-keji programme between 2000 and 2002. There, patients were more likely to attend follow-up screening if they were IDP (also mainly Dinka-Bor), living closer to the hospital and detected passively, irrespective of clinical markers that might have prompted behaviour in response to symptoms (Chappuis et al., 2004). Neither the Merlin nor the MSF HAT programme explicitly targeted its services to any ethnic or residency group in particular, yet, in this particular medical humanitarian context, minority Dinka ethnicity and/or IDP residency status appeared to profoundly and positively shape these patients' access to care for HAT.

But how exactly was this accomplished? Patient treatment-seeking behaviour is known to be heavily influenced by structural, social and political context (Farmer, 2005; Lock & Nguyen, 2010). For both Madi and Dinka people, tests were linked to modernity, development and the state (or state-like humanitarian organisations). In Nimule, Dinka IDPs appear to have been attracted to HAT services in the hospital because it was representative of the kind of progressively improved access to healthcare that Dinka people fought and suffered for and that could demonstrably control the unfamiliar threats to health associated with displacement and war. Entwined with moral and political aspirations, actively participating in diagnosis through 'trying tests' was therefore empowering but also an important behaviour that could lead to HAT detection—if HAT was one of the tests Dinka people thought of to try in the normal course of treatment-seeking.

For Madi people, tests were part of the 'social contract' (Bloom, Standing, & Lloyd, 2008) that the state agreed to provide when Madi people agreed to return to South Sudan, but which, for the moment, they were leaving behind in Uganda. Importantly, being unable to access tests physically also probably meant that Madi people had less opportunity to experiment and learn about health and healthcare in this new environment.

Encouraging populations to consider HAT screening during the process of treatment-seeking therefore requires more than simply announcements from health workers. Research in other rural

African contexts suggests that people learn about the quality and therefore usefulness of health services through the treatment-seeking experiences of their neighbours. Information is shared more often about new services, about services for diseases which are rare or serious, and over shorter distances (Leonard, Adelman, & Essam, 2009) and this may have improved trustworthiness of the HAT service in Nimule. Small, cohesive social networks also transmit information more quickly (Blanchet & James, 2011), so it is possible that the necessary channels of formal and informal communication were less developed among recent returnees to mainly rural areas than among long-term, urban Dinka IDPs. As in private sector interactions (Nichter & Vuckovic, 1994), the 'transactional character' of a self-referred service worked to reduce barriers related to asymmetric patient-provider power dynamics. In particular, this model may have appealed to Dinka people who otherwise perceived access to hospital services as controlled by health workers of a tribe that was contesting their right to reside in Nimule, close to modern infrastructure. Finally, information may have spread quickly in the Dinka population with the perception of a need for urgent learning, related to the amount of access Dinka people could expect in the future. While HAT control as active screening is experienced by humanitarian organisations in time-limited response terms, driven mainly by the logic of emergency and exception (Geissler, Rottenberg, & Zenker, 2012; Redfield, 2012a), Dinka populations in Nimule did not expect to be able to reliably access even the more sustainable passive screening services on return to Bor.

In this context, both Dinka IDPs and Madi returnees articulated a strong desire to be included in durable and equitable systems of screening and healthcare. While the humanitarian model of HAT control through active screening is arguably more even-handed than passive screening, its comprehensive approach is rarely feasible in a post-humanitarian funding context. In Nimule, an open door policy to passive screening services partially preserved that commitment to equity but required that patient populations exercise agency to access them. Agency, in turn, was fostered (among Dinka IDPs) or not (among Madi residents) by the different set of cultural values, political histories and landscapes of service provision—including humanitarian ones.

This study suggests that, in common with other time limited 'interventions' that (often inadvertently) transform health-seeking behaviours (e.g. clinical trials (Kelly et al., 2010)), relief programmes leave a lasting impression on the provision of care. To help ensure that this legacy is a positive one, medical humanitarian approaches need to better understand their potential impact and plan exit strategies that provide guidance on how the interventions they deliver can be adapted in non-ideal circumstances.

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## Tables

**Table 1. Characteristics of people screened and human African trypanosomiasis cases detected by screening method, April 2005 to April 2010**

	Active screening			Passive screening <sup>a</sup>		
	Cases n=136	Patients screened n=13,815	Case- detection prevalence %	Cases n=606	Patients screened n=21,690	Case- detection prevalence %
Overall prevalence	136	13,815	1.0	606	21,675	2.8
Gender						
Male	83	7,045	1.2*	318	9,906	3.2*
Female	53	6,770	0.8	288	11,780	2.4
Age						
0-14 years	28	6,870	0.4*	94	6,154	1.5*
≥ 15 years	108	6,945	1.6	507	15,351	3.3
Residency status <sup>b</sup>						
Residents	72	4,043	1.8*	81	1,085	7.5*
IDPs	39	7,291	0.5	496	20,301	2.4
Outside county	0	0	-	28	295	9.5
Distance from hospital <sup>c</sup>						
Hospital payam	55	5,756	1.0	457	19,023	2.4*
Neighbouring payams	68	6,208	1.1	103	2,157	4.8
Distant payams	13	1,851	0.7	17	206	8.3
Outside county	0	0	-	28	295	9.5
Referral route <sup>d</sup>						
Self-referred				28	816	3.4*
Health worker-referred				7	56	16.4
Other				3	5	60.0

<sup>a</sup> Data were missing for some demographic characteristics.

<sup>b</sup> Residents were Madi ethnicity in the hospital (<2 hours walk) and neighbouring payams (between 2 hours and 1 day's walk) and Acholi in distant payams (>1 day's walk away). IDPs were mainly Dinka.

<sup>c</sup> Cases were detected actively or passively from 29/34 villages in the hospital and neighbouring payams, village AS prevalence range 0-5.8%.

<sup>d</sup> Referral route data was collected over 6 months only (May-Oct 2009).

\*Chi-squared test p-values for comparison between categories are significant at <0.05.

## Figures

**Figure 1: Schematic of population movements and human African trypanosomiasis (HAT) programme events in the Nimule focus over time**

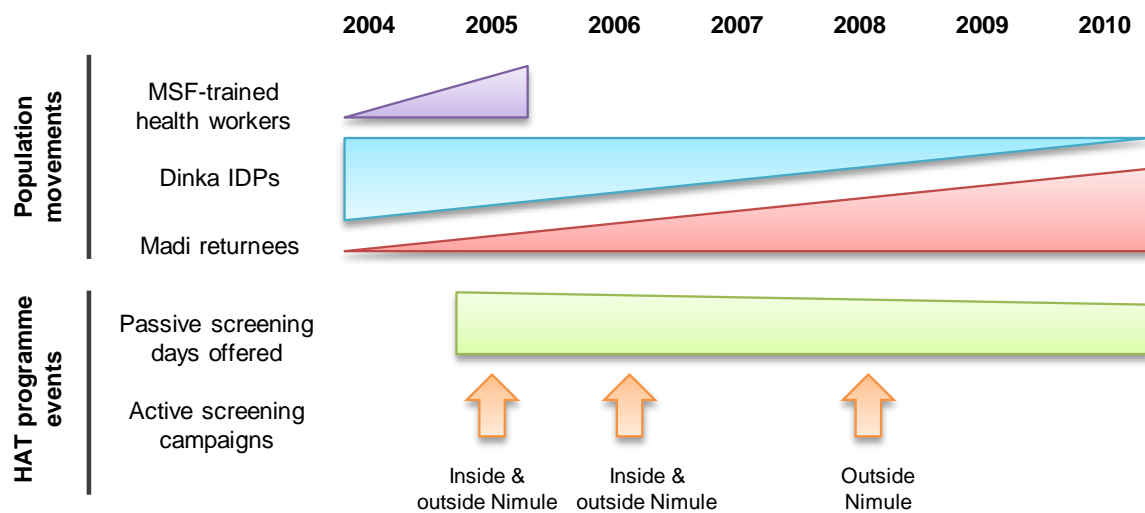


Figure legend:

Population movements: Healthcare workers trained in Médecins Sans Frontières (MSF) HAT programme techniques came from Kajo-keji to Nimule in 2005 to initiate the Merlin HAT programme. At that time, Nimule hospital served the majority Dinka internally-displaced person (IDP) populations living inside and outside Nimule Town. Over time, many IDPs left in anticipation of Madi populations returning, particularly in 2008. Madi returnees became the majority after this point.

HAT programme events: When MSF-trained health workers initially joined the programme, they were allocated exclusively to HAT activities. Over time, these staffs were integrated into the lab and the lab had to limit the number of days per week they could offer passive screening services to patients, particularly after 2007. Low coverage (<30%) active screening campaigns targeted mainly IDPs inside and outside Nimule in 2005 and 2006 and mainly returnees outside Nimule in 2008. In 2005, 25/2,481 people screened were detected as cases (1.0% prevalence), in 2006 this was 46/3,530 (1.3%) and 67/7,319 (0.9%) in 2008. Throughout this period, HAT detection and treatment services at Nimule Hospital were free of charge.

**Figure 2. Effect of distance from hospital and residency status on human African trypanosomiasis (HAT) passive screening service utilisation**

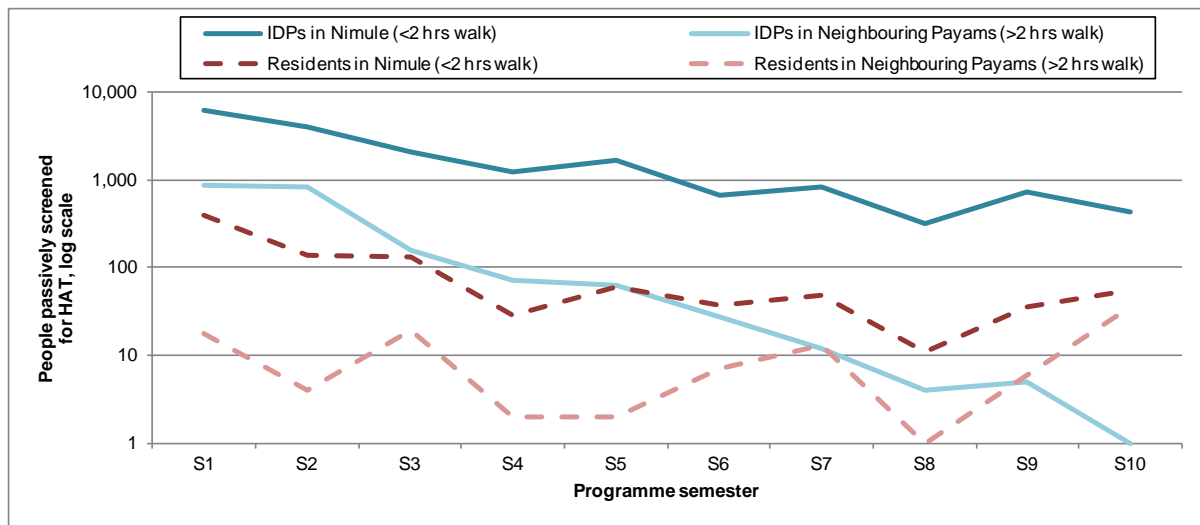


Figure legend:

Semesters (S) ran from April-September and October-March of each year, 2005-2010. This figure indicates that patients living closer to the hospital (people living in Nimule Town where the hospital is located) consistently tested more frequently than patients living farther from the hospital (in neighbouring rural payams, between 2 hours (hrs) and 1 day's walk away), regardless of residency status. Until the last year of the screening programme when most internally displaced persons (IDPs) left rural Madi areas, IDPs also consistently tested more frequently than Madi residents, regardless of distance to the hospital.

<sup>i</sup> Information on patient residency status (ie. IDP vs resident) was not collected in the 2005 survey.

<sup>ii</sup> By no means was this level of enthusiasm for Christian conversion seen in all areas of Dinkaland at this time, such as in northern Bar El Ghazal (Wheeler 2005, Jok 1999).