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Disrupting the Fatal Sleep:
Innovation and the Elimination of Human
African Trypanosomiasis in Northern
Uganda.

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PhD in African Studies

The University of Edinburgh

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Declaration

Date:

I declare that this thesis was composed by myself, that except where otherwise indicated, the research described within this thesis is my own, and it has not been submitted for any other degree or professional qualification.

Shona Jane Lee, 2019

Abstract

For more than a century, a wide variety of tools, techniques, and strategies have been deployed in attempts to control Human African Trypanosomiasis with mixed success. However, the recent development of more simple and cost-effective diagnostic devices, drug candidates, and vector control methods have culminated in renewed political commitments toward eliminating the disease.

This thesis draws on ethnographic case studies of these 'contemporary and emerging strategies' (Steinmann et al. 2015) at a critical moment between implementation and scale; where technologies form relationships and take on social connotations, and where policy struggles to become practice. These multi-sited studies provide empirical examples of how technologies of global health become commodities of governance, and objects of expertise, controversy, and advocacy.

This study critiques the global health community's fixation on technology as the harbinger of progress in sleeping sickness control, and argues that solutions continue to be overly simplistic and attentive to discrete devices. In doing so, programmes overlook the dynamic systems that govern technologies' social proximity to people.

Case studies on diagnostics and tsetse control illustrate how socially embedded technologies can become tools of advocacy by promoting horizontal forms of knowledge production and exchange. The social proximity of interventions are key drivers of sustainability, as more community embedded technologies take on, and persist through social lives of their own. Examining diagnostic capacity in the passive surveillance system reveals how infrastructures are relational as well as material, thus technology alone cannot address infrastructural paucity.

Global commitments to collaborative 'One Health' approaches to eliminating HAT disentangle in practice and become fragmented at the point of implementation. Decentralised and under-resourced district offices struggle to maintain operational cohesion, as a precarious network of health workers, entomologists, and veterinarians struggle to align vertical programmes with local priorities.

In summary, this study reveals HAT control as a fragile assemblage of actors operating in environments of uncertainty, and explores how introducing new technologies into these socio-technical ecosystems can disrupt and transform them in unpredictable ways. Due to the dominance of top-down technocratic approaches in global health, anthropological contributions to HAT programmes are widely underutilised (Bardosh, 2014). This thesis advocates critical, multidisciplinary approaches for developing adaptive, locally specific solutions to HAT in a landscape of elimination

Lay summary

This thesis examines the implementation and integration of contemporary technological strategies for controlling Human African Trypanosomiasis (HAT), and some of the prevailing challenges they highlight in tackling a complex and neglected tropical disease with closely interrelated social, environmental, and political histories amidst the present-day landscape of elimination.

The empirical body of work draws on case studies in Uganda, where two strains of HAT with different epidemiological profiles and lifecycles are being targeted for elimination by a 'One Health' coalition of international institutions and private partners. Examples focus on the introduction of a rapid diagnostic test-based passive surveillance strategy, the material laboratory infrastructures in the Ugandan primary healthcare system, the management of HAT patients and the implications of a revolutionary new oral drug treatment, and the implementation and scaling up of novel tsetse fly control methods.

The introduction of new rapid tests for gambiense HAT show how differently programmes imagine the pathways that people navigate to receive diagnosis and treatment, and the additional work that must be done by patients and health workers to make devices function in local, often resource poor contexts. The fixation on point of care tests and overall neglect of central laboratory infrastructure has dismantled HAT diagnostic workflows by undermining routine microscopy performance in referral laboratories. Meanwhile, new oral drug candidates propose to undercut this problem by removing the need for microscopies altogether, but may not fully appreciate the complex culture of expectations of care into which they will be implemented.

A concurrent challenge to all of these innovations is how they can be scaled, maintained, and their impact sustained to achieve their objectives. Sustaining pressure on the tsetse fly vector and on surveillance is critical to reaching 'the last mile' to elimination targets. However, as the case studies set out in this thesis illustrates, the social proximity of innovations is as important to their acceptability and sustainability as the physical attributes and cost-effectiveness of technologies themselves.

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In memory of Ajvir Singh Sandhu.

"To Friendship"

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Abbreviations and Acronyms

AAT	Animal African Trypanosomiasis
CATT	Card Agglutination Test for Trypanosomiasis
COCTU	Coordinating Office for Control of Trypanosomiasis in Uganda
CSF	Cerebrospinal Fluid
CTC	Capillary Tube Centrifugation
DIB	Development Impact Bond
DOTS	Directly Observed Treatment Short course
DNA	Deoxyribonucleic Acid
FAO	Food and Agriculture Organization of the United Nations
FIND	Foundation for Innovative New Diagnostics
FM	Fluorescence microscopy
GPS	Global Positioning System
HAT	Human African Trypanosomiasis
ISSEP	Intensified Sleeping Sickness Elimination Programme
LAMP	Loop-mediated Isothermal Amplification
LSTM	Liverpool School of Tropical Medicine
mAECT	Mini-anion Exchange Eentrifugation Technique
MSF	Médecins Sans Frontières
NECT	Nifurtimox–eflornithine Combination Therapy
PCR	Polymerase Chain Reaction
PPV	Positive predictive value
RAP	Restricted Application Protocol
RDT	Rapid diagnostic tests
RDT+ MS	Rapid diagnostic test positive microscopy negative
SOS	Stamp Out Sleeping Sickness
SIT	Sterile Insect Technology
SADs	Stationary Attractive Devices
VHT	Village Health Team
WHO	World Health Organisation

INTRODUCTION

The history of Human African Trypanosomiasis (HAT), or ‘sleeping sickness’, has come to be defined by moments of discovery and hubris. Decades of elegant scientific papers with “lofty notions of continent-wide tsetse eradication” (Bardosh, 2016:347), and periods where imminent elimination was proclaimed on a regular basis have been punctuated by resurgence and the repeated failure of technology to deliver the promise of conquering nature. Epidemics of HAT, both a symptom and result of the social, ecological, and demographic upheaval caused by colonial expansion at the turn of the 20th Century, spurred the establishment of Tropical Medicine, and the earliest examples of what might today be described as ‘Public Private Partnerships’ (Lachenal, 2017). In a bid to manage what was anything but a ‘neglected disease’ at the time, governments and researchers scrambled to characterise and control what came to be known as ‘the colonial disease’ (Lyons, 2002; Maudlin, 2006).

Conventional disease control approaches tend to adopt a blanket approach, overlooking complex socio-ecologies in rapidly-changing landscapes (Scoones 2014; Cunningham et al. 2017). Regimes launched centralised and coercive militarized campaigns; apparatus to govern African populations as objects of biomedical investigation, experimentation, and intervention. Consensus on the topic of control has been controversial, ‘subject to the tides of fashion and politics’ (Maudlin, 2006). Over time, targets of intervention have varied from tsetse, animal reservoirs, and population movements, to the parasite itself through chemotherapeutics. Approaches were often seated in the institutional politics of trypanosomiasis control, with colonial authorities evolving different positions between Francophone, Belgian, and Anglophone Africa, via their respective research institutions such as Institute of Tropical Medicine Antwerp (ITM) and the Liverpool School of Tropical Medicine (LSTM); one investing largely in medical

interventions such as diagnostics and drugs, while the latter focused on the tsetse vector (Scoones, 2014).

Yet after more than a century of efforts, the tendency of HAT to exhibit long periods of endemicity followed by large-scale epidemics led to the control and management of HAT being dubbed a “failure of both science and public health” (Molyneux, Ndung’u, and Maudlin 2010:2), reflecting a sea change in the global health community’s attitude toward conventional control approaches. Prolonged periods of neglect in disease management during endemic periods, with little or no response until human cases reached alarming levels would no longer be acceptable now that the tools to prevent it were to hand (Welburn et al., 2016; Acup et al. 2017). Now came the time for partnerships and political commitments to ‘stamp out sleeping sickness’. Control strategies are driven by various professional and institutional interests; people have built careers on HAT control after all. Thus research and intervention programmes are inherently “deeply political, and socially embedded in long histories” that reflect how scientists frame problems and their solutions (Scoones, 2014).

The idea that researchers should emerge from their siloes and work in collaboration has significantly reconfigured medical research. Driven by scientific developments and major funding initiatives, such as those of the powerful and influential Bill and Melinda Gates Foundation, the scale and scope of global health research has proliferated in response to calls for more efficient and collaborative knowledge production (Parker and Kingori, 2016). As part of this response, the One Health framework emerged as part of an assemblage of international institutions and policy initiatives that have coalesced to “promote particular ways of conceptualising, and doing, global health” (Smith, Taylor, and Kingsley, 2014:1). Today, Public-Private Partnerships are the ‘flavour of the month’ (Scoones, 2006), and so too the tides of fashion and politic have swelled, buoying a new moment of ‘historical opportunity’ (Jamonneau et al. 2014); the London Declaration and a

commitment to 'elimination'. The culmination of public-private partnerships to develop "simpler and more cost-effective tools and strategies [...] including diagnostics, treatment and vector control" (Welburn, Maudlin, and Simarro, 2009) have brought together "all the political, financial, and technical ingredients [...] to "make HAT elimination a success story" (Jamonneau and Bucheton, 2014). With these 'contemporary and emerging strategies' (Steinmann et al. 2015) on the horizon, it's hard not to feel we are once again riding the crest of technological progress and promise toward "putting sleeping sickness to sleep forever" (Scholtabers, 2018).

Uganda, where this study takes place, faces the unique challenge of being the only country where both forms of human African trypanosomiasis coexist (HAT platform, 2018). Despite this, Uganda may be the next success story in line to 'consign sleeping sickness to the dustbin of history' (*ibid*), an achievement widely attributed to the advancement of technology in diagnosis and vector control. But somewhere between the idealism of elimination and its achievement there is a gap to be traversed. This is the moment between implementation and uptake, where technologies form relationships and take on social connotations, where policy struggles to become practice, and where global assemblages (Ong and Collier, 2008) are rendered locally through the immutable mobiles of global health technologies (Latour, 1987; Law and Mol, 2001; Mol, 2003). This study tends to the 'unintended gap between theory and practice' (Mosse, 2004: 640), between the design of that "troublesome word" 'intervention' (Redfield, 2018) and its implementation. It aims to provide "thick descriptions" (Geertz, 1973) of HAT control, addressing a gap in the literature with empirical examples of how technologies of global health become commodities of governance, and objects of expertise, controversy, and advocacy (Lachenal, 2017).

This is not a study of sleeping sickness per se, nor the political economy of sleeping sickness control and its tangled history with colonialism from which it was borne and bound to. Rather, it is a study of how, against the back drop

of this troubled history, technology continues to be centralised as the harbinger of progress in sleeping sickness control. It explores how global health tools, focused on singular, discrete problems are conceived, framed, and deployed to intervene upon a disease which has multiple ontologies (Mol, 2003); comprised of two strains with distinct epidemiologies separated by a ‘thin line between two fatal diseases’ (Picozzi, 2005); one shrinking to the brink of elimination, while the other threatens to expand its reach. A disease of both biological and social framings; of humans, livestock, tsetse flies, as well as of poverty, neglect, and politics. This thesis uses technologies as departure points from which to examine and unpick the entangled socio-material relationships embedded in the diagnosis, treatment, and prevention of HAT.

New technologies from ‘m-health’ decision support or data collection tools, to rapid point of care tests are often posed as overcoming ‘dysfunctional infrastructure’ and ‘weak health systems’ because they allow surveillance or testing without relying on transportation, laboratory capacity and well-staffed clinics (Sariola et al., 2017). But the global health communities’ fixation on innovating around these gaps has distracted and marginalised efforts to address these structural issues, diverting investment toward developing discrete devices (Street, 2018).

Resisting these “conceptualizing projects” as singular interventions transported from the ‘outside’ to change their singular target (Adams et al., 2014), I use case studies as vehicles to advocate a socio-ecological approach and press the case for adaptive, locally specific solutions (Booth and Clements, 2018). This approach incorporates historical formations of HAT interventions, and how local ecologies and biologies (Lock and Nguyen, 2010) of HAT are both constituted “through multiple transactions and exchanges of resources, knowledge, and experience that have been formed over many years” (Adams et al., 2014: 184). This research contributes to a growing body of literature in Critical Global Health studies and Science and Technology Studies (STS), addressing the role of technology for health and

development, and seeks to appeal to scholars and practitioners of these disciplines.

Additionally, I hope that this work can also contribute to a small body of growing literature working to develop the concept of a 'critical epidemiology' (Krieger, 2000; 2011; Edelman, 2018). By this I refer to epidemiological approaches that give critical attention to research practices and knowledge production, and employs 'criticality' in its analysis of structural factors and relationships of power in epidemiological research and interventions, particularly as explanations of behaviour and health outcomes (Murray 2014, in Edelman 2018). Such an approach promotes participatory methods, such as participatory modelling (Grant et al. 2016) and locally-tailored interventions (Booth and Clements, 2018) informed by 'slow research' (Adams et al, 2014) and more nuanced modes of 'community engagement' and 'participation' (Rifkin, 2003; George et al., 2015). Despite the value of integrating these kinds of anthropological perspectives into HAT programmes, due to the dominance of top-down technocratic approaches in global health their contribution is widely underutilised (Bardosh, 2014; Brown and Kelly, 2014). A critical approach seeks to integrate social inquiry into the planning, monitoring and evaluating process of epidemiological research, ensuring "flexibility and adaptability to local realities are built into interventions" (Bardosh, 2014:1).

Furthermore, I address this work and the practical value that can be gleaned from its conclusions to the "serene entrepreneurs of contemporary global health" in their endeavour to solve complex and politically entangled problems with technological 'simple solutions' (Lachenal, 2017:16). The empirical body of the thesis aims to set out a detailed, critical ethnographic account of how global health interventions and policy play out at the local level, through selected case studies of technologically-oriented interventions in HAT control and elimination in Uganda. From these case studies, I argue several key empirical contributions to the literature can be made:

1) **Infrastructures are relational** as well as material, thus technology alone cannot address infrastructural paucity, nor the relational aspects of infrastructure that shape the epidemiological landscape of HAT. Devices like rapid diagnostic tests (RDTs) and mobile data reporting tools are designed to circumvent gaps in health infrastructures, however they often require more work, bureaucracy, and resources to work than envisaged.

2) **Global commitments to 'One Health' approaches are not reflected in local practice.** The HAT network encapsulates the 'one health' paradigm in successfully advocating collaborative interdisciplinary relationships and discourses which may hold at an international research and policy level, but this collaboration rarely plays out in practice at the ground level. In Uganda, collaboration and knowledge exchange is rarely replicated at district level between veterinary, entomological, or public health actors. The experience and expertise of community health, animal health, and entomological workers tend to go overlooked by programmes.

3) **The social proximity of technology is a key driver of intervention sustainability.** Technologies that have local community buy-in and participation are more socially embedded, and therefore have sustainability built into them through social networks and practices. Meanwhile, relatively aloof, expensive, and large scale vertical interventions that lack this social proximity to communities inspire little public awareness, understanding, or trust.

4) **Technologies can become tools of advocacy** for HAT awareness and control. Where new tools and interventions become socially embedded and take on their own social lives among local ecologies, they can promote awareness about HAT through more organic and horizontal forms of knowledge production and exchange. The HAT RDT for example is a socially distant technology and largely invisible intervention, and therefore does little

to promote awareness of HAT or HAT diagnosis in the areas it has been introduced. The tsetse control '*Tiny Targets*' devices on the other hand have been a highly visible technology, both in terms of their physical appearance and geographical positioning, but have also co-opted participation from local people who have encountered them and have shared knowledge about the programme, transmission, risk, and signs and symptoms of HAT through their social networks.

5) HAT control is comprised of a fragile assemblage of local socio-technical ecosystems, and introducing new technologies into these landscape disrupts and transforms them in unpredictable ways.

Technologies are often conceived as though they will be introduced into static systems comprised of a passive network of actors ('communities'). But tracing their implementation shows that this is rarely the case. HAT patients or suspects for example do not navigate the same imagined landscapes as HAT programmes envisage, and do not behave as their models presume. RDTs have impacted on laboratory HAT diagnostic practice, while discordant test results between HAT RDTs and microscopies affect trust in health workers referral structures. Elsewhere, negative experiences of large-scale vertical interventions such as the Stamp Out Sleeping Sickness campaign can leave negative feelings and intervention fatigue among populations and affect the uptake of livestock spraying. Populations are not passive recipients of interventions – their behaviour shapes, and is shaped by, these technologies.

Overview

Given the different epidemiological profiles and challenges posed by the two strains of HAT in Uganda, I conducted this research in two main sites in Uganda to understand how the various components of HAT control work together in each. In the West Nile, the elimination context requires that

intervention efforts focus on detecting very few cases. The region is endemic for mainly the human strain of HAT, thus my investigations focused on case detection and vector control. In central northern Uganda, there were many more cases and an animal reservoir to take into consideration, and so my investigations focused not only on the above, but also treatment (and post-treatment follow-up) as well as tending to the connections and entanglements with the animal health system (regarding both disease surveillance and vector control).

An enhanced RDT-based passive surveillance strategy

The first half of this thesis describes the conditions whereby HAT can be 'seen' by biomedicine and opened-up to clinical and epidemiological intervention, and more prominently, the ways in which it evades surveillance as bodies remain opaque to biomedical inquiry. This first chapter describes how HAT is diagnosed at the point of care, and the extent to which diagnostic devices form part of this performance, examining the implementation and use of Rapid Diagnostic Tests to passively screen for *T.b. gambiense* HAT. This is explored via two avenues of surveillance breakdown. The first concerns the challenges of detecting and identifying HAT cases in the first instance (i.e. symptomatic patients being found and recognised as a syndromic or serological 'suspects'). The second concerns the retention of suspected cases in referral until they are confirmed as a 'true' case through parasitological demonstration and molecular confirmation, or until they are no longer seropositive. A key challenge facing HAT control programmes and the prospect of elimination is case detection, a problem frequently owed to the similarity of symptoms to other endemic febrile illnesses and poor laboratory capacity at the primary healthcare level.

As HAT is pushed toward elimination, passive detection will become an increasingly important part of control strategies of gambiense HAT, yet it has received relatively little attention in the study of HAT epidemiology (Checchi

et al, 2018). The coverage of passive surveillance relies heavily on potential cases being recognised at the community level, and whether patients are referred to HAT treatment centres by other health facilities and are able to spontaneously present to them. Potential barriers may arise at each of these steps, however published evidence on these barriers are largely absent, with the exception of studies from western Democratic Republic of Congo and neighbouring Republic of Congo (ibid). This thesis contributes important evidence to this literature, by describing some of the structural and financial barriers that also feature prominently in treatment seeking decisions.

A new RDT introduced across peripheral (level II and III) facilities purports to close the gap in laboratory infrastructure by allowing health workers to easily test for HAT on suspicion of symptoms where tests for malaria are negative. This chapter presents findings from a patient-based study I conducted on referral non-completion among RDT-positive serological suspects in the West Nile region of north western Uganda. Here, HAT is traced along the treatment seeking pathways of seropositive suspects as they navigate the new RDT-based passive surveillance and referral system. Vignettes from mobile screening and microscopy examination focus on the moments leading up to diagnosis as the starting point of this enquiry, before HAT is re-inscribed as a biological entity by diagnostic technologies. Interviews with serological suspects in the West Nile reveal the collective memories of past control campaigns, which for a long time were “the most visual expression of the state” (Lachenal, 2017:7) and their legacy in the present day elimination setting on HAT awareness and perceptions of risk (Kovacic et al., 2016). These describe the diagnostic landscape and pathways to treatment navigated before being tested; from self-treatment and religious prayer, to consulting informal health providers such as drugs shops and natural herbalists, and how the social proximity of these practices and services influence these choices. These highlight the multiple ontologies and ways in which HAT can be ‘known’ and enacted prior to and outside of biomedical inquiry.

From this point of detection, the chapter then goes on to consider the relational position of rapid diagnostic tests in the HAT assemblage as it positions the body, or 'case' within the referral apparatus that must be repeatedly enacted through diagnostic alignment (between symptoms, RDT, microscopy, LAMP, lumbar puncture etc.) through follow-up to sustain the stability of the surveillance network (Law and Singleton, 2014). Confirmed case detection beyond seropositive suspects remains elusive as a small but significant proportion of RDT-positive cases do not attend follow-up examinations or complete referral, thus destabilising this network.

Testimonies highlight multiple socio-economic challenges to attending follow-up; financial costs, limited access to transport, difficulties in getting social support and hospital care. It also reveals how receiving discordant results between testing positive by RDT and negative by microscopy can have detrimental effects on trust in health workers expertise and a case management system that expects suspects to return for repeated follow-ups with no prospect of treatment or alternative diagnosis. These occurrences destabilise the fragile assemblage of HAT management, and highlight the importance of patient-health worker relationships, communication, while managing expectations and uncertainty at the point of testing.

This chapter argues that far from simplifying diagnosis, introducing new technologies can destabilise local ecologies of testing (Umlauf, 2017) with potentially iatrogenic effects on the health system. It shows how RDTs are ultimately social objects, entangled and embedded in social practices, and argues that the agency of diagnostic technologies is determined not only by their physical accessibility in terms of mobility and cost, but also by their social proximity to target populations and the diagnostic cultures that govern their positionality within local ecologies. Furthermore, I argue that RDTs are paradoxical, in that they fail to solve the problem that they claim to; namely eliminating the need for a laboratory, requiring corroboration and legitimisation from more sophisticated tools and laboratory infrastructures.

This raises questions of ‘where’ exactly diagnosis occurs in the structural apparatus of surveillance, and queries the concept of ‘infrastructure’, which I turn to in the following chapter.

Work from this chapter on integrating the RDT-based referral system into the Ugandan gambiense HAT elimination programme has been published in the journal *Infectious Diseases of Poverty* (Lee and Palmer, 2018).

Re-imaging the laboratory and infrastructures of surveillance

From detecting HAT in the community using RDTs, this chapter shifts to where HAT is brought into the clinic and ‘counted’ using the ‘gold standard’ microscopy (Umlauf and Beisel, 2016), and characterises the material spaces, or ‘infrastructures of surveillance’ as I describe them, in which HAT is brought in from the natural world and re-constituted through diagnostic enactments. This chapter draws on testimonies from health workers to establish what defines the clinical space, and how this is understood in terms of infrastructure. This departs from the trope of infrastructural systems being tightly bound to modernist notions of progress and development (Smith, 2009). Instead analysis will expand on Paul Farmer’s ‘staff, stuff, space, and systems’ interpretation (2014), by conceptualising the Ugandan clinic in terms of complex and complicated infrastructures as described by Harvey et al. (2016).

This chapter also moves from the *T.b. gambiense* elimination setting, to a region where zoonotic *T.b. rhodesiense* is reportedly spreading. While different in their epidemiological profiles, case detection remains challenging for both strains of HAT for different reasons. Here, HAT is new and unanticipated. Drawing on survey and interview data collected from 13 health centres across the Teso sub-region, this chapter documents how biomedical practitioners in Uganda’s health facilities struggle amid severe resource shortages to make the HAT infected body visible and knowable to the clinical gaze. This struggle is entangled with attempts to negotiate access to

resources in order to make themselves more visible to others in positions of power—to clinicians, scientists, politicians, and international organisations or control programmes (Street, 2014).

At the beginning of this chapter we meet Serena, a clinician working in Dokolo Health Centre IV, one of two treatment centres operating in the region. Her struggle to keep the HAT network stable demonstrates the difficult circumstances health workers face to make HAT policy work on the ground. Here there are few staff, little training, and no one to support or replace Serena when she's called away, preventing her from leaving to further her studies and medical career. Her experience highlights the precarity of the HAT assemblage, made up of informal connections between people like Serena and Frederick (a local veterinarian), who keep each other informed on human and animal trypanosomiasis cases in the region. The poor communication between lower health facilities with larger regional hospitals or district veterinary services means information is not shared, and this fragile assemblage relies on the continual communication and performance of an informal network of actors in order to function. Here, the 'one health' network breaks down, with a disconnection between national and local policy, and between district departments where there is no formalised systems of sharing and reporting information between health, veterinary, or entomological departments or personnel locally.

This is a place where many health centre laboratories are well equipped with working microscopes, but few have trained staff to operate them. Few have received any form of formal training for identifying or dealing with HAT cases in fact, and even where staff are trained, few feel they have time or confidence to perform microscopies for HAT, and are uncertain whether suspect referrals should be followed up or reported beyond the district level. While no RDT is currently available to screen for rhodesiense HAT, this is also a place where the introduction of RDTs for other endemic diseases such as malaria have nevertheless impacted drastically on the HAT diagnostic

ecosystem, by reducing performance of microscopies and thus weakening passive HAT case detection for *T.b. rhodesiense*. Malaria RDTs have created a diagnostic ecosystem whereby microscopy is now rarely performed, thus case detection for rhodesiense HAT is dependent on the suspicion index of trained health workers and referral to high level treatment centres in Lwala, Dokolo or Lira. Here there is no history of epidemics or active screening, and thus no lasting awareness among the community. Few health workers regard HAT to be a problem in the region but acknowledge that data on this could be skewed due to low microscopy performance. Surveillance relies on the awareness and training of health workers, and the resources to act on clinical suspicion where potential cases present themselves to the clinic. Under-staffing and high turnover of staff and infrequent or limited training has resulted in a lower index of suspicion among health workers and likelihood of microscopy being performed. These testimonies draw attention to the flaws of passive surveillance as in the previous chapter, where the implications of this in a setting where HAT may be spreading into new territories are significant.

Through enactments of HAT diagnosis, hospital infrastructures emerge as relational assemblages that, while on the whole appear large and monolithic, remain fundamentally fragile. The testimonies of health staff offer a different perspective of the diagnostic ecosystem to that described by the algorithms mapped out by the national control programme (see Wamboga et al, 2017); One that encounters the restraints of a decentralised healthcare system, the demands of target driven vertical programmes, and struggles of delivering care with little resources or structural support. Decentralisation of the health system has put HAT on a low priority setting for districts where it is not perceived to be a risk, therefore little training or resources are mobilised to these areas. Many wish their facilities to be upgraded to a higher-level to receive more resources and support for the district. Here, the presence of material diagnostic technologies such as microscopes however does not infer increased capacity for case-detection, where lack of staff (or lack of

training), and diagnostic cultures introduced by RDTs create disincentives to perform microscopy and find cases in frontline peripheral health facilities.

Given the emphasis on case detection as the primary challenge in contemporary HAT control efforts, it is reasonable to assume that once a case is correctly identified and diagnosed, that treatment and discharge is a relatively straightforward and stable process. However, as the following chapter illustrates, this too is a fragile and complex part of the HAT ecosystem subject to disruption from new technologies.

Treatment experiences and managing expectations of Fexinidazole

While remaining in the clinical space, this chapter shifts from HAT surveillance to management. Here, patients have been re-configured from suspects to confirmed cases through the alignment of diagnostic practices (parasitological and molecular demonstration) (Mol, 2003; Law and Singleton, 2014; Street, 2014). The infected body is transformed and subjected to biomedical intervention with drugs and monitored thereafter to confirm the success of treatment. This monitoring requires patients who have been discharged to return for quarterly follow-up tests, however patient experiences during treatment and logistical challenges have rendered this impractical to the point of being recently removed from clinical guidelines. This chapter draws on data from a referral non-completion study I conducted among treated *T.b. rhodesiense* patients discharged from Lwala and Dokolo treatment centres, and explores the social, economic, logistical, and material challenges of treatment, including completing post-treatment follow-up. It reveals the financial and social strains of long periods of hospital admission required for current HAT treatment, and asks how potential novel oral drug regimens could alter and potentially disrupt this landscape. Combining testimonies from patients and health workers, this study reveals the fragility of the HAT assemblage, and raises questions over how the introduction of new drugs could further destabilise the referral ecosystem.

Early in this chapter Serena laments losing patients to follow-up and not being able to achieve 'clinical closure' on these cases who 'drop off the radar'. Findings from my patient interviews go on to reveal the treatment seeking pathways that bring syndromic patients into contact with informal healthcare providers before going to hospital. They also describe the socio-economic challenges of being admitted to hospital for treatment, as well as attending follow-up after being discharged. This included financial barriers, access to transport, arranging social support and hospital care for the duration of admission. Other reasons for not returning for post-treatment follow-up included fear of the lumbar puncture procedure, and a lack of urgency due to a recession of symptoms since treatment. While it is now recommended that patients need not return for follow up in the absence of symptoms, Serena expressed the environment of uncertainty this creates where known unknowns hang over her. This poses similar dilemmas for health workers trying to reconcile epidemiological certainty with clinical pragmatism in the passive surveillance system. Interviews with historically-treated patients highlight the recent challenges patients have engaging with the programme for post-treatment follow-up. This is a unique contribution to the HAT literature, where the majority of studies focus on explaining delays until case detection, and echoes themes raised in the first empirical chapter.

In this chapter we also meet David, a *T.b. rhodesiense* HAT inpatient at Dokolo HC IV. Whilst observing his treatment, Dr Akello (Serena) describes the procedure and discusses the negative side-effects of melarsoprol, but also the difficulties patients face in being admitted to hospital for long periods, even for early-stage Suramin treatment such as David's. This foregrounds my inquiry into expectations and perceptions of a prospective oral treatment (i.e. Fexinidazole) that can be taken from home. Material from this sub-study and health worker interviews which also explored attitudes toward potential oral treatment for HAT suggest some interesting considerations for the introduction of Fexinidazole for early stage

HAT patients; long distances and time away from home makes admission to hospital problematic for most patients, however concern about home-treatment with oral drugs is shared between patients and health workers alike. Also, concerns over the seriousness of HAT and the need for continuous clinical observation and monitoring raised concerns over treatment adherence and suggestions that an observed treatment protocol (similar to TB DOTS) could be observed, but there were reservations over this too. Furthermore, some concerns were raised by patients over whether they can administer their own treatment properly, as well as feeling brushed off by health workers, thus preferring to be kept in hospital and 'seen' by the doctor throughout this period of crisis and uncertainty.

This chapter corroborates earlier arguments, that the landscapes of care imagined by the HAT programme are different to those navigated by patients. Many patients do not present at health centres for a long time, often after infection has progressed to late stage. It also suggests that introducing new drugs may address many problems with current case management, particularly if they can be administered without need for lumbar puncture, a painful procedure which deterred many patients from returning for follow-up. However, the introduction of Fexinidazole into the therapeutic assemblage will likely be disruptive in other ways in terms of how different types of treatments are perceived (i.e. between oral and injection administration), and how existing home-based drug taking practices may affect the safety and adherence of a new HAT drug.

Tiny Targets and community spraying: breaking the chain of transmission through sustainable vector control strategies

This chapter presents my final empirical case study on the communities involved in implementation of two tsetse control interventions; small insecticide impregnated nets called 'Tiny Targets', and mobile community sprayers, which have been implemented at scale in the West Nile, and Teso

and Lango sub-regions of Uganda respectively. Qualitative data was compiled from in-depth interviews with entomologists, veterinarians, and community animal health workers, community focus group discussions with smallholder subsistence farmers, alongside responses from interviews with HAT patients from my previous sub-studies (20 *T.b. gambiense* seropositive suspects and 25 *T.b. rhodesiense* treated survivors). These explored knowledge and awareness of HAT and transmission; local history and perspectives of tsetse control amid other human and animal health priorities; the definition of and collaboration between key stakeholders; and prospects of programme sustainability.

The first half of the chapter draws on ethnographic material from a mass cattle treatment campaign, discussing the use of drugs to clear the parasite in the cattle reservoir and restricted application of pyrethroid spraying during a feasibility trial in 2014 for a proposed third phase of the Stamp Out Sleeping Sickness ('SOS') programme. This describes the style and approach of the vertical SOS programme (large, militarised in its organisation and implementation, technology and data-driven). Sweeping through rural communities with large 'brigades' while leaving little capacity or incentives to continue interventions after withdrawal meant few local farmers took up the regular spraying required to sustain the campaigns gains, beyond the lifespan of the intervention's implementation phase. This helps to explain why previous phases of the SOS programme failed to capitalise on early gains and sustain prevalence reduction in the long-term.

This foregrounds findings from a sub-study on the 3V vets and mobile spray networks that grew out of SOS in a bid to build a more socially embedded intervention on the animal reservoir of HAT. Here we follow Dr Frederick Odongo and two of his mobile sprayers as they mobilise their communities for spray days, describing the local village spray network system and how it has come to provide services to the community beyond the remit of preventing HAT through spraying.

This is presented alongside data collected during focus group discussions with local farmers, some of which have experienced *T.b. rhodesiense* outbreaks and large-scale responses (Dokolo, Kaberamaido) and some which have only recently been affected by cases (Lira, Alebtong, Kole). This sub-study explores the agency of intervention target populations, such as the prioritisation of diseases of concern for farmers, spraying and treatment practices of livestock, and how these are shaped by local knowledge and awareness of human and animal trypanosomiasis.

The end of this chapter, and the last of my empirical material, ends where this journey began; with the Tiny Targets programme in the West Nile. It gives a detailed ethnographic account of target deployment in the field, and tsetse dissection in the lab. It describes how Tiny Targets were designed and field tested by the Liverpool School of Tropical Medicine (LSTM) in localised settings and adapted throughout scale-up with co-operation of local communities as part of an anthropologically-informed, women-led vector control programme. This involved ownership and participation from local communities from the outset, establishing a socially embedded technological intervention. Data from my RDT referral study in the same region also revealed local perceptions of risk and awareness of HAT directly associated with the visibility of the Tiny Targets programme. Meanwhile, interviews with local district entomologists and entomology assistants showed there had been some mismatched priorities and expectations between district staff and the vertical programmes in terms of what data is useful and how it should be used. However, it also showed how transparency and inclusion with local district staff had facilitated a smooth transition period from a vertical to national programme.

Finally, the findings also corroborate those of previous chapters and shows that despite successful national and international commitments to one health partnerships, collaboration between veterinary, entomological, and public

health staff at the district level is limited. Many local entomological assistants and Community Animal Health Workers claimed to feel overlooked as key stakeholders or important sources of knowledge by national control programmes but felt empowered by vertical projects like 3V vets and the resources and training they provided. Decentralised and under-resourced district offices often struggle to maintain operational cohesion, as a precarious assemblage of entomologists, veterinarians, and community animal health workers endeavour to align vertical programmes with fragile and fragmented control networks. Based on these findings, I make the argument that 'community' participation should expand to engaging implementation staff, whose agency is often overlooked as gatekeepers of local knowledge and trust.

This final chapter finely illustrates some of the key tenets of this thesis; that technologies do not exist and operate in a vacuum, nor do they work on a passive static ecosystem. They are part of a dynamic HAT assemblage and rely on the interaction and agency of the population they are intervening on to adopt and continue to use them. They can be used as tools for advocacy, as highly visible and socially embedded interventions promote awareness and understandings of HAT among local populations. Conversely, relatively high tech but aloof interventions which shift responsibility of referral, or treatment, or of preventative spraying, onto poor communities in subsistence societies is evidently problematic. Introducing technologies and expecting vulnerable communities to continue their implementation long after with their own resources does little to promote trust or incentive and is potentially damaging to communities and health systems. Thus, while modest and incremental, locally adapted interventions which are more socially proximate and integrated with 'local ecologies' achieve greater sustainability than some of their more elaborate predecessors, as they take on, and persist through, social lives of their own.

CHAPTER ONE

Background

Human African Trypanosomiasis: a 'tool deficient' Neglected Tropical Disease

As a group, the Neglected Tropical Diseases (NTDs) are not universally defined. The journal PLoS NTDs lists over 45 diseases, The Roadmap for Elimination gives 10, while the WHO lists 17 – which are split into "tool ready" and "tool deficient" NTDs (Fürst et al., 2017). Tool ready NTDs are generally subject to large scale, inexpensive donations of safe, single dose drugs with no need for individual diagnosis. For these reasons they are very attractive to donors, as “big bang for the development buck” (Cotton, 2014) can be achieved by mass treating NTDs like Schistosomiasis, Soil Transmitted Helminths, Onchocerciasis, Trachoma, and Lymphatic Filariasis (Vogel, 2006).

Tool deficient NTDs on the other hand are complex and difficult (or costly) to diagnose or treat. They may involve several epidemiological factors, true for many vector-borne diseases such as HAT, which require more cross-cutting strategic approaches, requiring more sophisticated laboratory and hospital infrastructures, or zoonotic diseases (such as HAT) which must also address the animal reservoir. These NTDs are less attractive to donors as there is greater expense and risk involved, which has led to new kinds of financing models, such as Development Impact Bonds (DIBs), being devised to encourage donor investment (Welburn et al. 2016).

Epidemiologically and socially, NTDs share some characteristics; they cause life-long disabilities, affect the most poor and rural populations, mostly in Sub-Saharan Africa, and are therefore widely underreported. More notably, NTDs are a product of lobbying, advocacy, and policy framing. Thus it is

important to think critically about the ways in which NTDs like HAT are framed politically and economically, as well as epidemiologically, when considering the global public health policy agendas, and how control and elimination programmes are designed and financed (Dry and Leach, 2010; Scoones, 2014; Parker, Polman and Allen, 2016).

Institutional architectures of contemporary HAT control in Uganda

Despite extensive research into the biology of the trypanosome, barriers to achieving the prized goal of elimination up to now have been blamed on an “extremely small” diagnostic and treatment toolbox “plagued with difficulties” (Franco et al., 2014). By the beginning of the twenty-first century, decades of neglect had led to alarming numbers of reported new cases of HAT across Sub Saharan Africa, with an estimated 300,000 people infected. The resurgence of the disease was considered a public health calamity, and through an ambitious campaign led by WHO, many NGOs, and a public–private partnership with Sanofi-Aventis and Bayer that donate the necessary drugs for distribution in affected countries this trend was successfully reversed (WHO, 2013). The global incidence of *T.b. gambiense* HAT had reduced to less than 3,000 cases in 2015. Based on this success, there are now plans to eliminate Gambiense HAT as a public health problem by 2020 (Aksoy et al., 2017).

Today, owing to its low caseload Uganda is deemed capable of managing its HAT programme without the need for external assistance, yet until recently this was not always the case. Initially entering the country to address a public health ‘emergency’ during a *T.b. gambiense* HAT epidemic that broke out in the late 1980s, the humanitarian NGO Médecins Sans Frontières (MSF) maintained an intermittent presence in the country over the course of two field missions to prevent an emergency of such proportions arising again by conducting active screening and treatment on a mass scale. Two MSF

branches assisted Uganda over the course of two field missions: MSF France (1986 - 2002) and MSF Spain (2010 – 2011). The NGO withdrew in July 2011 owing to low case numbers which made their presence in Uganda low “value for money” for donors (Smith et al., 2015: 16). Since then active screening has been replaced by an ‘enhanced passive surveillance system’ which relies on point of care rapid diagnostic tests in primary healthcare facilities (Wamboga et al, 2017).

Meanwhile, between 1985 and 2005 the area of southeast Uganda affected by *T. b. rhodesiense* HAT increased 2.5 times (Smith et al., 2015). By 2005, the two forms of HAT were only 150 km apart, described alarmingly at the time as a “thin line between two fatal diseases” (Picozzi et al., 2005: 1238), thus posing a significant human and animal health concern requiring immediate intervention on the zoonotic reservoir. The Stamp out Sleeping Sickness (SOS) mass treatment of cattle campaign initiated in 2006 involved multiple public and private partners and, though initially successful, has since battled to ensure treatments are continued to the level required to sustain impact. Poor access to veterinary drugs and services to support the spraying and treatments have hampered the lifespan of the project beyond the intervention phase since shifting from a free treatment to a fee-paying model which underestimated the perceived value of the intervention and purchasing power of individual small-hold farmers in Uganda (Smith et al., 2015).

Recent epidemics and the emergency narratives built around them have mobilized financial resources toward more applied research and the development of “new knowledge on parasite and tsetse vector physiology, genetics, and genomics and expanded the prospects for translational science for sustainable HAT control” (Aksoy et al., 2017: 2). Funds have also been provided to WHO to support national sleeping sickness control programmes to boost control and surveillance of the disease (WHO, 2013).

National Coordination: COCTU and the ISSEP

In Uganda the control of African Trypanosomiasis (AT) is overseen by the Coordinating Office for Control of Trypanosomiasis in Uganda (COCTU), the statutory body and secretariat for control and research into Trypanosomiasis established by an Act of Parliament in 1992. Based in Uganda's capital Kampala but seated within the Ministry of Agriculture, Animal Industry and Fisheries (MAAIF) (which is based in Entebbe), with a small team of just three technical staff, COCTU's mandate is to coordinate the activities of all involved government departments, donors and non-governmental organisations, but has no direct role in implementation.

MAAIF's mandate includes regulating cattle movements and providing guidance on Animal African Trypanosomiasis (AAT) treatment. However, the out-dated nature of this legislation (which dates from 1918) coupled with the effects of decentralisation (discussed further below) mean that the state's ability to directly control AAT is minimal. The day-to-day control of AAT in Uganda therefore is managed with a small budget by a handful of dedicated, centrally-based staff apportioned salaries to co-ordinate a country-wide programme. Consequently, the responsibility for AAT is otherwise on Uganda's system of decentralised local government to implement control and surveillance activities, and private farmers even though evidence suggests that livestock owners are often unable to diagnose and treat AAT effectively (Welburn et al., 2006). Capacity of these local actors to carry out their roles has however been constrained by competing demands on district budgets, and the low prioritisation placed on AAT.

The implementation of HAT control on the other hand falls under the remit of the National Control Programme within the Ministry of Health called the Intensified Sleeping Sickness Elimination Programme (ISSEP) at the time of study, consisting centrally of a single a programme manager. In keeping with the country's current policy of passive surveillance, Uganda has no surveillance staff in the field. The treatment of HAT is managed through

Uganda's decentralised healthcare delivery system, which, when HAT cases are positively diagnosed, issues free drugs donated through a WHO donation scheme (Smith et al., 2015). The Ministry of Health has set up free HAT treatment at a number of health centres and hospitals in endemic areas (including Omugo hospital in Arua, Lwala hospital in Kamberamaido, and Dokolo HCIV in Dokolo where research for this study predominantly took place),

The mobilisation of 'emergency' responses to HAT outbreaks, as demonstrated by vertical MSF and SOS campaigns typifies the brand of 'humanitarian biomedicine' (Lakoff, 2010) that has come to characterise the international global health community's approach to the control of NTDs like HAT since the public health arms of colonial administrations have ended. In its place, resource flows of technical interventions which aim to target neglected populations and "avoid political entanglement" (*ibid*: 67) have taken shape as a global 'One Health' assemblage (Ong and Collier, 2005; Smith et al. 2015). As the main body of this thesis sets out through empirical examples, circumventing state political structures has also had the effect of "hollowing out" state capacity to manage disease control programmes locally (Madon et al, 2017) and prevented the kinds of entanglements necessary to operationalise One Health beyond academic discourse and partnership models (Smith et al., 2015). The resulting disconnects between these contemporary technological solutions and the people who need them is the focus of this thesis.

Investigating Networks of Zoonosis Innovation

My PhD research has been conducted as part of a five-year interdisciplinary European Research Council funded project called *Investigating Networks of*

Zoonosis Innovation (INZI)¹. The €1.7 million award involved collaboration across Veterinary Medicine, STIS, and African Studies departments at the University of Edinburgh. INZI proposed to analyse the complex interplay of actors, policies and projects that have shaped the research and control of Human African Trypanosomiasis to the present day. Previous work by INZI members on Trypanosomiasis in Uganda has included work on the global and domestic policy processes influencing control (Okello, Welburn and Smith, 2015) and the importance of a central domestic coordinating body (such as the Coordinating Office for Control of Trypanosomiasis in Uganda, COCTU) to negotiate these policy processes (Smith, Taylor and Kingsley, 2015). It has also included consultancy work for the Foundation for Innovative New Diagnostics (FIND) in partnership with the Ministry of Health in Uganda to better understand and solve problems associated with the Intensified Sleeping Sickness Elimination Project (ISSEP) (Palmer, Robert and Kansiime, 2017).

By systematically analysing the evolution of these international networks, and their national and local implementation and implications, the INZI project contributes to growing explorations of the relationship between science and development to build our understanding of how science can work better *for* development, using the example of HAT as a case study. This thesis takes forward research to empirically describe and examine a different part of the science/development relationship concerning HAT in Uganda: the implementation of technological global health interventions for HAT control and elimination, and the implications of how this plays out in the landscape of an under-resourced and pluralistic healthcare system.

¹ For more information, see

http://www.cas.ed.ac.uk/research/grants_and_projects/current/investigating_neglected_zoonosis_innovation_inzi

The Ugandan State Healthcare System

In the 1990s, the Ugandan government undertook major reforms designed to decentralise state activities, especially service delivery and governance, with wide-ranging consequences for local health and veterinary services (Smith, Taylor, and Kingsley, 2014). In 1995 the constitution was amended and the 1997 Local Government Act delegated decision making to the district level. These reforms had wide-ranging consequences, including the neglect of 'soft' services such as appropriate advice on agricultural technologies to the rural poor. Many officials argued that decentralisation had been key in degrading rural veterinary and pest control capacity. For healthcare, this meant that local authorities were able to plan, budget and implement their own health agendas. As such, the district health service could recruit their own staff and manage their own resources. With the majority of funds distributed to districts earmarked by donors and the Ministry of Health for specific uses however, decentralisation introduced its own set of obstacles to service provision. Consequently, unbudgeted and unforeseen disease outbreaks have often not been addressed owing to local systems being limited to static healthcare delivery (Acup, 2013; 2017).

At the time of study, Uganda's health system was comprised of decentralised healthcare services, overseen by district health teams across 112 districts and the central ministry of health.² The decentralised district is the local level of decision-making for health services delivery, including the planning and implementation of human resources for health policies, budgeting for medicines, supplies, sundries, and infrastructural capacities such as electricity and water. District health teams and their managers are led by a District Health Officer (DHO) alongside other district departments and report to the Chief Administrative Officer. These technical departments are governed by the political arm of government headed by the Local Council

² Ministry of Local Government. List of Local Government Districts. Secondary List of Local Government Districts 2013. <http://www.molg.go.ug/local-governments>

chairperson, assisted by District Councillors. Each district has sub-districts, which are lower-levels of policy-making and monitoring of health services at the sub-county levels.

Ugandan health facilities are graded at different levels depending upon the administrative zones that they serve and their capacity to deal with certain admissions. Each district often has a General Hospital, and referral level Health Centre IVs at the health sub-districts. Each Health Centre IV at the health sub-district supervises a number of Health Centre IIIs, which often have maternal health services in addition to ambulatory care. Below the Health Centre IIIs are dispensaries labelled Health Centre IIs. At the community level, are Village Health Teams who provide day-to-day referral of patients from the community.

In Uganda's rural settings, most healthcare services are provided by the public and the private not-for-profit sector, the latter involving mainly faith-based organisations. Service delivery focuses on a defined minimum package of care which is delivered through a network of health units and a referral system. However, making the country's health system functional in order to provide modern health services remains a challenge. Human resource problems impact on service delivery, with a health worker to population ratio of 1.49 core health workers per 1000 population, which is still the WHO recommended minimum of 2.3 health workers per 1000 population. While the Ugandan government has steadily increased its budget allocation of funds to the health sector, it still allocates less than 10% of its budget to health care. Meanwhile, private out-of-pocket expenditure on health is still high, and most donor aid is not harmonised and aligned to the sector plan and is managed off-budget (African Health Observatory, 2018).

Even at relatively stable periods where the health service needs are relatively foreseeable, the distribution and frequency of funds and resources delivered to primary health care facilities is regularly cited as an on-going challenge to

delivering adequate care at the local level. Widespread disparities in the budgetary system have led to the 're-prioritising and re-rationing' of available funds (Ssengooba, 2004), and health systems continue to struggle in epidemic situations where healthcare provision is limited to midwives or public health nurses (Gyapong et al., 2010).

Tracing Trypanosomiasis: the lifecycle and epidemiology of HAT

Human African Trypanosomiasis is the human form of the vector-borne disease caused by the protozoan *trypanosoma brucei* parasite. Human infective trypanosomes are transmitted, much like Animal African Trypanosomiasis (AAT), by the *Glossina* tsetse fly via an infected bite (figure 1). Around 70 million people are estimated to be at risk (Cecchi *et al*, 2014), and rural populations living in regions where transmission occurs, and which depend on agriculture, fishing, animal husbandry or hunting are the most exposed to the tsetse fly and therefore to the disease. HAT is highly focal, developing in areas ranging from a single village to an entire region, and within an infected area the intensity of the disease can vary from one village to the next (WHO, 2014a). The remote geography of HAT foci is reflected in another name for HAT in Francophone Africa, '*la maladie au bout de la piste*' (Riolon, 2017), which translates as 'the sickness at the end of the track' (Regnier, 2017).

HAT is not a single disease but refers to two strains that present with distinct clinical features. ***Trypanosoma brucei gambiense*** (*T.b. gambiense*, Gambiense HAT, or gHAT) is the subspecies predominantly prevalent in the west and central regions of Sub-Saharan Africa that causes chronic sleeping sickness - its onset being notably gradual and asymptomatic in some cases. Gambiense HAT is transmitted between humans and therefore has a markedly different lifecycle and epidemiology to that of the zoonotic (a disease that exists in animals but can be transmitted to humans) ***T. b.***

rhodesiense (Rhodesiense HAT, or rHAT), which is most commonly carried by cattle. The zoonotic nature of *T. b. rhodesiense* necessitates that control strategies should not focus solely upon the human host, as the disease will remain endemic within the animal reservoir, and therefore it is vital that any treatment intervention incorporates locally present reservoir animal species (Selby, 2011).

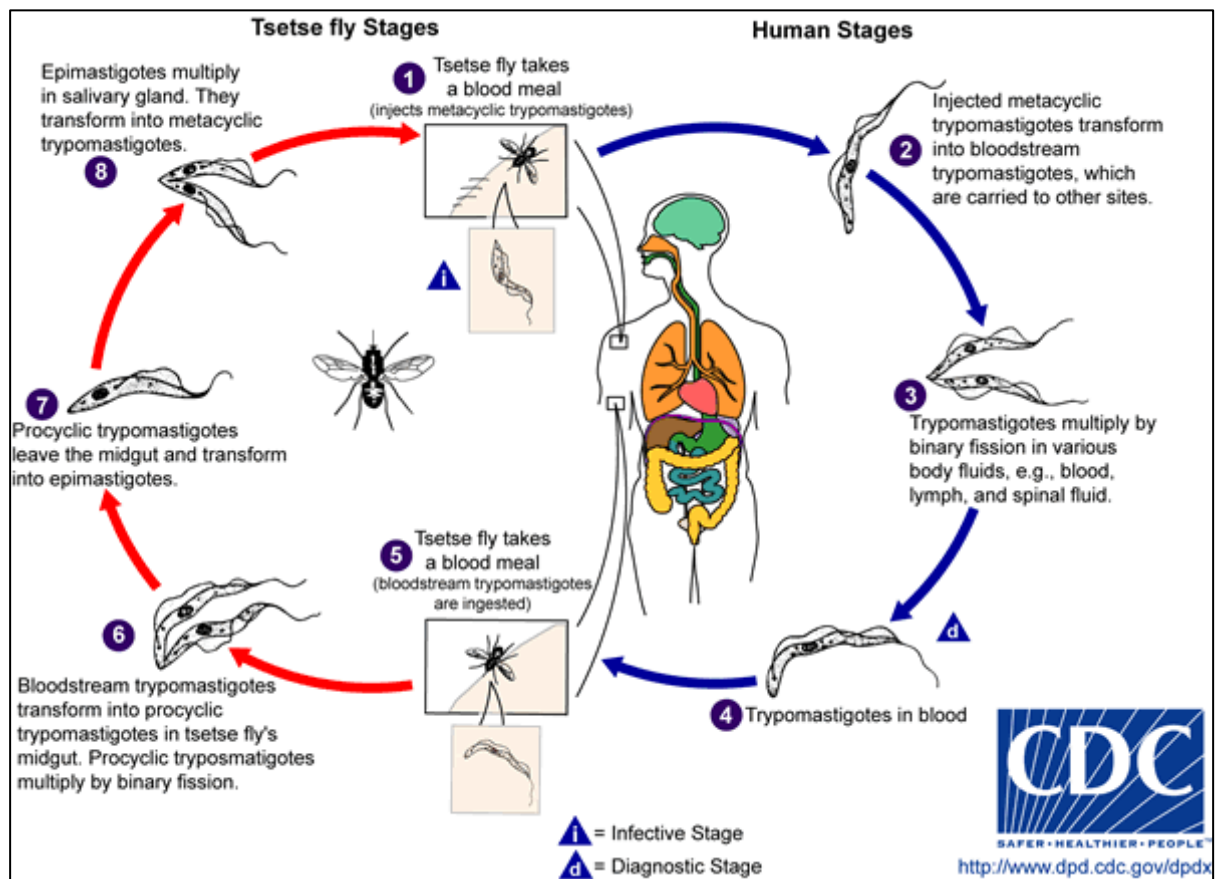


Figure 1: Lifecycle of Human African Trypanosomiasis.

(Centre for Disease Control and Prevention)

In addition to these human infective strains, cattle are also susceptible to strains (*T. vivax*, *T. congolense*, and *T. brucei brucei*) of Animal African Trypanosomiasis (AAT). AAT has a profound economic impact on domestic livestock, with adverse effects of the disease rendering animals visibly weakened, depreciating their value significantly (Selby, 2011). While many farmers may largely be unable to identify the cause of symptoms to be AAT

in their livestock, upon noticing the deterioration in the physical condition of an infected animal, owners of domesticated animals will infer diagnosis and treatment based upon symptom identification, rather than clinical laboratory diagnosis (Maudlin *et al.* 2006). Drugs are then supposed to be administered by a locally operating veterinarian or animal health worker, though these are not always available (Miller, 2017).

In Uganda the 'tsetse belt' runs from the highlands in south-eastern Uganda across Lake Kyoga to north-western Uganda and at least 70% of the entire country is thought to be infested with tsetse flies (COCTU, 2013). Following changes in land use, increases in human density, and a reduction in the wildlife population, Ugandan cattle are now considered the primary host of *T. b. rhodesiense* HAT (Holt *et al.*, 2016). The distribution of *T. b. rhodesiense* in Uganda has increased dramatically in the past 10 years, with outbreaks being attributed to the restocking of infected cattle into naïve areas following military conflict in the late 1990's (Selby *et al.* 2013). Since then, acute HAT has spread northwards to previously unaffected districts of Uganda (see figure 2) (von Wissmann *et al.* 2014).

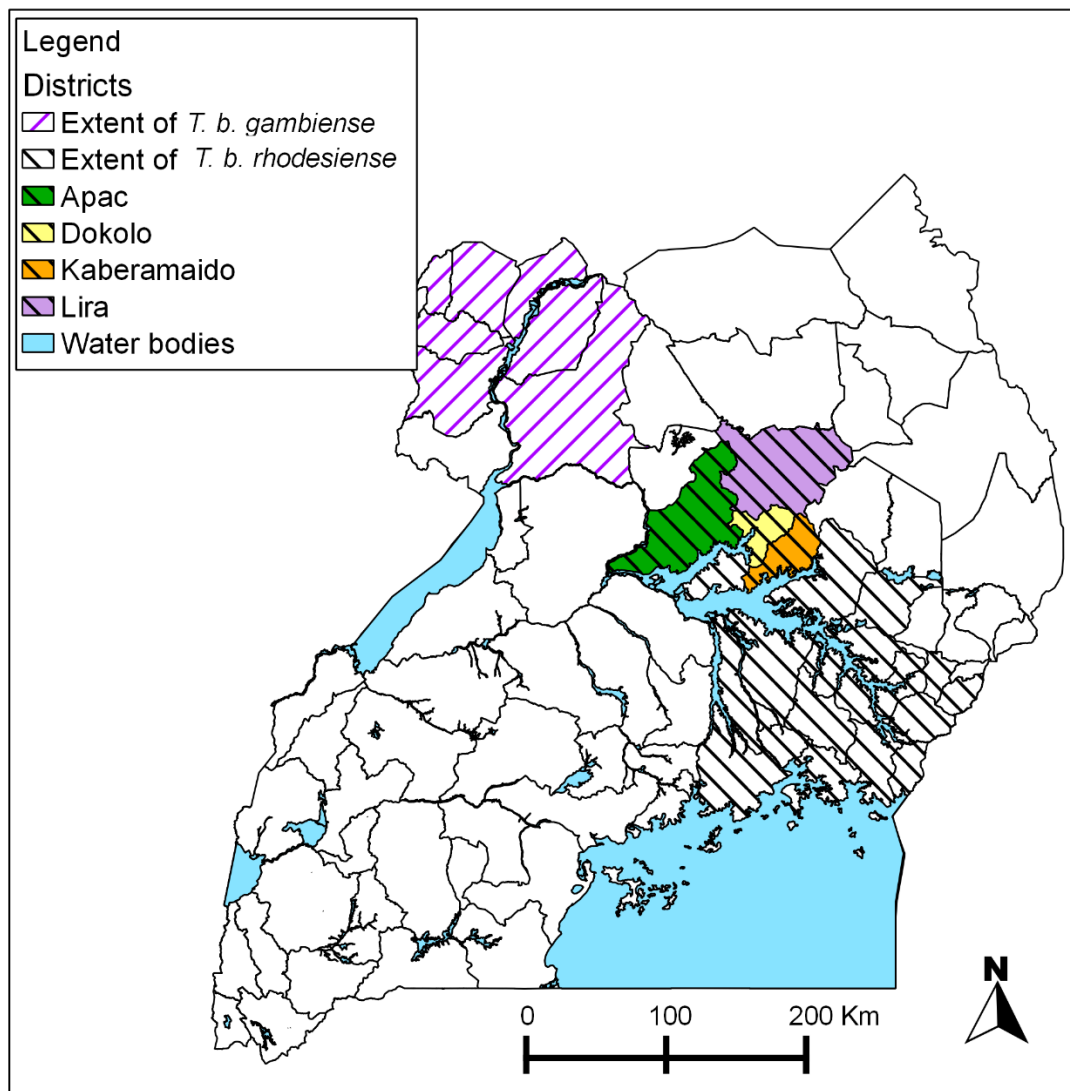


Figure 2: Map of Uganda showing the location of newly *T.b. rhodesiense* affected districts.

Purple area encompasses district boundaries for Lira, Kole, and Alebtong districts as of 2010. (from von Wissmann et al, 2014).

Human infection with the *T. b. rhodesiense* strain, which affects the eastern regions of Sub-Saharan Africa and predominantly southeastern region of Uganda (see figure 4), causes the acute form of sleeping sickness. Where the chronic form caused by *T.b gambiense* HAT takes a long period of time before the onset of clinical symptoms, rhodesiense HAT has a very rapid progression to severe disease, with 80% of deaths occurring within six months (Welburn *et al.*, 2001). Because of this rapid onset of severe pathogenesis, the early symptoms of acute rhodesiense HAT are rarely detected, particularly as many medical professionals are not trained to look

for and recognise these. As a result, the early signs are often confused with other endemic diseases in the area, such as Malaria, Tuberculosis, or HIV infection (Maudlin *et al.*, 2009).

Diagnosis and case management

HAT is initially diagnosed by recognising a patient's clinical symptoms. Owing to the very low parasitaemia of *T. b. gambiense* in infected human hosts, initial serological screening (which detects humoral responses suggestive of infection) in Gambian areas has for many years been carried out using a card-agglutination test (CATT), with positive individuals being later confirmed through parasitological analysis and diagnosis by microscopy (Chappuis, *et al.* 2004). Since the development of rapid diagnostic tests, serological screening using these point of care devices is moving to replace CATT as the norm. Infection is then confirmed by observing the presence of parasites either within the blood, lymph, or in the case of late stages of infection, the cerebro-spinal fluid (CSF) via a lumbar puncture. Another screening process that 'suggests' infection is possible using techniques such as PCR (Polymerase Chain Reaction) analysis. However, this is rare as the only diagnostic tools often available to local health workers are basic methods such as light microscopy (Picozzi *et al.*, 2002), and still requires parasitological confirmation. After the initial clinical diagnosis based on the symptomology in the patient, laboratory tests are used not only to detect and confirm the presence of parasites in the body, but to establish the parasites location within the body which will determine the degree to which the infection has advanced in permeating the body's boundaries. Often, no further tests are carried out to determine the sub-species of HAT, with the geographical location of the patient often informing the assumption as to which the patient is infected with (Selby, 2011. p.10).

This 'staging' process ascertains the intensity and location of infection in the body. Parasites found at this stage will confirm definitively the presence of

infection, only with this evidence can a case be re-classified from 'suspected' to 'confirmed'. Patients with no trypanosomes and ≤ 5 cells/ μl are in the first (hemato-lymphatic) stage, while patients with trypanosomes and/or an increased (>5 cells/ μl) white cell count in the CSF are classified in second (meningo-encephalitic) stage of infection (Eperon et al., 2014). In the case of parasites being present, then a lumbar puncture must be performed to establish whether it has crossed the boundary between the blood and the cerebral spinal fluid, thus entering the brain. Presence in the CSF will in turn require that more invasive drugs be administered which can also cross this blood-brain barrier, and thus eliminate the parasite from this part of the body. Because of the complexity and various toxicity profiles of anti-trypanosomal drugs (as described below), parasitological confirmation and lumbar puncture remain routinely performed to confirm the presence of HAT and stage the illness.

In rhodesiense HAT cases however, even the process of extracting a CSF sample presents an opportunity for parasites which have yet to enter this space to break through this boundary and enter the spinal fluid during the procedure. Therefore, to avoid this occurrence, a short prophylactic course of suramin is administered to the body in order to clear the blood of infection before the lumbar puncture is performed (Farrar et al., 2013)

In the case of parasites not being discovered in the CSF, then the treatment of suramin will be continued until the infection is totally cleared from the body. Where trypanosomes are found present in the CSF and therefore indicate a late stage or stage two infection in the body, a more invasive treatment is needed (Buyst, 1975). For Rhodesiense HAT patients, this is still currently administered in the form of Melarsoprol B, an arsenic derived drug which can (in 5-10% of cases) cause encephalopathy (swelling of the brain) and be fatal (Kuzoe, 1993; Steverding, 2010). It is therefore of paramount importance that the diagnostic, staging, and confirmation process is accurate to avoid Melarsoprol B being administered unnecessarily given the violence

that it also exerts on the body (Babokhov et al., 2013).

Until now, health workers and patients had two main treatment options for gambiense HAT. The first, as with rhodesiense patients, was melarsoprol. The second option, suitable only for early stage infections, is the more recent Eflornithine monotherapy, requires hourly infusions, to be given every six hours for two weeks. Eflornithine monotherapy is better tolerated and more effective than Melarsoprol, but owing to the high burden on health workers and the high cost of the medical equipment required to correctly administer it, patients in some sites still continue to be treated with toxic Melarsoprol (DNDi, 2009).

During 2001–2004 a trial of a co-administration of intravenous eflornithine and oral nifurtimox (NECT) was conducted in Omugo Hospital, the main treatment centre in Uganda at the time, and would go on to be launched in 2009. NECT has been a game-changer in the treatment of *T.b. gambiense* sleeping sickness, reducing the number of eflornithine infusions required, compared to when it is used as a monotherapy, from 56 to 14. Additionally, it shortens hospitalisation from 14 days to 10, which makes treatment more convenient for patients. Because NECT only requires 2 infusions a day which can be administered during the daytime, this is easier for health workers and makes treatment far more suitable for remote and resource-poor settings. With the WHO's recommendation of NECT as first-line treatment, all HAT endemic countries receive free supplies via drug donations by Sanofi and Bayer, and all Gambiense HAT stage 2 patients are now treated with NECT (DNDi, 2009).

While NECT has transformed the treatment of Gambiense HAT, the options for rhodesiense HAT patients remain limited to suramin (early stage) and melarsoprol (late stage). All treatment options for both Gambiense and Rhodesiense patients still require painful lumbar puncture and intravenous injections during hospital admissions. However, new therapeutic candidates

are currently in clinical development which could yet again transform HAT treatment, notably because they can be administered orally and treat both disease stages (thus eliminating the need for an invasive lumbar puncture) (Büscher et al. 2017). Two compounds, fexinidazole and an oxaborole, are currently undergoing clinical testing. Fexinidazole, a nitroimidazole can be taken orally once a day for 10 days, has concluded phase II/III trials and is currently seeking a review from the European Medicines Agency (EMA) (DNDi, 2018). These trials are also investigating the potential for home treatment, as this is the primary setting (depending on case severity) the developers aim to introduce the drug into (Powell, 2017). Combined with confirmatory parasitological diagnosis, this would remove the need for lumbar puncture. This could also reduce dropout/no-show rates of HAT suspects identified with rapid screening tests. The oxaborole candidate Acoziborole SCYX-7158 was selected as a promising candidate in late 2009, and following successful preclinical trials, the drug entered clinical development in 2012. A Phase II/III trial to assess the safety and efficacy of acoziborole when given as a single dose to adult patients with *T.b. Gambiense* was initiated in late 2016 across seven study sites in the Democratic Republic of Congo (ibid). SCYX-7158 has some advantages over fexinidazole, requiring only a single oral dose as opposed to 10 daily oral doses. Owing to the high level of active compound retained in the body over at least 2 months, Acoziborole also offers protection against re-infection for a limited period (Steinmann et al, 2015). Some have argued that the benefits of the new RDT and a safe, relatively cheap and easily administered (i.e. oral) drug for both stages of both gambiense and rhodesiense HAT “could justify the unintentional treatment of a certain number of false- positive cases” (ibid: 711).

Post-treatment follow-up

Policy on the assessment of treatment outcomes until recently required patients be followed-up for up to 24 months with laboratory exams of body

fluids, as parasites may remain viable for long periods and cause relapses (Ngoyi et al, 2010; Büscher et al, 2017). Given the relatively low prevalence of infection in areas endemic for HAT, infections confirmed in previously treated patients in an elimination context are typically interpreted as a relapse, rather than reinfection (WHO, 2007). In rural Africa such a follow-up plan is challenging, and in practice compliance with follow-up is low, with patients rarely following programme protocols after their first follow-up visit, especially if they remain asymptomatic (Hasker et al. 2012). For rhodesiense HAT, patient compliance with scheduled follow-ups decreases with time, from 65%–85% at 12 months to 25%–70% at 24 months, whereas 40%–90% of relapses occur within 12 months and 70%–90% occur within 18 months (Ngoyi et al, 2010), and compliance with follow-up is as low as that for gambiense HAT (Küpfer et al, 2012). Due to the acute character of the disease, for patients treated for rhodesiense HAT symptoms may reappear quickly in relapsing patients. Because symptomatic patients are likely to present themselves for follow-up examinations, systematic follow-up after treatment for HAT is no longer recommended, and patients are instead advised to consult if symptoms reappear (WHO, 2013a; Büscher et al, 2017:9). These recommendations apply only for routine treatment outcome assessment and not for clinical trials of new drugs or new treatment regimens (WHO, 2013a:132-133), where 18 months of follow-up are recommended (WHO, 2007).

Recent and current trends in ‘Tor omele’ control in Uganda

In Uganda, HAT is more commonly referred to as ‘sleeping sickness’, owing to the symptoms observed in infected humans. In this sense, it is thought of as the sickness that causes excessive sleeping, though local definitions can vary. In the rhodesiense affected Lango region, the translation is ‘*Tor anino*’, the ‘disease of sleeping’ was used by many of my interviewees and colleagues in the Lango sub-regions of Dokolo, Lira, and Alebtong. Elsewhere, others in the Teso sub-regions such as Kaberamaido, the

Kumam term frequently used refers to '*tor omele*' [disease of the fly]. The differences in terminology between two closely related languages may seem trivial, yet the distinction in terms of their explanatory frameworks for HAT are telling. Indigenous names for disease can converge with biomedical understandings of disease, and reveals diverse understandings of disease aetiology, embodied in indigenous names (Simmons, 2009). Just as this name is attributed to the mechanism of transmission, so too '*tor omele*' centralises the significance of the tsetse's role in HAT. This may trace back to historical interventions that have positioned tsetse firmly at the centre of the problem and solution, emphasising the importance of bush clearing and proximity to tsetse infested areas as key risk factors for local populations.

Numerous control campaigns to control Tsetse and Trypanosomiasis (T&T) were conducted in various regions of Uganda as tsetse invaded new areas of the country throughout the 20th century (table 1), but none have proved sustainable in the long-term (Okoth, 1999). Before the 1950s, Trypanosome and Tsetse (T&T) control relied heavily on methods such as expansive bush clearing, ground spraying with dichlorodiphenyltrichloroethane (DDT) and wildlife culling, which had harmful environmental impacts. From the 1980s, more ecologically and politically acceptable methods were developed: selective bush clearing, sequential aerial spraying (SAS), insecticide-treated traps and targets (ITT), insecticide-treated cattle (ITC) used as live baits, and eventually the sterile insect technique (SIT) (Meyer et al. 2016). al. 2012).

Table 1: Key documented T&T control operations implemented in Uganda since 1980. (from Meyer et al. 2016).

Leading institutions	Location (scale)	Time period of project	Objectives	Level of community participation	Interventions	Reduction of tsetse level	Reduction of AAT prevalence	Difficulties	Sustainability
Government services	Busoga (2,200 km ²)	1988–1990	Control of HAT epidemic	Labour contribution	ITT + ITC	99%	100% reduction of HAT in certain parishes	Persistent tsetse reinvasion from adjacent areas	Not reported. However similar HAT control was sustainable in neighbouring Tororo
LHRI	Busia (130 km ²)	1991–1993	AAT control	Not reported	ITC	98.4%	92%	Diminution of coverage led to disease upsurge	Not reported
LHRI	Tororo (1,350 km ²)	1991–1995	AAT and HAT control	Information only	ITT +/- ITC +/- TRY	99.5%	94%	Persistence of mechanical transmission	Lack of funding but AAT prevalence still lower in control area in 2000
FITCA	Busoga (2,000 km ²)	1999–2004	AAT and HAT control	Resource contribution. Farmers' groups to manage ITC. Community assistants for ITT	ITT + ITC + zero-grazing units	75 to 90%	'Insufficient'	Low level of coverage. Farmers' groups did not persist in time.	Unsustained. Tsetse reinvasion by 2009
PATTEC	South-East (15,000 km ²)	2005	Tsetse elimination	Information only. Stronger involvement was planned	ITC + TRY (SIT planned)	50 to 75% in 12,000 km ²	Not reported	Failure to implement SIT. Failure to reorient project due to management issues.	Unsustained. Funding came to an end in 2011. Tsetse reinvasion may occur in the absence of barriers
Makerere University	North-East (8,800 km ²)	2006	Control of HAT epidemic	Resources contribution	ITC + TRY	Not reported	75%. Large reduction of HAT prevalence	Low level of coverage due to community hesitation. Wide use of amitraz. Cattle immigration.	Unsustained. The control activities were not followed by community involvement.

Abbreviations: FITCA, Farming In Tsetse Controlled Areas project; ITC, insecticide-treated cattle; ITT, insecticide-treated traps and targets; LHRI, Livestock Health Research Institute; SIT, sterile insect technique; TRY, trypanocidal drugs.

Political unrest up to the early 1990s has had a major impact on control operations in Uganda. Although early campaigns were initially successful, conflicts often disturbed operations, discontinuing them completely in some areas (Allsop, 2001). After decades of military conflict in the northern and eastern regions (Karamojong cattle rustling, the Teso War, and the Lord's Resistance Army insurgency), cattle restocking programmes doubled the parasite's ecological range, which had previously been limited to the Lake Victoria Basin (Selby et al. 2013). In response to large outbreaks in the early 2000s caused by the northward spread of infected cattle, a public private

partnership called Stamp Out Sleeping Sickness (discussed further below) was created to disrupt transmission among the animal reservoir. In addition to socio-demographic upheaval caused by internal conflicts driving outbreaks of HAT, conflicts over Uganda's borders, particularly to the north in gambiense endemic South Sudan in recent years has driven hundreds of thousands of refugees into the country, posing a threat to elimination efforts in the north (Picado and Ndung'u, 2017).

Present methods which depend on trapping or killing tsetse flies with insecticides have proven difficult to sustain at the local community level for human disease control. Some argue that those tasked with managing trypanosomiasis or committed to poverty alleviation in Africa should consider continuing large-scale, area-wide tsetse control methods like aerial spraying and Sterile Insect Technology (SIT) (Allsop, 2001), which was used for the successful eradication of the tsetse fly *Glossina austeni* from Unguja Island of Zanzibar (Vreysen et al. 2014). However, despite this victory leading to the establishment of the Pan African Trypanosomiasis and Tsetse Eradication Campaign (PATTEC) in 2002, SIT is only effective when the target population density is low and is too costly to scale up and sustain outside of island and similarly isolated foci of tsetse populations, as they are soon re-invaded by surrounding tsetse populations (Vreysen, 1995).

Less technologically sophisticated but highly effective are the wide-scale deployment of Stationary Attractive Devices (SADs). These attract female tsetse flies to a device e.g. cloth traps or targets that either kill the flies through contact with insecticides applied to the surface of the target (Vale, 1993), or by heat or starvation after being guided to trapped inside a non-return cage (Brightwell et al., 1991). Tsetse trapping is usually regarded as the responsibility of the government, although farmers are often willing to contribute labour to their deployment and maintenance (Meyer et al. 2016). More recently, efforts to control tsetse in the West Nile region of the country using so-called "tiny targets" as an effective tool for HAT control have yielded promising results (Tirados et al. 2015).

Like the colour attractant targets, the 'live bait' technique exploits finely studied behaviours of tsetse, in this case on their blood-sucking feeding behaviours. Using insecticide treated livestock, tsetse flies take up a lethal dose of insecticide whilst feeding and die (Leak, 1998). Pour-on formulations require no particularly sophisticated equipment, and the insecticide application is rapid and easy. Unlike with SADs, the technique is also less prone to theft and does not suffer from maintenance problems (Vreysen et al. 2012). In regions affected by rhodesiense HAT, it is generally agreed that the curative and prophylactic use of trypanocidal drugs administered by farmers remains the most important method of controlling AAT in Africa today (Leak, 1998). The market logic underpinning this approach is that farmers should be willing to pay for treatment of their own cattle with insecticides and trypanocides as the benefits of these techniques are perceived as private (Meyer et al. 2016).

The failure of various top-down approaches in Uganda eventually led to the feasibility of community-based interventions, such as the FITCA (Farming In Tsetse Controlled Areas) and SOS (Stamp Out Sleeping Sickness) campaigns, being explored. However, these programmes also faced sustainability issues. A lack of engagement of the project recipients was attributed to financial issues with community-based programmes, and the levels of coverage achieved using Insecticide Treated Traps (ITT) and Insecticide Treated Cattle (ITC) were ultimately not enough to interrupt the transmission of parasites (ibid).

One Health: an integrated approach to disease control

The London Declaration on NTDs in 2012 was shortly followed by the World Health Assembly 66.12 Resolution in May 2013, which encouraged the coordination of Veterinary Public Health actors under a 'One Health' approach, owing to the animal and environmental contributions to

transmission and control. This was a crucial step for implementing sustainable control programmes for Neglected Zoonotic Diseases like HAT (Mableson *et al.* 2014). While *T.b. gambiense* has also been targeted for elimination, *T.b. rhodesiense* is still often spoken of in terms of ‘control’ only, reflecting the multitude of factors involved in tackling the zoonotic form.

The ‘One Health’ paradigm is a broad movement that recognises the interdependency of human, animal and ecosystem health, and that multidisciplinary collaborations are a necessary approach to achieving optimum health solutions (figure 3). The model is broadly constituted by a collective of actors from a diverse range of disciplines, histories, practices and politics. The physical locality of the participating actors within the One Health network, whether a philanthropic donor in the US, a Ugandan Vet in Tororo district, or a database located on a server in Belgium, is irrelevant in this model. Considering Law and Mol’s performative accounts of Actor-Networks (in Law and Hassard, 1999. p.17), the question of *what* passes between these links and defines this relationality becomes critically important. Different contexts shape all of these connections and relationships, constraining agents to act in a particular way based on their training, the internal politics of their lab or department, and funding climates. The required co-operation of more disciplines and sectors, and the merging of previously distinct and at time conflicting paradigms in many ways epitomises the challenge of the One Health approach in general; an assemblage of international institutions, coordinating bodies, organisational models and policy initiatives – converging to sustain and promote particular ways of ‘doing global health’ (Smith, Taylor, and Kingsley, 2014: 1).



Figure 3: Thematic representation of One Health model.

(from Okello et al. 2014: p.3).

Despite the consensus towards a broader One Health system, combining veterinary, medical and environmental disciplines and integrated holistic solutions – such networks remain inherently compartmentalised, and constrained by the inflexibility of its actors. The One Health concept, while grounded on the premise of shared knowledge and political will toward common goals, is comprised of such a disparate set of actors that the practical application of unification across disciplines and sectors is ultimately undermined by the rigidity of its purported greatest strength; ‘interdisciplinarity’.

“Everyone is fighting their corner, trying to get limited funds for their technologies, tied up with a particular narrative of vector and disease control that suits their technical solution” (Scoones, 2014. p.28).

Tackling neglected diseases and the issue of “neglect” in itself requires a high-level of advocacy, and the language of advocacy plays an extremely important role in constructing what Scoones refers to as ‘justificatory narratives’, relying on selling points to invoke action: “It has to kill people. Fly bites man, man dies, we should do something [...] the key is generating success stories” one researcher in Scoones’ study commented (Scoones, 2014: 5). These narratives are based on a range of factors that vary not only between diseases, but also between the two strains of disease in the case of HAT.

Catherine Grant’s work on Tsetse control in Zambia has revealed how contested methods and views on how best to control Trypanosomiasis has depended greatly on the narrative and perspective of stakeholders, while “the validity of these debates is often not what drives policy and programming” (Grant, 2014: 11). For example, the Government of Northern Rhodesia introduced a largely ineffective policy of introducing game fences in the 1940s in attempts to control the wildlife host reservoir, despite their documented failure to impact on tsetse populations. This led to anger among wildlife conservationists “at a failure to use evidence available at the time showing this”. As one interviewee described;

“Tsetse barriers only have a social function [...] they are a reference point for people, but there is no use or point of them for tsetse flies. Fly gates are completely useless and are only there so people can show that they are doing something.” (informant in Grant, 2014: 12).

It is widely understood that not all policy is informed by evidence, and largely shaped by narratives advocated by key stakeholders. Grant concludes that better monitoring will lead to “increased understanding of the impact of policy options and greater motivation for control” and enhancing surveillance will in turn allow “narratives to be based on a solid evidence base” (Grace, 2013 in

Grant, 2014: 24). However, the conditions under which surveillance data is collected and knowledge produced deserves critical attention. A comprehensive consideration of all available evidence and knowledge forms, including that of indigenous, local knowledge and experience, something that Grant herself alludes to as a widely overlooked driver of disease dynamics in control programmes (*ibid*: 13), might help to shape a more rounded and all-inclusive narrative that empowers all stakeholders.

Political environments continue to inhibit the successful collaboration and pooling of expertise and resources to meet shared goals across the different sectors and disciplines for Trypanosomiasis control in Africa (Scoones, 2014). Discord between policy narratives and practice occurs at various levels throughout implementation, described by Mosse as an unintended 'gap' between theory and practice. In this climate of ambitious "sector-wide approaches, state-level partnerships and policy-based budgetary assistance" (2004: 640), these relationships and their influence on the research agenda and production of evidence require further investigation. Thus, my research attempts to pry open the "black box of unknowing" between policy and its effects (*ibid*) by better understanding the convergence of different agendas and interests in Trypanosomiasis control in Uganda.

Stamp Out Sleeping Sickness: performing One Health through Public Private Partnerships

Partnerships that facilitate the market outreach and funding necessary for implementing effective and sustainable intervention strategies are hugely important for One Health programmes. However, it may be argued that such relationships place large pharmaceutical and commercial partners in favourably powerful positions to 'call the shots' on what constitutes good evidence and appropriate indicators of impact (Hawkes, 2014). This is a complex issue that not only highlights power differentials between global partners within financial networks, but the way in which evidence is ultimately

constructed and fed back into epidemiological and scientific investigation. In order to better understand these dynamics and their influential mechanisms, it is important to examine the role of such funding models and their impact on HAT control.

The control and surveillance of AAT and HAT in Uganda are run in co-operation with numerous international organisations, research institutions, development agencies, NGOs and private firms. These collaborations form the basis of the network of relations that co-produce epidemiological evidence, upon which policy decisions for disease control are based. Founded in response to a major outbreak of *T.b. rhodesiense* in the 1980s, COCTU (the Co-ordinating Office for the Control of Trypanosomiasis in Uganda) is one such institutional element of the One Health assemblage in action. Seated within the Ministry of Agriculture, Animal Industries and Fisheries (MAAIF), its mandate is to co-ordinate policy and oversee all Human and African Trypanosomiasis control in the country (Smith, Taylor, and Kingsley, 2014), and is a “unique example of Uganda’s commitment to One Health long before the approach became “fashionable” (Okello *et al.* 2014: 2). COCTU’s involvement in the national *Stamp Out Sleeping Sickness* (SOS) campaign is a principal example of this commitment.

As previously mentioned, the two separate sub-species of HAT are sensitive to different chemotherapeutic regimes, and therefore treatment needs to be suited to the causative sub-species presented. Therefore, while the two have always been spatially distinct, if overlapping of the two strains were to occur then accurate field diagnosis would become virtually impossible, and thus treatment may be administered incorrectly. In areas recovering from conflict and upheaval by the Lord’s Resistance Army (LRA) insurgency, SOS was initially conceived as an emergency intervention to maintain a ‘buffer zone’ between the two HAT strains (Bardosh, 2016). The SOS programme, framed within the context and narrative of this emergent threat, i.e. the “thin line between two fatal diseases” converging in Uganda (see figure 4) (Picozzi *et al.*, 2005, p.1238), was an initiative that, albeit only focussing on rhodesiense

HAT, successfully encapsulated both the Public Private Partnership (PPP) and One Health approaches.

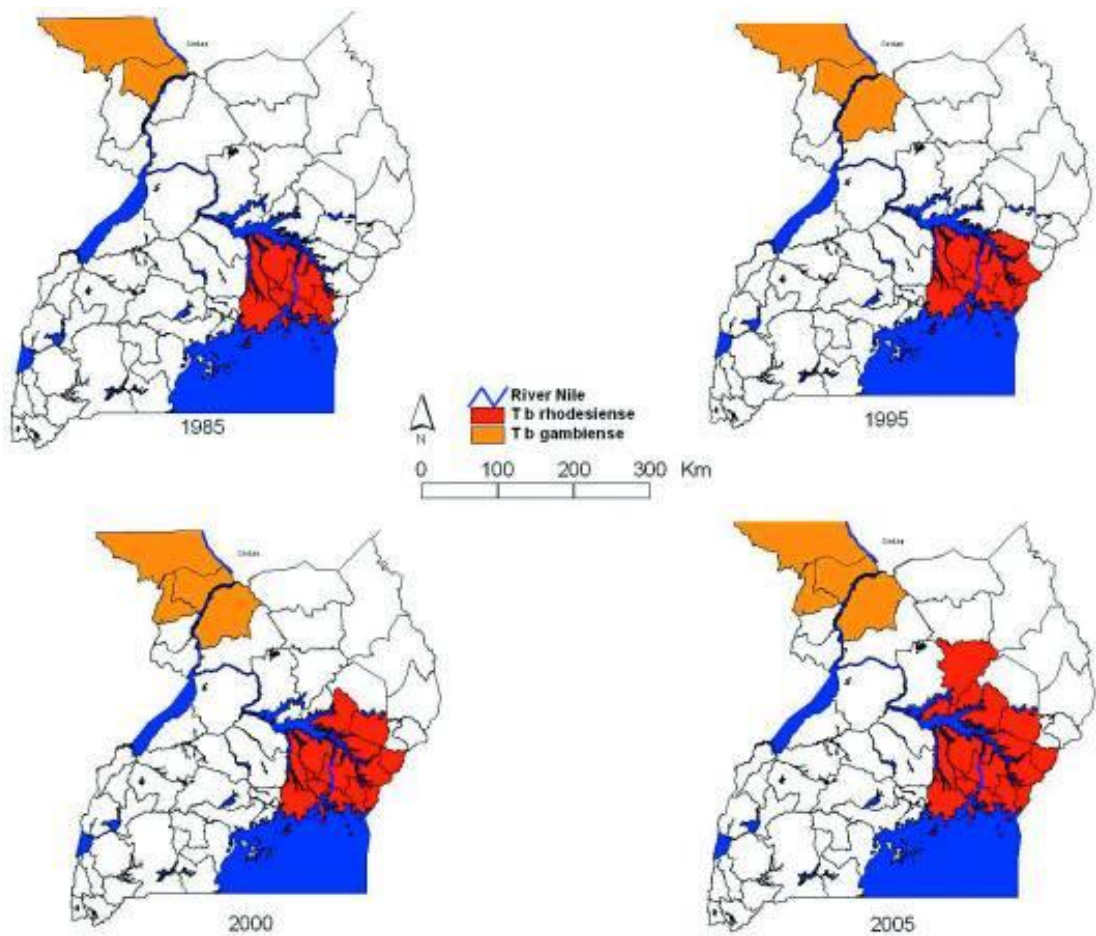


Figure 4: Sequential maps of areas of Uganda affected by sleeping sickness.

T b gambiense (orange) prevalent in northwest Uganda, *T b rhodesiense* (red) has been spreading since the mid-1980s, and its transmission is now occurring within 150 km of the *T b gambiense* active focus. The tsetse belt for *Glossina fuscipes fuscipes* extends across this region (Picozzi et al. 2005).

The first cases of rhodesiense HAT in Kaberamaido and Dokolo districts were reported in 2004, and the continued presentation of new cases to this day indicates active transmission in the region (Hamill et al. 2017). In response to the initial outbreak, in 2006 a mass chemotherapeutic intervention was co-ordinated through a public-private partnership called SOS (Stamp Out Sleeping Sickness), comprising of academic partners at the University of Edinburgh and Makerere University, business (veterinary pharmaceutical company Ceva Sante Animale), philanthropy (IK Aid and

Relief Enterprise (IKARE)), and development through the UK Department for International Development (DFID). The ambitious intervention targeted cattle in the affected region in an attempt to prevent the northwards spread of HAT (Welburn and Coleman, 2015), and continued sporadically until 2008, owing to the persistence of HAT cases in parishes along the border between Dokolo and Kaberamaido (Batchelor et al. 2009).

The word 'campaign' derives from the Latin word for 'field', just as military campaigns were fought in fields (Rogers, 1995). It is a fitting term for a many historical HAT control interventions (a number of which were actually coordinated by colonial and post-independence military forces) and is no less true of the kind of approach taken by SOS. In an attempt to halt this 'catastrophic' crossover, in 2006 the SOS project undertook an emergency intervention comprising of a combined mass trypanocidal treatment campaign and insecticidal spraying of cattle in newly infected regions, based on the premise that this would remove cattle as a reservoir of the disease, thus halting its spread northwards (Smith et al. 2014, p.4).

The mass chemotherapy and spraying was applied in three rounds of mass cattle treatments in seven districts between 2006 and 2010, resulting in the treatment of 200,000 cattle across Amolatar, Apac, Dokolo, Kaberamaido, and Lira districts (8025 km² and 750,000 people) in Phase One (2006–2008), and a similar number in Soroti and Serere districts (2873 Km² with 369,789 people) during Phase Two (2010) (Bardosh, 2016). To achieve this, the PPP model was considered the most effective means of delivering the veterinary medicines and sprays (provided by CEVA Santé Animale) and achieving a feasible and sustainable intervention (*ibid.* p.4). In a "collaborative effort involving product, people and know-how" a Public-Private Partnership between key academic, pharmaceutical, governmental and private sectors was brokered to launch a mass treatment campaign to rid cattle of the disease (and thereby protect the human population) (Stamp Out Sleeping Sickness, 2014). In a renewed response to this threat, at the time of

study, plans to re-implement and scale up the SOS programme on a more comprehensive and sustained level were underway, and aimed to test the suitability of Development Impact Bonds (DIBs), a novel financial model to achieve its targets (figure 5).

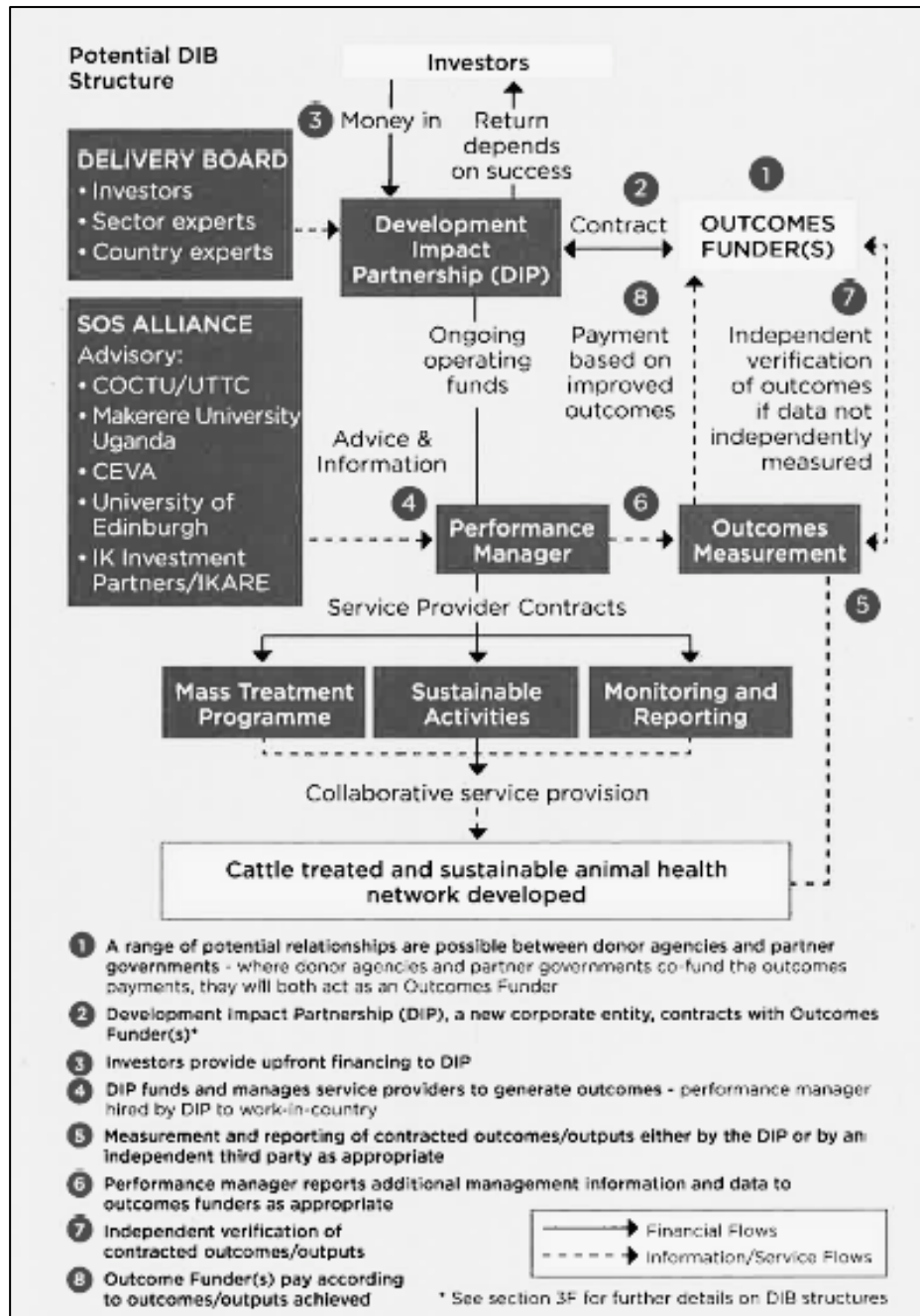


Figure 5: Development Impact Bond structure chart for the SOS intervention model.

(Centre for Global Development, 2013: 51),

At a time when Public-Private Partnerships are “very much the flavour of the age” (Scoones, 2014. p.71), it is increasingly important to scrutinise the impact these relations have on which research questions are asked, what data is collected to answer them, and how that information is then dealt with thereafter. The ways in which data are mobilised and construct evidence to frame policy narratives and justify proof of concept for investment is hugely important yet largely overlooked. I hope that this thesis will draw attention to this process by tracing the kinds of advocacy language deployed by interventions and policy back to practice and the evidence used in these ‘justificatory narratives’ (Scoones, 2014). While the two have been conflated in the SOS model, linking business ventures to health outcomes in a post-conflict, subsistence economy is problematic, something partners pondered in Kevin Bardosh’s study of the SOS programme’s legacy, asking to what extent “is this business or public health?” (2016: 346).

SOS was initially successful, significantly reducing HAT incidence from pre-intervention period, and maintained lower HAT incidence during the intervention year, and two years (2007 – 2008) post-intervention (Mukiibi et al. 2017). They had established that preventative chemotherapeutic treatment, when drugs are applied to enough of the reservoir cattle population, could significantly reduce the prevalence of trypanosomes and end transmission cycles. Modelling indicated that widespread treatment of more than 86% of the cattle population with trypanocidal drugs could eliminate *T. b. rhodesiense* circulating in cattle (Welburn et al., 2006). However, monitoring from the first phase of SOS showed that despite treating 200,000 cattle across Amolatar, Apac, Dokolo, Kaberamaido, and Lira districts (8025 km² and 750,000 people) and achieving a near 70% reduction of the HAT parasite in cattle, reinfection subsequently recurred in the reservoir population over the following 18 months (Welburn and Coleman 2015), and HAT incidence significantly increased in 2009 (Mukiibi et al. 2017).

The sickness that sleeps: HAT in the landscape of elimination

Today, we find ourselves in a familiar situation. While cases have largely dwindled over recent years (figure 6), so too has public awareness and vigilance of HAT. It seemed for a time that the political will to invest in long term solutions for a disease that posed no immediate threat too had waned. “We have been here before, but we are too quick to forget”, as one prominent Ugandan entomologist remarked solemnly at the end of our interview, “complacency is our greatest challenge”.

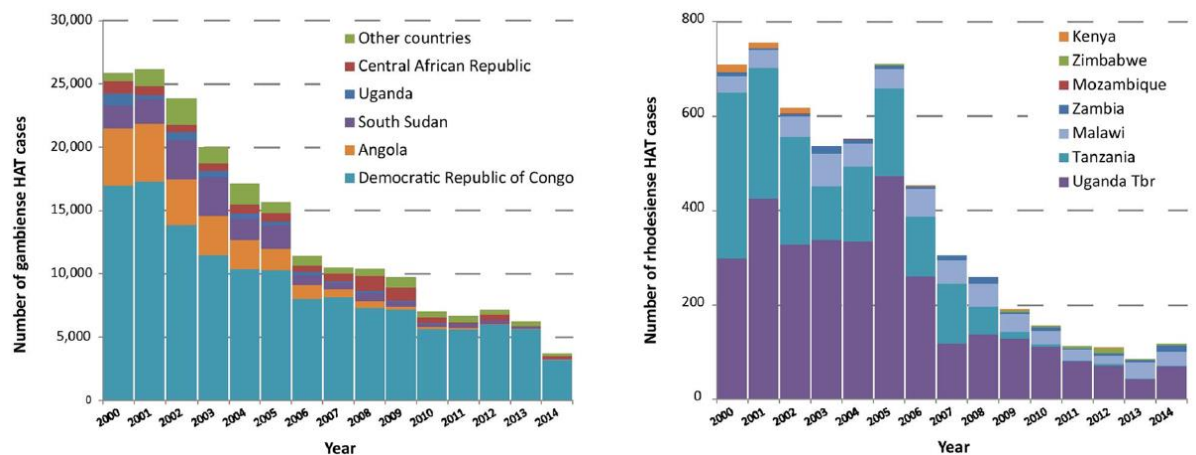


Figure 6: Number of reported cases of gambiense HAT per year and per country and number of reported cases of rhodesiense HAT per year and per country.

(Franco et al., 2017: 6).

In 2011, owing to the 70% decrease in cases reported to WHO since the previous decade (see figure 7), the goal of elimination was deemed feasible by the WHO Strategic and Technical Advisory Group for Neglected Tropical Diseases. A “roadmap” on neglected tropical diseases set *T.b. gambiense* as a target for elimination as a public health problem by 2020. In January 2012, partners from public and private sectors gathered to launch an unprecedented effort to tackle NTDs by signing the London Declaration, marking a coordinated effort to control or eliminate 10 infections, including HAT (WHO, 2013c). This signalled a renewed commitment to ‘putting

sleeping sickness to sleep forever’, as one article celebrated. Since then, international teams ‘waging a decisive battle against the deadly disease’ to ‘consign sleeping sickness to the dustbin of history’ (Scholtabers, 2018) have made significant headway.

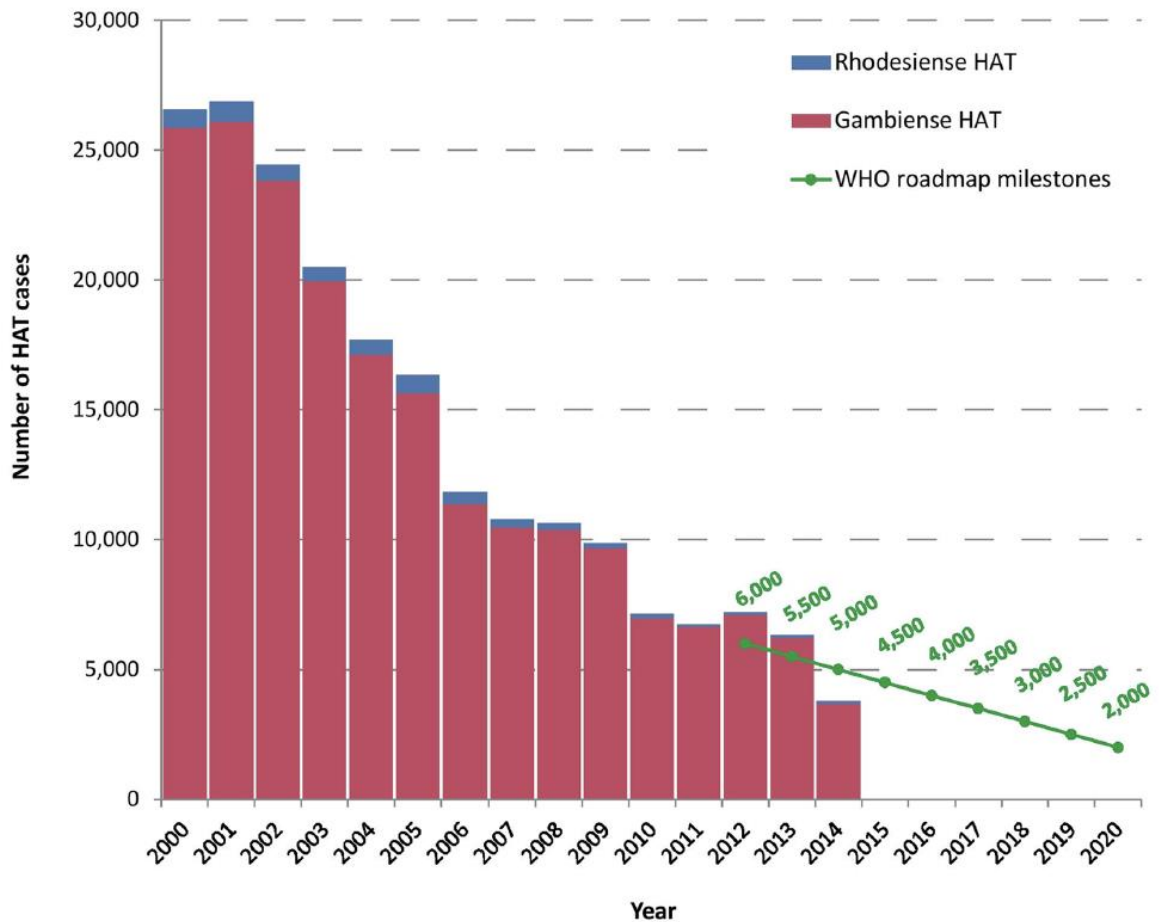


Figure 7: Total number of reported cases of HAT (gambiense and rhodesiense) per year.

The green line plots milestones set out in the WHO Roadmap for HAT elimination (Franco et al., 2017: 6)

In some respects, gambiense HAT can be considered a more ‘tool ready’ disease to control. For rhodesiense HAT however, owing to the added complexities of its zoonotic reservoir, total interruption of transmission has for a long time not been considered feasible (WHO, 2013b). Just months after the gambiense HAT elimination roadmap was launched however, participants in the first rhodesiense HAT stakeholders meeting in October

2014 declared their interest in joining the international network to advance efforts to eliminate the zoonotic disease by “accelerating biomedical research, expanding the scientific knowledge base, implementing cost-effective vector control, improving diagnosis and clinical care, and enhancing the efficacy of medical and veterinary public-health measures for the control and monitoring of the disease” (WHO, 2014).

In February 2018, Uganda celebrated its one-year anniversary since the last domestic case of gambiense HAT was detected in the country (FIND, 2018), an achievement attributed to the implementation of novel diagnostics and tsetse control interventions through the new ‘Intensified Sleeping Sickness Elimination Programme’ (ISSEP). Now re-branded as ‘Trypa-No!’, the programme’s challenge now is to capitalise on this success and sustain this pressure ‘to the last mile’ (Reynolds, 2018).

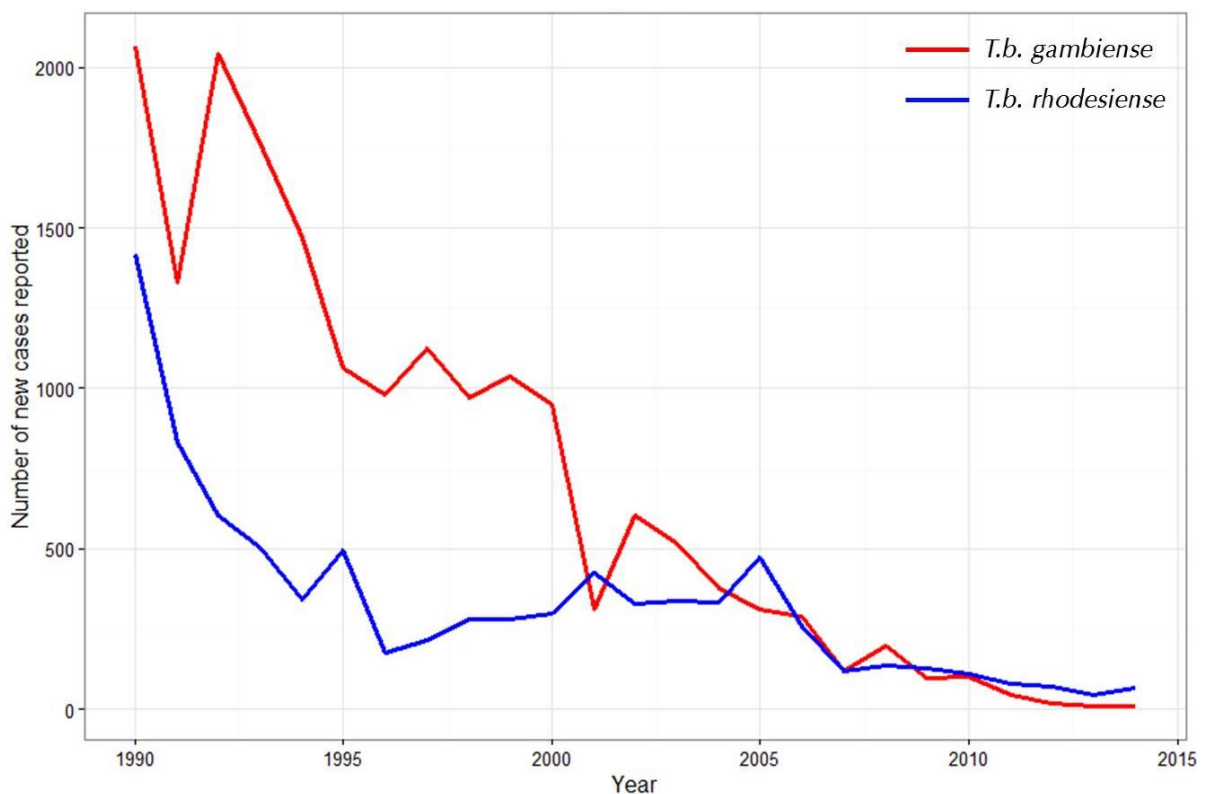


Figure 8: Trends in HAT in Uganda 1990-2015 (WHO, 2017).

Efforts are now being concentrated on priority areas in efforts to not only maintain the geographical gap in the 'cattle corridor' between the gambiense and zoonotic rhodesiense HAT (figure 9), but to sustain them to eliminate both strains.

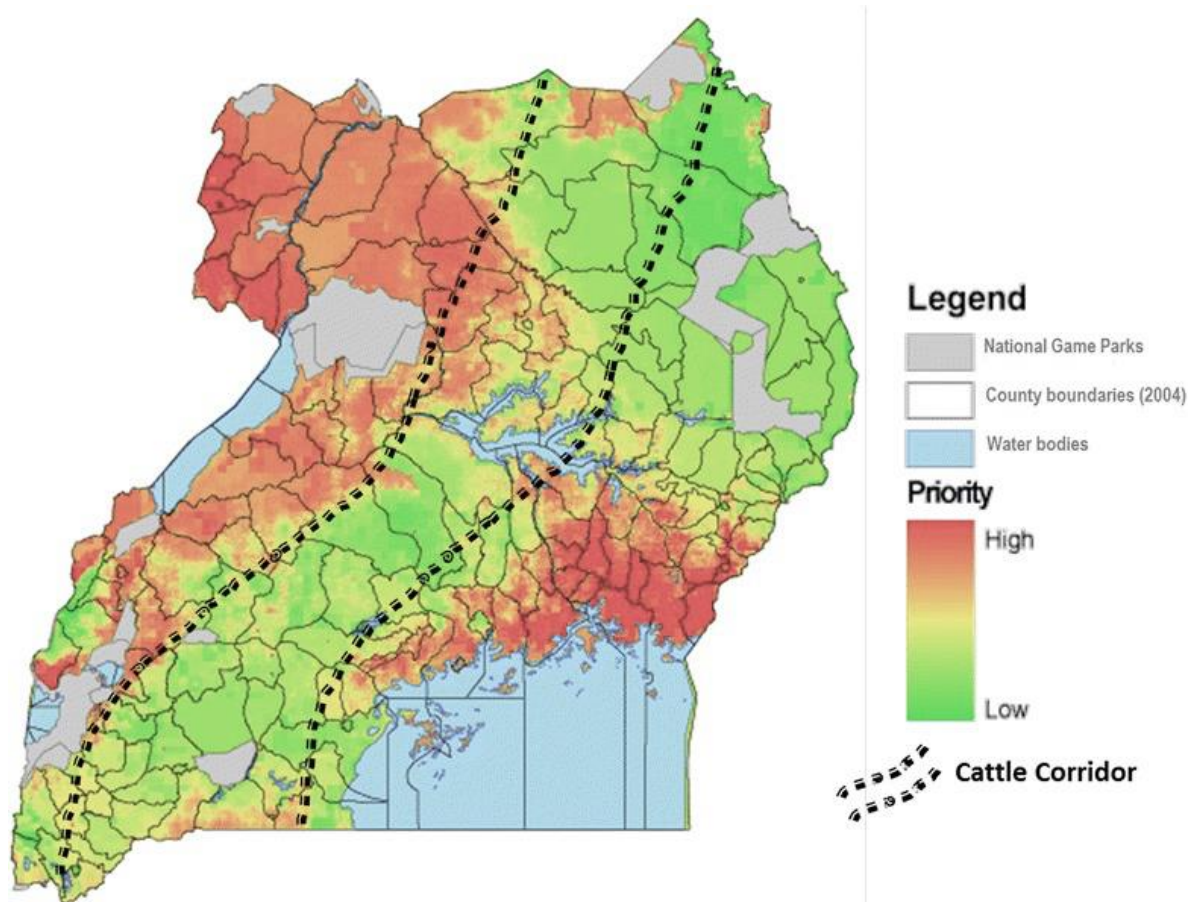


Figure 9: Current Uganda trypanosomiasis control priority map.

Credit: Coordinating Office for Control of Trypanosomiasis in Uganda (From Muhanguzi et al, 2017).

But how is elimination defined and known? Long, asymptomatic periods of gambiense HAT infection in human reservoirs, combined with its frequent misdiagnosis for other endemic fevers makes it particularly difficult to find in non-endemic settings. In elimination scenarios, as we find ourselves in Uganda, the imperfect specificity of diagnostic tools means that, in the low prevalences we see today, their positive predictive value (PPV) diminishes (Chappuis et al., 2005). Finding HAT beneath the biomedical radar can be like finding the proverbial needle in a haystack. In the elimination landscape, 'sleeping sickness' can invoke a new interpretation; not only the sickness of

sleeping, but as the sickness that sleeps; latently waiting for social and ecological conditions, and transmission cycles to align and configure favourably to produce pathogenic possibilities for its resurgence in ‘patches’, or ‘hotspots’ (Scoones et al., 2017; Brown and Kelly, 2014).

In her history of disease eradication programmes, Nancy Leys Stepan describes characteristic features of the relatively modern eradication model in public health, and ‘their useful ambiguities’ (2011: 10). In doing so she interrogates funding institutions’ (and consequently the global health community’s) historical fixation on techno-centric solutions. Hookworm for example, “first and foremost a disease of social misery”, proved to be a challenging disease to take on, given the Rockefeller Foundation’s preference for technical solutions over social ones. Similarly, just as their techno-centric approach by itself “would not eradicate a disease so entangled in multiple determinants of social and economic kind” (*ibid*: 76), the social, economic, and environmental entanglements of HAT with conflict and poverty make it less amenable to singular technical solutions for elimination.

Passive case detection and the decentralisation of HAT control and referral

Historically, mobile teams have been extensively used to screen at-risk populations in epidemics throughout the 20th century (Franco et al. 2017) and typically travelled with all laboratory equipment needed to confirm a case who would then be treated in hospital. In non-epidemic scenarios such as in Uganda today, when mobile teams are regarded as too expensive, programmes typically revert to a passive case detection strategy with diagnosis restricted to places, usually hospitals, which can similarly perform all screening and confirmation tests in sequence. In the rural areas where HAT is most endemic, however, such well-equipped hospitals are rare. HAT screening campaigns have sometimes been considered “vertical

interventions [...] deployed in the absence of local healthcare infrastructure” (Steinmann et al. 2015) with the risk that the “progressive dismantling” of highly specialised mobile teams who possess the most expertise in HAT diagnosis could therefore have “grave consequences at the individual and community level” (Büscher et al. 2017).

HAT presents a particularly unique challenge to disease surveillance in terms of diagnostic capability, treatment, and surveillance. As most cases are picked up syndromically during presentation at healthcare centres and hospitals, patients who have not been misdiagnosed with malaria (as is often the case) and are suspected of having Sleeping Sickness are referred to a specialist health centre, which is equipped with the necessary laboratory equipment, trained staff, and stocked with drugs to diagnose/confirm and treat the disease. As these centres are often long distances away and treatment requires a long period of hospitalisation, many patients may fail to complete their referrals. The discrepancy between syndromic suspects referred from peripheral facilities and those who go on to become diagnostically confirmed cases are often unrecorded and un-traceable, therefore posing an enormous challenge to the adequate surveillance of HAT prevalence.

Reaching the stage whereby a patient will eventually find themselves receiving treatment is reliant on connections between a highly decentralised healthcare delivery system that rests heavily on the likelihood of health workers suspecting HAT and having access to appropriate diagnostic equipment. Owing to low awareness – both in the community and among health workers – and the multitude of factors that obstruct patients successfully being suspected and then diagnosed as a case, the system of passive surveillance is widely regarded as an inadequate strategy for elimination targets given problems with case detection (Smith et al., 2014: 3).

Case detection is beset with concerns surrounding under-reporting; a problem particularly true of *T.b. rhodesiense*, where evidence suggests under-reporting to be as high as 40% in some foci (Fevre, 2008). Figures indicate a steady decrease of HAT cases over the past decade, however it is important to recognize that WHO incidence data are based on reported cases (Welburn and Maudlin, 2012:312). In the context of sleeping sickness, cases that do not reach a hospital are not reported. For example, in Uganda it is estimated that 92% of deaths from *T. b. rhodesiense* sleeping sickness go unreported (Odiit et al., 2005). Studies in several countries endemic for rhodesiense HAT (Odiit et al., 2004; Odiit et al. 2005; Matemba, 2010) showed patients make up to seven visits to various health care providers prior to being successfully diagnosed. Delays in case detection increase the chance of late-stage presentation. Given that the fatality rate among patients with second-stage rhodesiense HAT is 2.5 times higher than that of patients with first-stage disease this is a major cause of public health concern (WHO, 2013b: 194).

Underestimation of disease burden is inevitable in sub-Saharan Africa due to extrapolation from scant data. Consequently, this means estimates can only be approximate, with a strong tendency towards underestimation of disease burden. This problem is amplified where only passive screening exists, in areas where health staff may be inadequately trained to detect and identify the disease. Even where facilities are sufficiently equipped and staffed to diagnose HAT however, case detection thereafter relies on adequate reporting of cases.

This presents particular concern in regions where Rhodesiense HAT is spreading further north-westerly where cases are relatively new, and current data management and surveillance systems are notably inadequate to deal with them (Acup, 2013). It also poses questions regarding how we go about detecting HAT in such a landscape; how can spaces of surveillance be created whereby an infected patient can be seen by the state? How do spaces like the hospital, the private clinic, or the laboratory facilitate their

movement through referral in a way that makes them visible, and to what extent is it possible to extend such spaces through new technologies in order to widen the clinical gaze beyond the confines of a few centres of expertise?

Contemporary innovations and emerging strategies in HAT control

For over a century multiple efforts have been undertaken to control HAT to little or no avail. Today, cases in Uganda have dropped significantly, a decline frequently attributed to a proliferation of technologies and their wide-scale implementation. At the Silver Jubilee celebrations for the Ugandan Trypanosomiasis Control Council (UTCC) and COCTU in October 2017, IKARE director Anne Holm Ranaleet drew this conclusion:

“Slowly but surely our efforts over the last 10 years to control the disease are paying off and we can see a steady lowering in the number of Human African Trypanosomiasis cases to very few cases per year. Two initiatives in particular have contributed to this development. The Tiny Targets and rapid diagnosis activities carried out in the West Nile region, and our SOS initiative in Northern Uganda”. (IKARE, 2017).

It is these key ‘emerging’ strategies and technologies (Steinmann, 2015) and the socio-material assemblages they co-produce that I turn to as the subject matter, or units of analysis for my case studies.

Innovations in diagnostic capacity: introducing a rapid test for HAT

At the forefront of these ‘important innovations’ has been the development of lateral flow rapid diagnostic tests that can be used for the serodiagnosis of HAT in place of the Card Agglutination Test for Trypanosomiasis (CATT), which requires a constant electrical supply, a cold chain, and trained personnel (Jamonneau et al. 2014). In 2013, an RDT-based passive

surveillance strategy was implemented in Uganda to spearhead an intensified *T.b. gambiense* HAT elimination programme. The finger-prick test (figure 10) developed by FIND with academic, manufacturing and endemic country partners, detects antibodies in fresh blood samples against two trypanosome antigens. It ostensibly requires minimal training of health workers and produces a positive or negative result within 15 minutes.

In 2013, a new RDT-based referral system was implemented by the Intensified Sleeping Sickness Elimination Programme (ISSEP) (now called 'Trypa-No!') as part of an enhanced passive surveillance system (Wamboga et al. 2017). Tests provided by FIND were delivered through the national elimination programme to frontline health facilities as part of a new HAT diagnostic algorithm, to be conducted where symptomatic patients tested RDT negative for malaria. As the elimination programme area is also endemic for malaria, staff at all facilities were already familiar with performing malaria RDTs. This familiarity prefigured the implementation of an RDT for HAT and it was assumed the test could be absorbed seamlessly into a pre-established diagnostic routine.



The SD BIOLINE rapid antigen test for *T.g. gambiense* HAT developed with FIND

With diagnostic technologies now spread across three (or more) levels of the health system (Wamboga et al 2017), however, this means that for the first time in the history of HAT control, the diagnostic algorithm is routinely split up over geographic spaces.³ This requires patients and/or samples to travel between them and programmes to monitor these movements. People who screen positive in these new strategies are implicitly expected to undertake a significant role in confirming (or disproving) their own diagnosis. Moreover, there is substantial work involved for both programmes and patients to make sense of discordant results, since patients who screen positive with RDTs but negative in subsequent tests must be followed up at quarterly intervals until

³ In the past, in extremely remote areas inaccessible to vehicles, mobile teams have collected blood samples from patients on filter paper to be screened remotely (Chappuis et al. 2002, 2005). If a patient tested positive, they were asked to report for confirmatory testing at a site where the mobile team could access. However, this practice was not widespread.

they become seronegative or are confirmed as cases, for up to two years (WHO, 1998). Even without the extra layers of referral introduced by passive RDT-based systems, most HAT programmes typically achieve low levels of serological suspect follow-up (Chappuis et al. 2004; 2005).

Fexinidazole: a new oral treatment on the horizon

Current treatment options require identification of the clinical stages of HAT (i.e. whether the parasites have entered the central nervous system). The painful lumbar puncture procedure and potentially toxic drug regimens this entails however may soon become redundant, since new oral drugs effective against the both stages of the disease look promising (Kovacic, 2015).

Fexinidazole (or 'Fexi' as it is commonly abbreviated) is a well-tolerated oral treatment that can be given for 10 consecutive days (Tarral et al, 2014). It is currently in phase III trials in patients with stage 1 and stage 2 HAT and is due to come onto the market in 2019, with a high possibility that it might be available for both stages of the disease (Sutherland et al. 2016).

Phase II/III study results published in 2017 confirmed that fexinidazole is safe and effective and has significant advantages over NECT. Fexi was recommended by the European Medicines Agency in November and registered in Democratic Republic of Congo (DRC) in December 2018 (DNDi, 2019). Not only would a safe oral drug, effective for both stages of the disease greatly improve access to treatment, it would also remove the need for staging through lumbar puncture, a painful and poorly accepted part of the referral process (Simarro et al., 2014). Furthermore, its developers, the Drugs for Neglected Diseases Initiative (DNDi) are expected to run a phase IIIb trial examining the effectiveness of fexinidazole in patients treated as both out-patients and in clinical hospital settings to produce information on "the drug's use in settings replicating what the DNDi hope will become standard" (Powell, 2017; DNDi, 2017).

Meanwhile, a phase IIIb trial to obtain more information about special populations not included in previous fexinidazole trials (such as children and pregnant women) started in 2016 and is ongoing (DNDi, 2018).

In isolation, this new drug regimen could have significant impact on the feasibility of treatment of HAT, but only incremental bearing on HAT control as a whole. However, combined with other 'emerging technologies' such as the HAT RDT and Tiny Targets, Fexi has been celebrated as one of the most promising candidates among the arsenal of tools toward elimination. The potential effect on patient perceptions is significant, as removing the need for lumbar punctures, painful IV administration, and the risk of melarsaprol B induced encephalopathy, the diagnostic and treatment practices and interactions between patients, health workers, and technology will be altered forever.

Tiny Targets: cheap insecticide impregnated nets for tsetse fly control

Devised and developed by the Liverpool School of Tropical Medicine, the Tiny Target device was honed to its present form through repeated field experiments in East Africa. Aimed at impacting local populations of riverine tsetse that transmit *T.b. gambiense* HAT, these small insecticide treated flags have been deployed and expanded across the West Nile since 2011, alongside conventional bi-conical tsetse traps that monitor their impact on the population. Donor support from the Bill & Melinda Gates Foundation and industry partnerships with Vestergaard-Frandsen has enabled them to scale up their prototypes into large-scale manufacturing of targets that can be produced cheaply and easily (Lindh, et al., 2012; Tirados et al., 2015; Lehane et al, 2016).

A substantial part of the project was not just refining the design of the target (Lindh et al., 2012), but preparing the pilot study area for its introduction, conducting preliminary social science research and sensitisation prior to

implementation. Part of this anthropologically informed approach the programme initiated included a women-led tsetse control pilot study, as well as continual monitoring and investigation into rumours and concerns circulating about the tiny targets as they were deployed.

During the pilot study, local women were recruited to carry out HAT control by placing tiny targets along river banks. These activities were compared with another village where field technicians and entomological ‘experts’ ran the control programme. Overall, women were found to be willing, motivated and organised to successfully manage the tiny targets operation independently. The ownership and sense of empowerment the initiative gave them proved to be cost effective too. Importantly, because communities became invested in the benefits of targets and maintained them, more tiny targets were functional at 6 months post-deployment in the study site than the control site (Kovacic, 2015).



A group of women build and prepare a batch of tiny targets for deployment. (Photo: FIND Trypa-NO! Partnership press release, 2017).

A recent review on current strategies for engaging women in vector control cited this study alongside others in concluding that programmes benefited from increasing women's participation in vector control, as they create economic opportunities for women, and provide access to communities that may otherwise be hard to reach. Crucially, a programme's success was often "contingent on working within existing networks or finding women in the community who were considered trustworthy" (Gunn et al, 2018: 8). This approach to implementing Tiny Targets proved to be a turning point, with several members of the programme remarking in personal communication that the input from an anthropological perspective was instrumental in improving the acceptability of the programme beyond merely changing the physical design of the targets.

3V vet networks: targeting cattle using community mobile spray teams

After failing to sustain the impact of their first two mass cattle treatment campaigns, the SOS programme found itself at an impasse, as the prevalence reductions achieved initially could not be maintained without the regular application of insecticides to cattle after treatment brigades withdrew. This underscores the need to complement mass-treatment activities with better sustainability programs to prevent the need for recurring emergency interventions (Mukiibi et al. 2017). This prompted a revision of the SOS strategy, flipping the top-down vertical intervention model on its head to a more 'bottom-up strategy' (Bardosh, 2016). Over the course of 6 months in 2008, five graduates from Uganda's only veterinary school at Makerere University were employed to gather information, educate livestock keepers, and sell the Vectocid (insecticidal spray) and the trypanocides VerebinB12 and Veridium (Morton 2010), which were previously donated by Ceva through the programme.



A 3V Veterinary drug store in Kaberamaido district.

As anthropologist Kevin Bardosh wrote in his study of what became the ‘3V Vet’ franchise, the emphasis on “farmers-doing-it-for-themselves” (Boiardi and Hehenberger 2014) and building “local innovation systems” (Morton 2010) was hailed by the global health community as a triumph of One Health in action. Over the following 6 years, IKARE would invest more than \$450,000 in this ‘3V network’, reflecting an emerging trend in social entrepreneurship, where pathways for development and public health are forged through business, poverty alleviation, and empowerment (Prahalad 2006). The spray services offered by the 3V network transformed the concept of ‘farmer incentives’ for tsetse control, by blurring the line between the perceived private goods of livestock health/animal trypanosomiasis control, and the public good of HAT prevention (Leonard 2000). Shifting the ‘public good’ of trypanosomiasis control into the hands of market forces was seen as a cost-effective solution, with proponents avowing that “SOS addressed one of the perennial challenges to global health: sustainability” (Bardosh, 2016: 339).

Kevin Bardosh's study captures the tail end of Phase Two of SOS in 2010 which expanded the intervention to Soroti and Serere districts, and eloquently describes the establishment of the 3V vet network and how it evolved as a 'social experiment' (2016). The publication came at a pivotal moment in the project's history, as programme partners by this time were bidding to rollout another ambitious control campaign spanning 32 districts based on the SOS model. Phase Three of SOS depended on partners fundraising for one of the first Development Impact Bonds (DIBs)—a novel funding model which uses private investors, with the potential for returns on their investment based on the achievement of various 'trigger points' in program outcomes (Centre for Global Development and Social Finance, 2013). This time, to procure the vast amount of funding needed to sustain the intervention's impact, SOS had to marshal the evidentiary charisma (Kelly, 2018) and justificatory narratives (Scoones, 2014) to build a case for the DIB model that could achieve its targets to the 'last mile'. "Time will now tell where the 'experiment' goes from here", Bardosh signed off with cautious optimism. It was not long after this time that I entered the field and joined the 3V vets and their sprayers.

CHAPTER TWO

Theoretical Framework

Disentangling HAT: a socio-ecological approach

This theoretical framework foregrounds the series of multiple, multi-sited, sequential case studies by drawing on socio-ecological approaches, and employing ethnographic methods to produce “thick descriptions” (Geertz, 1973) of contemporary HAT control. I have chosen to depart slightly from the foundational conceptual frameworks of actor-networks and assemblages, toward the more recently developed and relevant concepts of ‘entanglements’ (Nading, 2014), ‘hotspots’ (Brown and Kelly, 2014); and ‘ecosystems’ (Yellepa et al. 2017), that account for the complex dynamics of socio-ecological systems in which HAT exists. ‘Ecosystems’ and ‘ecologies’ capture the complex, entangled, dynamic, and adaptive nature of the social, technical, environmental, and biological assemblages that configure disease events and shape the conditions whereby individual agents and political structures react to and intervene on them.

Theorising science and technology for global health and development

Popular discourses on technological determinism, whereby technologies are made the subject of an active force for change, convey a vivid sense of technology as a driving force of history, whereby technical innovations appear and cause important changes to happen. In each case, for example, “the contraceptive pill produced a sexual revolution”, “the microscope transformed biomedical understandings of disease” and so on, a complex event is made to seem the inextricable result of a technological innovation. Technology has typically been understood as a linear pattern of development; a straightforward application of science, whereby scientific

knowledge is crafted into technological artefacts to deal with easily identifiable problems or opportunities (Sismondo, 2004 in Smith, 2013). Unlike other, more abstract forces for change such as socio-economic, political, cultural, and ideological factors, the tangibility of material technologies creates a perceivable sense of causal efficacy (Smith and Marx, 1994). While it is true that technology is inextricably linked to development, the linear progressive and causal nature of this association can be misleading.

At the other end of the spectrum, “soft” determinists remind us that the history of technology is a history of human agency, and upon reflection “it is evident that artefacts only have significance in the hands of people” (Whyte, van der Geest, and Hardon, 2002:104). An innovation, once introduced into society, is depicted as taking on a social life of its own; it’s adoption and proliferation diffusing throughout society until it becomes entangled with intricately interrelated socio-technical ecosystems, until “its continued functioning is a precondition for the reproduction of the entire social order” (Smith and Marx, 1994). Indeed, technology and society are mutually constitutive, comprising of people and objects in social relations expressed in purposeful practices (Pickstone, 1994:14). They are embedded in the other to the extent that it “subsumes our identities, shapes how we interact with the world, and circumscribes our future” in positive and negative ways. “Each propels the other along, and the successes and failures of both are bound together” (Smith, 2009: 1).

Likewise, the history of medicine, and the history of biomedical technologies might not be an example of a long struggle toward a shared understood set of concrete biological mechanisms. Instead, “it is better represented by the interplay of different coexisting systems of explanation, each filling a role where the other fails” (Keil et al., 1999). Current Science and Technology Studies (STS) go beyond emphasising the social complexities and ramifications of technologies, to return to the aetiology of *techné* as a

'practical art', a concept that suggests intention, purpose, and goals. Through participant observation, STS hones in on the purposeful relationships between people and things, how they take on meanings through routinisation, and together co-produce effects (Whyte et al. 2002:104). STS recasts science as a social and political activity, scrutinizing the way science frames questions, its methodologies, and means of reaching consensus (Leach et al, 2005).

The emergence of STS in the 1970s initially turned to this task through ethnographic studies of laboratories, scientific communities, and the implementation of technologies (see Collins, 1974; Latour and Woolgar 1986; MacKenzie, 1990; Kohler, 1994; Pinch and Klein, 1996). Through the STS lens, scientists, engineers and technologists are trained as members of 'epistemic communities', all with their own norms, and institutions. They adhere to ascribed rules and standards, conforming to devices created by their communities. STS rejects the essentialist conception that scientific method and technology holds the key to producing 'pure' knowledge, or immutable 'truths', or that scientists and technologists undertake their work "inoculated from the politics of their own communities of practice" (Smith, 2013:8). By treating all modes of knowledge equally, or 'symmetrically', and adopting a supposedly impartial approach to explaining people's beliefs, STS attempts to place science in a social and cultural context (Bloor, 1991).

Actor-network theory (ANT), developed by prominent French STS scholars Michel Callon and Bruno Latour, and the British sociologist John Law, is less of a theory as a 'material-semiotic' method, in that it attempts to map relations that are simultaneously material (i.e. between things) and 'semiotic' (between concepts). For example, the HAT control network is one comprised of many things (both human and non-human); vets, doctors, tsetse fly traps, maps, diagnostic tests, hospitals, patients, and organisations. But it is also constituted by shared concepts; of one health, of development, of humanitarianism, and the public good. ANT posits that networks are

precarious by nature and must be continuously performed through repeated enactments in order to maintain their stability. For the HAT control network to stabilise and function, its component actors must enact relationships that hold the network together. Patients must present with symptoms at local health facilities and attend follow-up referral appointments. Health workers must recognise symptoms and follow diagnostic algorithms. Cases must be reported and travel up through a hierarchy of institutions; to the Ministry of Health, to COCTU, to the WHO, setting in motion a series of pre-planned events and protocols. Entomologists and veterinary staff co-ordinate with district and national offices to deploy tsetse fly traps or conduct cattle spraying campaigns. Research institutions collaborate with donors and engage in public-private partnerships to develop new ways to implement and monitor novel technological interventions.

'Assemblage' thinking shares some striking similarities with ANT. Both propose a relational view of the world, where action results from the 'becoming together' of initially disparate elements. Both share the idea of emergence, whereby the whole system is more than the sum of its parts, and both promote distance not as a geographical construct, but as a function of the intensity of a relation, i.e. a topological concept of space. Furthermore, they both emphasise the importance of the socio-material, that is, "that the world is made up of associations of human and non-human elements" (Müller and Schurr, 2016). 'Global assemblages' (Ong and Collier, 2005) describe the systems through which global forms of techno-science, economic rationalism and expert networks gain significance and influence. The global assemblage is a tool for the production of 'global knowledge', that is "knowledge about global forms and knowledge that strives to replace socially, politically and spatially context-bound forms of knowledge" (Smith, Taylor and Kingsley, 2015: 2).

Rather than contending to deconstruct the multiple agencies of actors within the disease "network", between the 'local' and 'global' scales of

epidemiological surveillance and the narratives that frame their daily practices, I conceptualise these entanglements as socio-technical “ecosystems” (Yellepa et al., 2017; Michael and Madon, 2017). In these systems, epidemiologists are also political actors, as are veterinarians, community health workers and laboratory staff, whose lives are all ‘entangled’ (Nading, 2014) with those of parasites and tsetse flies. Indeed, acknowledging the shortcomings of ANT (Law and Hassard, 1999; Latour, 1999), Bruno Latour’s revised emphasis away from the agency of actors toward the ‘*circulatory forces*’ that shape their position within the network follows Donna Haraway’s assertion that, rather than focussing on misleading notions of stable objects or entities, it is better instead to think of “relationships” as “the smallest patterns for analysis” (Haraway, 2010. p.26). The concept of entanglement therefore adheres to modern iterations of ANT that reject definitions of entities and essences in favour of terms such as ‘fluid’, ‘trails’ and ‘ontological choreography’ (Cussins, 1998). Rather than analysing opposing notions of micro and macro, individual and structure, I argue that the complex and entangled epidemiology and ecology of Sleeping Sickness renders the scalar distinction between local and global infrastructures, bodies, and forms of knowledge increasingly difficult to maintain; “They are themselves entanglements of relationships [...] a set of attachments” (Nading, 2014. p.10).

In more recent years, STS has expanded beyond the traditional spaces and topics of laboratories and controversies, relocating and engaging outwith the natural and physical sciences in the Global North. It is perhaps a natural progression then that scholars of Critical Global Health are increasingly embracing a ‘messy hybrid’ of their own field and STS, as they turn to the “mundane infrastructures of Global Health [as] the local elements of a well-oiled machinery” to “trouble the grand narratives of assumptions underpinning many Global Health projects” (Montgomery et al. 2017:6). Throughout this thesis I present a response to this call, making the argument for a ‘critical epidemiology’ (Edelman, 2017) of HAT that encompasses a

biosocial perspective (Parker, Polman, and Allen, 2017). The precarity of the HAT network and paucity of reliable surveillance data on its prevalence and distribution in multiple bodies (human and non-human) calls for an approach that is mindful of how epidemiological knowledge of HAT is constructed out of social interactions (Smith, 2009:10) with the technologies that produce epidemiological data. This argument draws on an increasing body of literature on anthropological approaches to epidemiology and critical global health.

Critical Global Health and STS

Departing from the colonial era and post-war framings of ‘tropical medicine’ and ‘international health’, the contemporary field of ‘global health’ brings together an immensely diverse range of actors. Today, an industry of private and public actors have proliferated from the field, as pharmaceutical companies have rebranded themselves as ‘global health companies’ (Biehl and Petryna 2013), while public–private partnerships (PPPs) and product development partnerships (PDPs) between industry and non-profit partners are booming. These ‘partnerships’ are a key mobilising metaphor generated by development policy discourse “whose vagueness, ambiguity and lack of conceptual precision” conceal ideological differences to facilitate compromise between parties, “so that agency can be distributed within project systems” (Mosse, 2004: 230). Often, as is the case with HAT, donors preferentially fund specific and technologically oriented vertical programs. However, philanthropic efforts to improve health outcomes may inadvertently end up reinforcing the inequalities they seek to overcome, as the interests of public health agencies give way to an ‘asymmetry of power’ between private-sector actors and public interests (Birn 2014). Those scrutinising the power and governance of public–private formations argue that on the one hand these can be viewed as “successful social technology innovations”, while on the other seen as “regressive and imperialistic regimes of neo-colonialism” (Montgomery, 2012).

A prominent voice against the 'structural violence' wrought by neoliberalism, anthropologist-physician Paul Farmer takes a community-based approach to tackling poverty and disease by placing a focus on making health systems work over technological interventions (Keshavjee 2014). Critiques of 'top down' approaches in global health traditionally attended to the problem of ignoring local specificity (Foster 1976). Proponents of a 'slow research' method cite the need to make the 'local' as the starting point, tailoring policies to local conditions, and creating research platforms that centre local features over those that are labelled as 'global' (Adams et al. 2014).

Hopes for a 'magic bullet' and the power of 'data' continues to be fetishized, while the visions of technocrats tend to outweigh other forms of practical and meaningful evidence. While new technologies will always hold an important place and be in demand, there has been increasing concern and calls to move away from an overemphasis on 'surrogate endpoints' and the search for 'silver bullet' solutions in global health; as although searching for solutions are worthwhile endeavours, these cannot expect to be 'silver bullets' when introduced into suboptimal systems (Pai et al. 2018). This is why I have focussed on the socio-technical ecosystems into which new HAT technologies are being introduced, as opposed to their cutting-edge attributes, which are described and widely lauded in the literature elsewhere.

Multiple and fragmentary global health interventions also consolidate what anthropologist Susan Reynolds Whyte and colleagues (2014) working in Uganda call 'projectified' landscapes of care. Within these landscapes, the supposed beneficiaries of interventions are rarely visible, appearing either as having nothing of import to contribute, or as uncritically and passively receptive to interventions. A strong biomedical emphasis remains pervasive, casting the concept of community engagement as politically necessary but 'scientifically' irrelevant (Biehl 2007). But as global health has emerged as a

dominant assemblage of actors and institutions, its consolidation as a field has prompted new calls for scrutiny (Janes and Corbett 2009).

Numerous critiques have emerged that destabilise the assumed architectures and imperatives governing global health, challenging discourses and what defines the 'global'. A large body of critical literature frames global health as a neocolonial or postcolonial imperial project. For example, historian of medicine Warwick Anderson (2014) argues that biomedicine is 'constitutively colonial'. Introducing a special issue in '*Social Studies of Science*' (2002) on postcolonial technoscience, Anderson emphasises a postcolonial perspective to focus on global flows of knowledge and practice as key, to "show us how scientific and technological endeavours become sites for fabricating and linking local and global identities, as well as sites for disrupting and challenging the distinctions between global and local" (Anderson, 2002). Studies have since engaged with STS concepts in attempts to deconstruct how Eurocentric ideas are embedded in how science is enacted in the Global South (Chakrabarty, 2012).

Beyond postcolonial work, Global Health and STS projects have coalesced on common ground. First, by examining global flows of knowledge and fluidity, i.e. how science and technology 'travel'. Second, by bringing to light the testimonies of those actors and regions, predominantly in the Global South, which have been traditionally absent or hidden from STS, while actively seeking new theoretical concepts from these places (Engel et al. 2017). Another critique of global health takes a more Foucauldian approach, focusing on the new regimes of governmentality and biosecurity reconfiguring discourse and practice around health and risk (Collier, 2008; Lakoff, 2010).

The illusion of impartiality: situating myself within the epistemic community

The pinnacle of Bloor's Strong Programme in STS, the concept of 'symmetry in practice' as the impartial and equal treatment of different modes of knowledge, has since been criticised as little more than "a misconceived methodological cloak" (Pels, 1996:278), representing an unrealistic and illusory endeavour. Some have pointed out that scholars of STS are no less engaged in knowledge politics than the scientists and technologists they study (Engel et al. 2017), as they involve themselves in scientific controversies by necessity, subverting the dominant view and thereby elevating that of the 'underdog' (Wynne, 2006). In presenting my case studies I too have had to be mindful of how this work may be interpreted as one of championing 'frugal innovations' (Prabhu and Radjou, 2015) over the dominant model of technologically sophisticated programmes that have come to define trypanosomiasis and tsetse control. While there is valid critical value in questioning dogmatic global health structures, I have had to check my own overenthusiasm for simplicity as an inherently desirable attribute in itself. If anything, this thesis builds a case against the global health community's fixation on simplification where complexity should be embraced.

Coming from an multidisciplinary background, I have inevitably brought some of my own disciplinary baggage to this work. Anthropologist Ashanté Reece has recounted similar reflections on the value of bringing these diverse disciplinary backgrounds (our 'elsewheres') into our ethnographic work from the margins and rejecting anxieties that such work will be deemed 'not anthropological' by those working from 'the centre' of the discipline (Reece, 2019). Having studied biological and medical anthropology before moving into the growing field of evolutionary medicine and public health, I came to this project with certain preconceptions about the biomedical and epidemiological profile of HAT. I appreciated the eloquent scientific discoveries and developments made in trypanosomiasis and tsetse research but struggled in critically evaluating these against a backdrop of rich social

science research on the political economy and social history of HAT (Ford, 1971; Barrang-Ford, 2006; Scoones, 2014; Grant, 2014; Lachenal, 2017). While grappling with where these new technologies and approaches to HAT control aligned amidst the vast expanse of theoretical literature, I regularly found myself falling back on metaphors from ecology and evolutionary biology to make sense of new theoretical concepts, from Actor-Networks to Assemblages. This was partly a retreat to an epistemological comfort zone of sorts, but also in response to many of the overlapping themes and terminology used between disciplines.

In my readings of assemblage theory (Deleuze and Guattari, 1980; DeLanda, 2012) and Global Assemblages (Ong and Collier, 2005) for example, concepts of social complexity, constellations, and fluidity resonated with the intricacy and dynamicity described in the field of Ecology. In its earliest definitions, Ernst Haeckel in 1866 defined ecology as “the whole science of the relationship of the organism to the environment including, in the broad sense of the term, all the ‘conditions of existence’ “ (Stauffer, 1957:140). McMichael (2001) provides a more comprehensive and contemporary definition of the term:

“Ecology refers to the interconnected relationships between populations of plants and animals and between them and their natural environment. There is an emphasis on integration, interdependency, and feedback processes, all within a systems context (p.17). Ecology is a way of observing and thinking about the complex natural world; it is integrative, not disaggregative” (p.20).

Social ecology perspectives explore the relations between people and their social and physical environments, over time and across several levels of analysis: personal, familial, cultural and institutional (Stokols et al., 1996; Butterfield & Lewis, 2002; Golden and Earp, 2012). In this thesis I adopt a social ecology approach, and the stance set out by Panter-Brick et al. (2006) in their case study on malaria prevention, that for global health interventions to be culturally appropriate and compelling (and result in demonstrable public

health impact), the design of interventions must be situated “within the social and ecological landscape of local communities” (Panter-Brick et al., 2006: 2812). Drawing from the same thread as Veena and Ranendra K. Das’s “local ecologies of care” I aim to understand how everyday experiences of HAT are crafted in specific configurations protocols and practitioner behaviours (Das and Das 2006). This approach takes up an ‘ecological’ framework that conceptualizes interventions in terms of their potentially simultaneous impact across a broad range of social, biological, and political economic relationships (Adams et al., 2014) Medical anthropologists have captured this conceptualisation of ‘diseases of development’ in tracing the inadvertently iatrogenic effects of interventions such as mosquito eradication and deforestation on health outcomes (Hughes 1969). Here, as one piece of the ecological reality is altered, with the introduction of a new diagnostic device for example, its implications and effects are systemic and affect the socio-technical ecosystem as a whole.

Elsewhere, the rhetoric of ‘therapeutic landscapes’ deployed in human geography and medical anthropology (Gesler, 1992; 1993; 2017; Winchester and McGrath, 2017) evoke comparisons with the ‘adaptive landscapes’ metaphor once used as a heuristic tool for qualitative reasoning in evolutionary biology (Svensson, 2016). In a dynamic socio-ecological landscape such as HAT, populations adapt in response to changing landscapes as they evolve, such as the shift from active screening to a passive surveillance strategy, the introduction of new diagnostic tests, algorithms, or new therapeutic drug regimens into the treatment landscape. This appreciation of the dynamic, adaptive processes involved in producing and stabilising landscapes makes an ecosocial approach (Krieger, 2011) to exploring the socio-technical ecology (Michael and Madon, 2017) of HAT a compelling conceptual framework for this thesis.

Introduced in the early 1990s in the field of health geography, the concept of therapeutic landscapes was an attempt to bring together ideas about place

and human health (Gesler, 1992; Andrews, 2004). The defining elements of the therapeutic landscape centred around physical (natural and man-made) environments, social environments, and symbolic environments. The idea that an individual's health is influenced by physical environments is taken on face value, with variables like noise, light, dirt, or ventilation for example, having easily measurable effects on health. However, though harder to quantify perhaps, social and symbolic elements of a therapeutic landscape can have as significant effect on healing as physical elements (Gesler, 2017). Researchers who took up the therapeutic landscape metaphor however, have pointed out that certain aspects of a healing space that is therapeutic to one person might not be to another (ibid). This draws attention to the phenomenological nature of the landscapes that individuals traverse amidst subjective and relative experiences of health and well-being. The concept has since been expanded beyond human-environment interactions to encompass the analysis of structural and symbolic constructions of place. Originally utilised as a conceptual tool to examine patterns of health-care seeking, medical anthropologists have since applied the therapeutic landscape “in the study of holistic health care, treatment seeking, risk negotiation, clinical spaces and design, social networks of therapy, regional political economies of health, landscapes of resistance and exclusion, and other health processes” (Winchester, 2015).

I have taken up the landscape metaphor in my own analysis where it relates to the environments in which suspected HAT infected individuals are detected and subsequently confirmed and managed by local HAT control systems. The term and concept is encountered regularly throughout the thesis when describing the journeys people make in seeking treatment, reaching a diagnosis, negotiating complicated referral algorithms, and receiving treatment. It is also employed when discussing the diagnostic landscape within and outside of clinical spaces, such as the cultural evolution of diagnosis toward point of care testing in Uganda's primary healthcare system.

The landscapes I describe throughout this thesis are not physical per se, although they often comprise certain physical elements; the condition of roads and transport networks; the geographical distances between primary health centres to referral hospitals; the availability of electricity in a laboratory that determines which diagnostic devices it can house; or the geospatial distribution of tsetse habitats. But these landscapes are also socially constructed, by the social proximity of people to private drug clinics or traditional healers (Chandler, 2011), by household level cost-benefit analyses of spraying cattle, fears and anxieties of medical procedures or drug side effects, collective memories of past interventions (Kovacic et al., 2015), or relationships of trust between people and services (Lee and Palmer, 2018). The landscapes that determine a person (or population's) risk of exposure to HAT, or their likelihood of being detected as a case, emerge as an imagined environment, or 'response surface' (Svensson, 2016) against which people make calculated decisions about their own (or their animals') health.

To situate HAT as both a feature and event in this metaphor I have drawn on Brown and Kelly's 'hotspot' metaphor to conceptualise "the mundane interactions that create the conditions for pathogenic possibility" (2014: 3). Initially developed to analyse the complex relationalities driving Viral Haemorrhagic Fever (VHF) transmission, the hotspot is a useful analytical heuristic to identify sites where various human– animal–nonhuman entanglements facilitate pathogen movements and transmission. More than a single state of aligning criteria, the hotspot describes the transient moments, or "context in actions" (Lezaun and Woolgar 2013), where the temporary convergence of political designs, economic strategies, agricultural techniques, armed conflict, built environments, and practices of care come together to create the conditions for disease communicability (ibid: 2). This speaks to an 'ecological imaginary' that goes beyond singular moments of exposure or contact into 'the assemblages of diseases' (Audy 1954:962 in Brown and Kelly, 2014).

Here I have also found the concept of ‘patches’ as described by Scoones (1991; 2017) a helpful metaphor to conceptualise the spatial plane of intersecting social and environmental elements come together in moments of transmission. Patches are defined in ecological terms as biophysical features associated with particular vegetation and animal populations for example (Pickett and Cadenasso 1995 in Scoones et al., 2017). But patches also form part of social landscapes (Scoones 1991), shaped by “an intersection of social relations, institutional dynamics, and political contestation” (Scoones et al., 2017). When landscapes change, bringing transmission cycles into contact, disease dynamics in turn may also fundamentally transform with profound implications (Adams et al., 2017). The mass displacement of populations during civil conflict allowing tsetse habitats to proliferate, followed by the re-introduction of large numbers of infected cattle for example created patches, or hotspots, in which conditions for pathogenic possibility coincided to produce notable outbreaks of rhodesiense HAT in the 1980s and early 2000s.

Troubling the techno-centric narratives that define contemporary global health interventions (Mongtomery et al., 2017), I question the extent to which programme strategies which emphasise rigid, blueprint-driven interventions, are able to effectively deal with the “open socio-ecological dynamics, complexity, uncertainty, and non-linearity that underlie parasitic transmission in human communities” (2017: 2). Given the complex socio-ecological dynamics of HAT, I join them and others that argue for an interdisciplinary approach to HAT control, not only between natural and social science investigation, but involving meaningful local participation (Bardosh, 2016; Michael and Madon, 2017; Scoones et al., 2017; Booth and Clements 2018).

Critically evaluating Community Participation in interventions

Public-Private Partnerships and donors have historically centred cost-effectiveness to programme sustainability, but much less so the broader socio-ecological dynamics of disease control (Michael and Madon, 2017; Scoones et al., 2017). Much of the recent literature on the sustainability of global health interventions concerns strategic 'community participation' for improving sustainability, but this has largely focused on technology acceptance and co-operation. There has been a long tradition in critical development studies of questioning whether rhetorical appeals to 'community' and 'participation' actually correspond to anything substantial (Oakley, 1989; Rifkin and Kangere in Hartley, 2002; Howard and Wheeler, 2015). To date, few studies have explored who exactly comprise the 'communities' concerned, and to what extent or end their participation is encouraged (Montgomery and Pool, 2015; Kelly et al., 2016; Madon et al., 2018). Rifkin's (2014) review of community participation interventions on communicable and non-communicable diseases concludes that while many participatory interventions seem to have an impact on improved health outcomes, the role of community participation and its relationship with these outcomes remain poorly understood or defined, with no standard definition for the terms 'community' and 'participation' even. Community participation has come to be loosely conceived as an intervention evaluated only through health related outcomes, rather than through all of the dynamic changes that occur throughout the participation process.

While my research does not employ participatory methods per se, it does concern itself with participation and collaboration as a variable in the sustainability of interventions. A growing body of literature in global health and development views 'community participation' as an essential driving force for health program sustainability, based on the assumption that engaging with communities makes interventions more relevant to local priorities (Rifkin, 1986, 2014; WHO, 2002; Draper et al., 2010). However, the

mechanisms by which community participation leads to sustainable health outcomes exactly, and to what end, remain unclear (Hossain et al., 2004). Intervention studies are dominant in health research, largely designed by health professionals seeking to test hypotheses by introducing interventions and evaluating their outcomes. However these outcomes are determined by context, and context varies (Rifkin, 2014). Given that large, population-wide vertical programmes have traditionally dominated HAT control, I am interested in how these emerging strategies are evolving with shifting development discourses on the relationship between intervention sustainability and community participation, since calls for community participation in the Alma Ata declaration (WHO 1978).

Participation in this context is concerned with 'handing over control', and the ownership of activities, outputs and outcomes to beneficiaries, viewing beneficiaries of interventions or research as drivers of the process, rather than interventions being imposed on them (Cornwall and Jewkes, 1995). Community participation encompasses a range of different approaches, from health delivery and promotion, community development, to social, economic and political justice (WHO, 2004). My research specifically focuses on the health intervention delivery framework, and engagement between HAT control programmes and their perceived local beneficiaries. I also expand the category of 'local people' to include the local staff implementing these projects, as they too form part of the micro-level socio-ecological systems into which programmes seek to integrate.

My research takes the definition of community participation as a "process that supports interventions" (Kovacic, 2015: 34), which centres the transformative and dynamic process of participation as being equally important in driving health-related outcomes. While my study does not employ participatory methods, it is interested in understanding how engagement and participation with target 'communities' are used as methods for making HAT technologies acceptable and sustainable. To this end my

research is interested in how interventions measured domains such as empowerment, ownership, capacity building, resources mobilisation, management, cost-effectiveness, and sustainability (Rifkin, 2014). In choosing to conduct case studies on technological interventions delivered through donor funded public private partnerships, by a range of government and non-governmental actors, I also aim to explore issues of participation in the context of authoritative power and control, where divisions of power are exercised among participants themselves, between facilitators and participants, or between donors and beneficiaries (Cook and Kothari, 2001).

Debate has revolved around whether community participation ought to strive toward improving service delivery, increasing the uptake of interventions, or addressing broader structural inequities in healthcare (Rifkin, 2003; George et al., 2015a). The Tiny Targets standard operating procedures for example stipulate that “the main goal of sensitization is to achieve community acceptance of a tsetse control operation [...] to promote behaviours that will optimize trap and target performance in the field” (Torr, 2016: 13).

Measurable indicators for evaluating behavioural change and impact however is complex and difficult to define. How one defines ‘community acceptance’ for example could be interpreted in a number of ways and subject to some debate as to on whose terms a technology is accepted or not accepted.

Furthermore, Mosse (1994) argues that the term ‘participation’ can be used by ‘experts’ to manipulate local communities and extract ‘local knowledge’ to serve their own interests. Knowledge is created by the dominant views, while less dominant opinions, (particularly if they do not align with the project objectives), are often excluded. Robert Chambers has written extensively on Community Participation and points out that contrary to common misconception, local participation, particularly in East African development projects, has “often been inequitable because of compulsory labour, contributions in kind exacted by force, regressive levels of contributions, and

the capture of benefits by local leaders and elites” (2005: 86). Medical anthropologist Paul Farmer (2013) also interrogates ‘whose knowledge counts’ and the institutionalisation of the of external ‘expert’ authority in public health, arguing that inequalities in global health are fuelled by such disparities.

Indeed, there is growing recognition that by its very nature community participation must address issues of power and control (Madon et al., 2018). For example, one study of community-led treatment interventions for onchocerciasis (river blindness) control across four African countries revealed the need for programme implementers to improve communication and outreach activities, allowing communities more control over planning the timing of treatment administration and ownership of the intervention (Amaziqo et al., 2002). Another recent study in Uganda has also showed how unrealistic community expectations, limited drugs and supplies, poor supervision and lack of compensation resulted in feelings of disempowerment amongst health workers, with adverse effects on their motivation to deliver health services for febrile children (Banek et al., 2015). As this thesis goes on to show, interventions may also be compromised due to lack of understanding or trust between the community and frontline health workers, as well as the capacity and morale of community health workers delivering interventions in resource constrained contexts. Drawing on existing evidence from other studies an theory I would expect that HAT interventions which are less collaborative or participatory are less sustainable, as they fail to make interventions culturally appropriate, appealing or culturally effective (Panter-Brick et al., 2006).

Research Rationale

As the previous chapters have made clear, there is a need to better understand the relationship between science and global health and development, and more specifically the ways in which appropriate technologies can be made available to those living in extreme poverty

(Conway and Waage, 2010). While global investments in scientific research since World War II have undoubtedly helped achieve progress in many domains of 'development', progress has also been uneven. Many of today's so-called neglected tropical or zoonotic diseases (NTDs or NZDs) of poverty, for example, have been overlooked for decades by the assemblage of governments, actors and systems responsible for determining priorities in global health. With focused advocacy efforts over the last two decades, however, these diseases have received increasing attention and resources, which have in turn attracted new actors and the development of innovations. This also matters theoretically, as while normative discourses on the subject describe science as leading to development in a linear way, an important body of critical social science literature describes this relationship as symbiotic (Smith, 2009; 2010). Development may be driven by the implementation of new technologies, but science is also pushed forward by our desire for progress. The risk in this relationship is that science can effectively absolve us of developmental responsibility, leaving us in a position whereby action today is easily retracted in favour of future techno-solutions.

Uganda is a priority country in which to observe the interaction of science and development in HAT for at least two reasons. First, in the post-colonial period, it is one of the only countries in Africa which experienced both large-scale, debilitating outbreaks and large-scale, impressive control programmes. Second, the multiple forms of Trypanosomiasis (human *Tb gambiense* and *Tb rhodesiense* as well as the several strains which cause disease in animals) that occur here make coordinating the scientific and developmental, human and animal, social and economic systems influencing their control particularly complex. This project aims to identify the political and social processes by which epidemiological evidence on what constitutes a 'case' of disease is constructed (Krieger, 2011; Broadbent, 2013; Edelman, 2018), and how scientific technologies and practices re-inscribe the social processes shaping evidence construction on the ground. This study comprises ethnographic observational analyses of the daily practices of

different groups involved in the surveillance, management, monitoring and analysis of both forms of HAT, across a number of settings through a series of case studies. The reasons behind my choice to focus on HAT to examine these key issues are threefold;

Firstly, Trypanosomiasis is an ideal candidate for the 'One Health' approach, particularly given the range of complex interactions between human, animal, vector and environmental ecosystems at play in *T.b. rhodesiense* HAT (Coker *et al.* 2011 in Scoones, 2014. p.1). This makes it an ideal case study to disentangle questions relating to the dynamic drivers of neglected disease in this region and its impact on development. The symbiotic, co-evolved relationship between the disease, its hosts, vectors, and the environment (both physical and social) typifies both the One Health and eco-political entanglements, whereby each element interacts with and influences the agency of others within this complex system.

Furthermore, Sleeping Sickness is what is described by the WHO as a 'tool deficient' Neglected disease. Rather than being amenable to large-scale, cost-effective, Mass Drug Administration programmes, as are some 'tool ready' NTDs (WHO, 2008), the complex (zoonotic in the case of *rhodesiense*) epidemiology of HAT requires more cross-cutting and interdisciplinary approaches to control. Firstly, the vector is difficult to control, and what drugs are available are often toxic and thus dependent on a positive diagnosis, which in itself presents major technical problems (Brun *et al.*, 2010). Patients co-infected with other diseases such as malaria not only risk delay in treatment due to misdiagnosis in the first instance, but also require initial treatment to clear the malaria parasite before treatment for HAT can commence. Many patients for *T.b. gambiense* HAT have been shown to present at health clinics only after reaching the second stage of infection (Kovacic, 2009:28), and while the severe onset of symptoms in *T.b. rhodesiense* patients may lead to earlier clinical presentation, the urgency for accurate diagnosis and swift treatment cannot be understated.

Finally, HAT poses a particularly unique challenge to data collection and evidence formulation, owing to problems with poor surveillance and case detection, under reporting and misdiagnosis. These ultimately amplify difficulties in delivering effective healthcare and resources diagnostic tests, training, equipment and drugs where they are needed most (Acup, 2013). This is particularly the case in decentralised and resource constrained health systems such as Uganda's, and one of the reasons for the country being my chosen field setting. The levels of under-detection in newly affected northern districts of Uganda such as Kaberamaido, Dokolo and Lira will likely be even higher than in other parts of the country (Wissmann *et al.*, 2014. p. 7), where for every person that is reported to die of sleeping sickness, it is suspected a further 12 die of the disease undetected (Odiit, *et al.*, 2005).

Many ANT studies typically focus on 'network builders' such as scientists, while larger actors often include representatives of industry and government, as those who "initiate scientific and technical innovation and exert influence over its direction and trajectory" (Latour, 2005). My study moves beyond these narrow definitions of scientific communities, recognising and encompassing the agency of all actors initiating and generating data in this system, from farmers and healthcare professionals, to laboratory staff and patients. Following these individuals and their daily practice allows me to trace the 'trails of entanglements' (Nading, 2014) that Sleeping Sickness leaves behind. Drawing on existing ethnographic work (Latour and Woolgar, 1986; Mol, 2003; Nading, 2014), I carried out a series of micro-level case studies in the field, laboratories, and clinics, tracing the production of epidemiological evidence through the HAT control system. Bringing ethnographic insights from the community and the hospital together reveals and highlights practices that transcend the confines of the hospital, in the care provided by family members during hospital admission, or the practices of local health workers who occupy both domains (Brown and Kelly, 2014).

The findings of this research contributes to growing debate around how data is produced, and knowledge constructed in decentralised health systems in spaces where technological capacity and support for adequate disease surveillance is reportedly lacking. The observations outlined in this thesis will furthermore feed into a critical analysis of the framing and advocacy for HAT control and elimination in global health policy literature, and offer a front line perspective on the practical operationalisation and implementation of policy recommendations at the ground level. By describing the daily practices, negotiations, and trade-offs that occur throughout various stages of the HAT case detection process, the construction of evidence and its authoritative claims on power and expertise within the science and development relationship are critically examined.

CHAPTER THREE

Research Design

Study Objectives

In order to contribute to the literature on how scientific knowledge is produced, valued and acted upon, my research design aimed to move beyond describing scientific consensus on the spatial distribution and epidemiology of the disease, toward critically analysing how technologies for sleeping sickness control are implemented in the field and come to produce this knowledge. This explores how HAT is positioned topologically and conceptually across disciplines and groups of actors by investigating the structure and integration of HAT control and elimination strategies through connections between key stakeholders operating across human and animal health networks.

Broadly, the study aims to develop a critical ethnographic account of HAT control in Uganda. Specifically, it seeks to:

1. Describe how HAT and perceptions of risk are constructed socially through technology, biomedical practice and global health discourse
2. Examine how technologies of surveillance are integrated into the passive screening system for HAT and to what extent they address challenges to access and uptake of HAT services and overall case detection
3. Identify gaps between HAT elimination strategies and policy, and the practical enactment of these on the ground.

4. Ascertain the relationship between 'community participation' and intervention sustainability.

Research design

Some anthropological theorists have argued the case for an “ethnographic empirical lantern in the critical studies of global health” (Petryna and Beihl , 2013). I hope to contribute to this with body of literature empirical ethnographic examples toward a critical study of HAT control.

The original research design for this project was structured around the core elements of social research design outlined in key methods texts by Blaikie (2000) and de Vaus (2006). Based on my research of existing literature and my experiences from preliminary fieldwork in 2014, I chose to conduct a series of ethnographic, embedded case studies (Yin, 1994) across multiple settings across Northern Uganda, which took technology-based interventions as the unit of analysis. Case studies are often seen as prime examples of qualitative research which adopts an interpretive approach to data by studying 'things' within their context (de Vaus, 2006: 10). They have generally been discussed and viewed – from a methodological point of view- as 'soft' options, but they have been fundamental to the substantive and methodological development of the social sciences (Yin 1989;1993). Good description is fundamental to this endeavour and has added immeasurably to our knowledge of the shape and nature of science and development. I aimed to design a research study that uses in-depth descriptions to provoke questions toward theory building, the process by which research begins with observations and uses inductive reasoning to derive a theory which attempts to make sense of these observations - or *post factum* theory (Merton, 1968). When adopting a more inductive, theory building approach, a sequential design, whereby case studies followed one another, is more appropriate than a parallel approach (de Vaus, 2006: 227). An advantage of the sequential

approach is that the selection of each case and some of the issues examined can be informed by other questions identified in earlier cases.

Qualitative data was collected over an extensive period spanning 12 months to allow sufficient time to access and fully describe these case studies. Within this methodological framework, the in depth, semi-structured interview played a key role, as well as extensive and descriptive observational field notes.

The cases, or 'objects' of study, are the units that we seek to understand as a whole. It is helpful to distinguish between cases as a whole and cases that consist of various levels or components. Yin (1989) uses the terms 'holistic' and 'embedded' designs to refer to this distinction. Some cases consist of multiple levels or components. For example, the national HAT control programme as a case study includes government staff, health workers, patients, entomologists, and policy makers, and so on. The control programme can be conceived of at the 'holistic' level where we focus on characteristics of the programme the level of the global One Health assemblage. But there are also many sublevels of elements to the programme. A full picture in all its complexity can only be obtained if I collect information from a wide range of the constituent elements (embedded units) of the larger unit (de Vaus, 2006: 220). I sought to build up a picture of each case by taking into account information gained from many levels in the hope that the cumulative body of work would tell us more than, and something qualitatively different from, that which any constituent element of the case could tell us. The insights gained from health workers, patients, community animal sprayers, programme managers etc. would probably differ and, when taken together, provide a much fuller, more complex understanding of the whole than would the perspective provided by any particular element of the case; "the whole is greater than the sum of its parts" (ibid: 221). Since many cases will consist of different elements, different methods of data collection may be required. A survey of health centres might be appropriate,

observation of point of care testing or treatment, while interviews are a good way of gaining information from programme managers and frontline health workers. Taking a mixed-methods approach, my research also employs some use of surveys (of health centres) and some limited quantitative analyses of responses from patient interviews.

Data was collected over a period of twelve months from July 2015-2016, with the assistance of translators/research assistants identified with the assistance of COCTU and local collaborators. Research assistant(s) were recruited and briefed on the study objectives and trained in the qualitative methods prior to data collection commencing. In order to develop a complex understanding of the services, organisations, social networks and systems of thought influencing access to care, I used a range of qualitative, ethnographic methods. To describe narratives driving HAT service provision, key informant interviews were conducted with health care workers delivering HAT services as well as government and NGO officials who organise HAT and health services for local communities. Focus group discussions (FGDs) with local communities, as well as community health workers and animal health workers were used to elicit narratives about HAT and general risks to health in the population. These were further supported by interviews with people seeking HAT tests at facilities. Non-participant observation of these services was used alongside these activities throughout the fieldwork period to describe the context of HAT testing and delivery of health services at facilities serving local populations.

My fieldwork was split into four sub-studies, examining technologies of surveillance and case detection, community perceptions of HAT, and practices of surveillance and control from the point of care up to programme level. Therefore all of the research objectives outlined above are covered in each study while focussing on different technologies, perceptions, and practices operating across the country and across control systems for both strains of HAT.

Study locations

The fieldwork setting for my research took place in the borderlands separating the two strains of HAT on the continent. While cases of *T.b. gambiense* to the North West of Uganda are arguably declining, *T.b. rhodesiense* has become increasingly established in the Teso and Lando sub-regions of northern central Uganda, namely Kaberamaido, Dokolo and Lira (figure 12). By working on the fringes of these HAT border regions I aimed to gain a unique insight into the different surveillance networks (human, animal, and vector) operating and responding to the outbreak narrative (Leach & Dry, 2010) being enacted on the “thin line between two fatal diseases” (Wissman *et al.* 2014) within a geographical space of epidemiological contention.

One half of my research would be based in the West Nile region, where new RDTs for HAT have been rolled out in order to enable faster, cheaper diagnosis of chronic *T.b. gambiense* HAT. Local communities in West Nile use pluralistic health services (Leslie, 1973). ‘Medical pluralism’ refers to the multiple treatment systems that spatially co-exist alongside biomedicine. It is extremely common in the health seeking process in this region for people to use different treatment options, ranging from the formal health system to traditional methods, such as herbal treatment and traditional healers. Self-treatment with medications purchased at informal local drug shops, often run by lay people, is also extremely common (Kovacic, 2009). I chose to conduct half of my research here as the West Nile is where two new innovations in HAT surveillance and control (the new RDT and the Tiny Targets) were being rolled out and scaled up at the time of study. I conducted my investigations into these alongside each other while based at the Liverpool School of Tropical Medicine’s field station in Arua town where I was able to utilise the Tiny Targets project facilities, vehicles, and occasionally staff for my own research.

The other focus of my fieldwork took place across four districts (Lira, Alebtong, Kaberamaido, and Dokolo) in the Teso and Lango regions of northern central Uganda which have been affected by Rhodesiense HAT since 2004 (Hamill et al. 2017). The on-going threat of a potential public health crisis given the increasing spread of *T.b. rhodesiense* northward highlights the importance of heightened surveillance in this region, and has partly informed my intention to focus my research here. By following the activities of community animal health workers along these edges, insight may be given into how such vertical, disciplined approaches to data management shaped by PPPs and DIBs models potentially affect the quality of evidence collected on the ground. Here I also conducted a study of treatment experiences among recovered rhodesiense patients discharged from the two main treatment centres in the region; Lwala Hospital and Dokolo Health Centre IV.

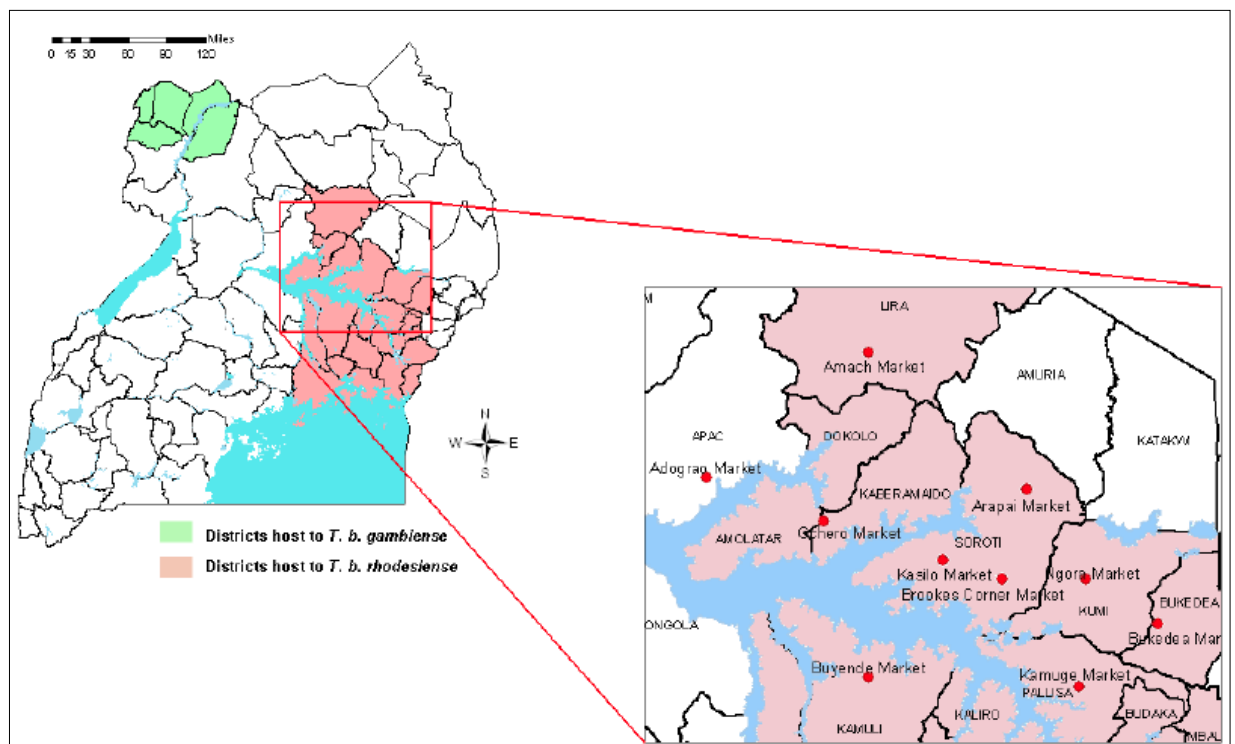


Figure 10: Study regions for case studies 2, 3 and 4 in Lira, Kaberamaido, and Dokolo districts (Red), and studies 1 and 4 in the West Nile (green) (Selby, 2011: 173).

Home to the mostly Christian Lango, Iteso, and Kumam peoples, the predominant economic activities in these areas are agriculture and fishing, with most of the population engaged in or dependent on subsistence mixed crop- livestock farming (Bardosh, 2016). This is a region where, owing to the relatively recent establishment of *T.b rhodesiense*, capability for detecting the disease is low, while the need for heightened surveillance is great.

I chose to work in these specific districts owing to the relatively recent establishment of *T.b. rhodesiense* in this region, necessitating the assessment of local healthcare facilities' ability to adequately detect and respond to new cases. Based on the most recent available figures of HAT cases and *T. brucei* sero-prevalence among cattle (indicated by recent prevalence sampling conducted by the then recently completed SOS feasibility study), I was able to narrow my study location down to specific areas. Within this region I also visited a selection of Health Centres of various levels from the facilities represented in the national census and in previous studies (figure 13), and carried out a survey of the levels of diagnostic, laboratory equipment, personnel and data recording systems present. This way my observations relating to the infrastructural capacity of surveillance spaces could be analysed in relation to their material and technological aspects.

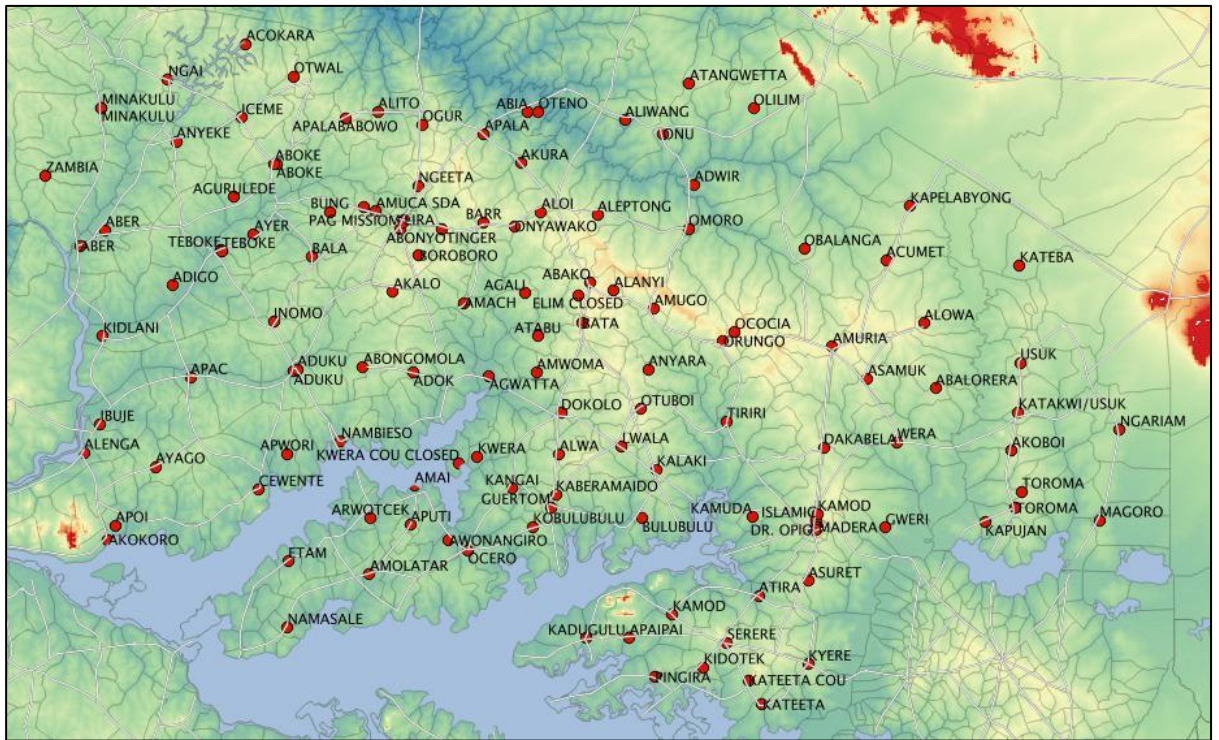


Figure 11: Map of Health Centres across Northern Uganda.

Including Dokolo, and Lira. Produced on QGIS with data provided with permission by N. Wardrop, (2011).

During this phase of research I was based at the HAT treatment centre at Dokolo HC IV in Dokolo town centre, where I was also hosted by Dr Frederick Odongo, a co-founding member of the 3V vets franchise and community mobile spraying network. Being based at Dokolo HC gave me access to up to date data and records on HAT patients treated and discharged from the treatment centre, as well as plenty of opportunities to work alongside and speak with staff who manage HAT cases on a daily basis, as well as any HAT patients that were admitted during my study. Dokolo HC was an ideal location to base myself from conducting the survey of health centres across Kaberamaido and Dokolo districts being located at a major trading centre junction with easy road access.

Data management, storage and analysis

Where translation was required, research assistants were trained prior to fieldwork to record, transcribe, translate and store qualitative data. Where translation was not required I recorded interviews and transcribed these accordingly, storing data on both a local and secure cloud network (University of Edinburgh DataSync server). Each interview or Focus Group Discussion transcript, associated field notes, contact summary notes and audio recordings were labelled with an ID number substituting for the name of the participant and saved as a single document. These qualitative documents were then imported to NVivo software (version 11) for thematic coding and analysis according to the objectives and design outlined above.

Ethical Considerations

A research protocol for this research was reviewed and approved by the University of Edinburgh School of Social and Political Sciences' Ethics Review Board, Busitema University IRB, and the Ugandan National Council for Science and Technology (see appendix 1, 2, and 3), and approved by the President's Office of Uganda (appendix 4).

Following the ethical guidelines outlined by the ASA (Association of Social Anthropologists of the UK and Commonwealth) I ensured that all participants were fully informed regarding the purpose of my study and give their oral consent and understand the following:

- i) That participation in my study is entirely voluntary
- ii) They may choose not to answer any question that might cause concern or discomfort
- iii) They may leave the study at any time without having to give a reason for leaving.

Consent was obtained by asking respondents' permission to record interviews on tape (Fontana & Frey, 2000: 645) Where consent was given to

do so, professional titles have been used in publication, but no names given. Elsewhere, names of individuals (e.g. healthcare workers and community sprayers in ethnographic vignettes) have been changed to preserve the identity of participants (Homan, 1991; Wiles et al., 2005). Interview and focus group participants were given the option to have their responses and data anonymised, whereby respondents are referenced only by a unique numerical identifier code in interviews and descriptive categories instead of names (e.g. health centre nurse, farmer, lab technician etc.).

No participants were exposed to any physical or psychological risks or harm for this study. No interviews were conducted without informed consent (consent forms in appendix 5), and particular care was taken to explain that participation in the study is voluntary. When approaching patients waiting for tests, interviewers stressed that neither I nor they are clinicians and so cannot offer any medical advice. Oral consent scripts were translated into local languages (and back-translated into English to verify accuracy) with the assistance of research assistants fluent in local dialects. Written consent was obtained from health workers and staff representing organisations. Where low levels of literacy among local populations presented barriers to providing written consent, witnessed oral consent was obtained with the option of participants providing a thumb print to consent forms. Participants were also offered the option of not being audio recorded but still contributing to conversations. No remuneration was given to people who participated in the study, and all participants were anonymised in reports of the study findings.

Participation in the research may have been voluntary, but several scholars have also acknowledged that there are few compelling reasons to engage, and participants are rarely presented with economic incentives (Maanen, 1991; Clark, 2008, 2010; Way, 2013). When conducting my research, I was careful to make clear that no remuneration for participation could be made, and that the impact of my research was unlikely to be directly beneficial to specific individuals or communities. While I did not have the time or resources to return and relay my findings to communities, I communicated at

the time that important aspects of my findings, informed by participants' anonymised responses would be communicated via various channels of research distribution to hopefully improve certain aspects of the national HAT control programme.

Methodology

To capture the most rounded perspective I used a range of ethnographic methods including in-depth interviews, focus group discussions, and observation, with the large body of my data coming from interviews and recorded observations of practice and conversations with key informants.

Key Informant Interviews

Key informant interviews offer a combination of structure and flexibility, with face-to-face interactions offer a relaxing, intimate and informal context to allow a constructive conversations to develop between myself and the respondent (Ritchie and Lewis, 2003). Key informants in my study include practitioners taking part in the diagnostic, treatment and data collection process – as the generators of data (whereas 'experts' can be considered producers of evidence), as well as patients. I held these with a wide range of individuals, varying from policy makers and representatives from key stakeholders in PPPs, and knowledge brokers (i.e. those delivering evidence to policy makers such as academic researchers), to healthcare professionals (both animal and human), lab technicians, to members of the local community and recovered patients.

While I intended to negotiate access to some of these individuals from my base in the UK, the initial period of time in Uganda during preliminary fieldwork in 2014 was used to establish contacts and familiarise myself with informants, and address any other outstanding logistical issues regarding

access and schedules. I anticipated, correctly, that some complications may arise, such as informants changing appointments or reluctance to participate in interviews. This pattern reflects Hertz and Imber's account of accessing and interviewing elites and other key informants (1993, p. 3). These experiences had implications for cost and time management, and to some extent were unavoidable. However the few occasions where access was hesitant were largely mediated by approaching interview subjects formally, well in advance. In the end no-one I approached for this study refused to be interviewed.

Focus Group Discussions and Participant Observation

Focus Group Discussion (FGD) data draws on participants' spontaneous interactions with each other in a safe space to share ideas and opinions among people of similar social, economic, cultural and gender backgrounds (Lincoln and Denzin, 2000). FGDs provide opportunities to explore different perspectives, although compared to interviews, they are generally more prone to generate opinions accepted as norms in a given social context (Richie and Lewis, 2003). For my study, focus groups were held with farmers to explore local animal health priorities and approaches to treating cattle for animal and human trypanosomiasis. Robert Chambers' material on Participatory Rural Appraisal (1994; 1997) and workshops (2002) provided some useful insight into various approaches to consider when designing my own workshops and group discussions. I was also extremely fortunate in being able to accompany Dr Jennifer Palmer at the beginning of my fieldwork in July 2015 in conducting focus groups in the West Nile for her own concurrent research. This gave me some first-hand observation and experience of setting up, mobilising, and running focus groups with research staff.

The basis for the content of topics and themes covered in FDGs was informed by a review of the literature and previous studies, and feedback and

interviews with local 3V vets regarding local attitudes and farmer's reception of the SOS intervention and local community sprayers. My research assistants and I aimed to gather natural groups of 8-to-10 people that could feel comfortable in each other's company to share their thoughts freely. Occasionally, particularly during election season in 2016, this was complicated by the frequent touring of political candidates in motorcades which would gather people and hand out sums of cash or items of party affiliated campaign merchandise. This sometimes led to initial confusion or disappointment with our arrival and purpose of mobilising groups, which was delicately handled by my research staff.

On other occasions, focus groups were interrupted by inebriated individuals which disrupted proceedings. However in most cases this was no more than innocuous interruptions or interjections, and only once escalated into an altercation between group members which resulted in the focus group being suspended. This was later re-scheduled to the following day at a time in the morning when we were informed we would be more likely to find people in a state of sobriety, and we decided to conduct FDGs early on in the mornings thereafter.

It was important for me to make my position as an independent researcher with no affiliation with local healthcare services or the Ministry of Health very clear to participants. During one of my first focus groups, some respondents aired their concerns about the consequences of sharing negative experiences with local health services:

“For instance, coming here and getting information like this, all these problems, these people will now punish us for telling you”.

“Politicians up there they will come and shout at them [health workers] for telling you these things”.

- Focus group participants, Lira district

Although it had been made clear whilst explaining the study and obtaining consent that all respondents would be anonymised, the topics covered in the discussion – on health and local healthcare services, elicited concern that we were conducting a report for the Ministry of Health, and that any complaints might lead to serious repercussions for local health workers or the population being served by local government health centres. Although we managed to allay these concerns, and greater lengths were taken to make ourselves and the project distinct from any formal association with the health sector, I was mindful that responses during discussions may be influenced by the nature of the topics discussed, or simply by my fitting the image of a white European working with health and development projects in an historically research fatigued region. This would be true for one-to-one interviews as much as focus group discussions.

Health Centre Survey

During my survey of level II and III Health Centres across Kaberamaido, Dokolo, Alebtong, and Lira Districts, I visited 13 facilities, (2 HC IV, 12 HC level III, and 10 HC level II) and interviewed 29 members of staff. These would generally be the most senior available members of staff on duty on the day of visitation, such as the clinical in charge or medical superintendent. Each health centre visit would always include a viewing of the laboratory facilities (if any) and an interview with lab staff. This allowed me to get a rounder view not only of the health centre's general capacity and position within the local area in terms of community outreach, but also an insight into the material, technical capacity of the testing capabilities on site. Most of the facilities visited had a working lab with at least one member of laboratory staff, a laboratory technician, or lab assistant, and in some cases both (generally level III facilities only).

Marsh (1982) argues that quantitative surveys can provide information and explanations that are 'adequate at the level of meaning', but recognises that survey research is not always good at capturing the subjective dimension of behaviour. This is why I have incorporated semi-structured interviews with staff, and in-depth observational data through ethnographic methods. By recording the diagnostic capacity in technological terms, I could evaluate the extent to which the presence or absence of these material objects are in the diagnostic assemblage, compared to say the syndromic suspicion of staff, or their confidence in performing certain tests or knowing how to report or manage HAT cases if they arose. Responses to these kinds of questions are less amenable to survey methods and overly reductive, and so a mixed-methods, largely qualitative approach to this case study allowed for a contextual analysis of diagnostic infrastructures.

Study limitations and responding to problems in the field

While some adverse circumstances during my fieldwork were averted or mitigated through meticulous planning, not all eventualities can be accounted for in risk assessments or fieldwork plans, and at times I found myself having to adapt to rapidly evolving situations as they arose. This ranged from frequently occurring and relatively benign events, such as delays in gaining permissions and approvals from authorities, loss of hardware or data, transport breakdowns, and becoming stranded by adverse weather and environmental challenges, to less common but disruptive and potentially serious events. In my own experience these included becoming seriously ill in a remote place, bereavement (for which I took leave from fieldwork and returned to finish data collection later than scheduled), team members needing to leave at short notice for personal emergencies, losing access to finances, defusing conflict situations with agitated or inebriated individuals, and navigating signs of potential political unrest (e.g. during election season).

I have also had to adapt and respond to changing relationships between collaborating research groups, or fieldwork plans and partnerships falling through. Having a flexible, iterative research design meant that I had alternative options available to me, and after revising my research design more than once due to changing circumstances, I was able to build a stronger and more resilient project. The motivation to conduct a large and ambitious project such as mine also enabled me to adapt to multiple changes to circumstances and plans throughout my fieldwork, and having this flexible research design allowed me to navigate and respond to changing circumstances to minimise negative impacts on the schedule or implementation of my research.

For example, the unfortunate timing amidst the uncertain and critical stage of the feasibility study phase of the SOS mass cattle treatment campaign I was planning to work alongside, eventually rendered my collaboration with the programme untenable. Possibly owing to uncertainty of securing investment at the time, my involvement may have become a subject of discomfort and contention with some partners. To avoid potential conflict or disruption to the programme (and minimise potential risk to my own research), I responded quickly to an opportunity that had arisen with the Tiny Targets tsetse fly control programme that was being piloted and scaled up in the West Nile region of Uganda. This was in a more advanced stage of implementation, and would allow me much greater access to participating communities for my own research. Being able to be flexible in this way meant that I was able to respond to a changing situation on the ground and strengthen my research the better for it.

Reflections on positionality and responsibility

I have sought to align this thesis with a body of ethnographic research that concerns itself with how interventions work in the context of global health and development. However, this is not in itself an ethnographic piece of work per

se, although it does employ a suite of qualitative methods from the ethnographic toolbox, namely in-depth interviews, naturalistic observation, and discourse analysis. Moving from one technology or intervention, and thus study site, as often as I did for this research, meant that the length of time, extent to which I could immerse myself as part of one particular scientific community or role was too limited to describe the insights produced as truly ethnographic. Other distinctions must also be drawn between ethnographic studies and my own, given the socio-economic and epistemological characteristics that preclude me as an 'outsider' from securing the degree of engagement with various communities required for a full ethnography. As a white, middle-class British-Irish woman, my physical appearance and identity as a 'mzungu' in Uganda would always be my most prominent and defining presentation in most social interactions.

During one particular encounter at COCTU headquarters, after delivering a progress report from my research to a member of staff, I was asked whether I planned to return to Uganda to 'become a consultant' after I finished my PhD. *"People from your countries make nice careers in consulting. They fly in at great expense and interview everybody, then make a nice report to tell us what we already know!"* We laughed, but I found myself hesitant, embarrassed that I had been 'caught out' with my privilege on show.

Of course, the observation was entirely on point; my position as a white, western woman conducting research under a well-funded project with a renowned British university could never be anything but conspicuous. One of the key lessons I took away from my fieldwork was just how these intersecting layers of privilege are only inconspicuous to those who benefit from it. Daily realisations through such interactions provoked moments of overwhelming reflexivity, and brought home a profound sense of responsibility. Not only in terms of how I position myself as a researcher, but how I raise the 'voices of the field' (Okwaro et al., 2015) my research was drawing on. My expertise often paled significantly against the collective

wealth of my informants' knowledge, which had been packaged in the potted summaries of my own 'analyses', and the concern that my relationships with local practitioners was extractive or exploitative in some way became an uncomfortable point of existential contention for me during my fieldwork. I also learned that acknowledging and confronting this discomfort is a good thing, and that situating my anxiety in context can serve productively as good praxis toward being critically reflexive of my work. That I had the funding and institutional backing to be in Uganda conducting this research seemed revealing of a long and problematic relationship between global 'northern' institutions, often forged through ties to colonial pasts, with countries in the global south.

The privilege afforded to me by my association with Edinburgh University, an institution with a long-standing relationship with the COCTU and wider HAT community in Uganda, was revealed to me frequently in daily interactions and performances of institutional and reputational power. For example, my ties with Edinburgh were often conflated with an association with the Welburn group and the SOS programme. In my early days of fieldwork this was at times a great facilitator to gaining access to certain individuals in COCTU or the Ministry of Agriculture for example, but also a barrier in other situations where this relationship had not necessarily been positive. In the early stages of my project, from my co-supervision with Professor Sue Welburn and during preliminary fieldwork in 2014 accompanying the SOS programme, this association was more tangible and a source of reputable association I could draw on when arranging meetings or interviews with key stakeholders. However, as this supervisory and collaborative relationship changed over time up to when I began my main phase of data collection, my association with SOS diminished, and to some degree my status with it. I now had to present myself more as being from the University of Edinburgh, but independent from the Welburn group and SOS, a frequent source of confusion given the interchangeable conflation of 'Edinburgh' with 'SOS' that had developed over the past decade. However, emerging as an

'independent' researcher from an institution with well-established ties to the HAT network in Uganda, but unaffiliated with any particular intervention project was also liberating and made my interactions with other research groups or programmes much easier, being perhaps viewed as unthreatening, or relatively impartial.

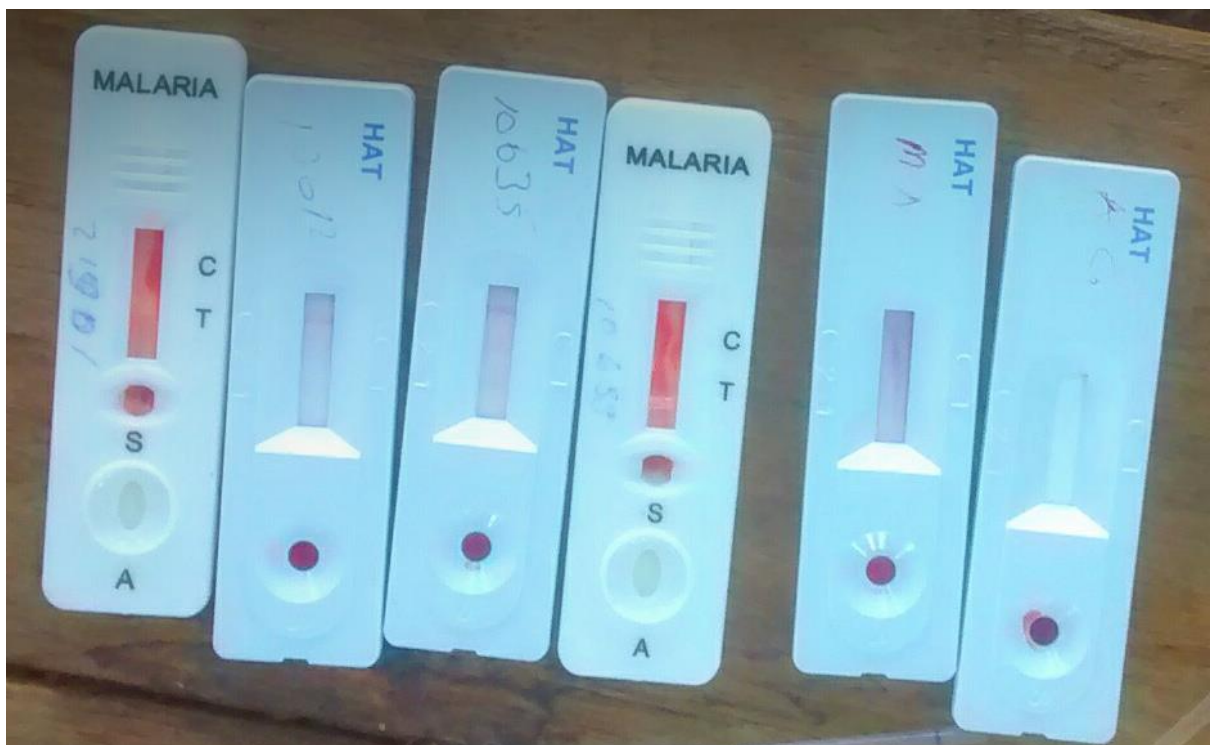
Additionally, coming from a multidisciplinary background, it is logical that I would draw on a number of disciplines when designing and conducting my research. The original project I attained my studentship for was funded by an Advanced Quantitative Methods ESRC studentship, which encouraged students with a quantitative background to pursue multidisciplinary PhDs. However, despite my initial enthusiasm for surveys, models, and Social Network Analyses in earlier research proposals, it became evident very early on that the kinds of questions this project was asking could not be answered using quantitative methods. Therefore, this thesis drew on a mixed methods - and largely - qualitative approach. Taking a mixed methods approach was advantageous in that it allowed a flexible approach to my research design, and the freedom to adapt my topics of study in response to the reality, including the changing nature of collaborations, that I encountered on the ground.

By tracing Trypanosomiasis from the point of detection through to the preventative control, I found not a singular version, but multiple '*Trypanosomiasis*', enacted by different actors across different settings (Mol, 2003) in different ways. By following the trajectory of the disease through the landscape of elimination, I aimed to characterise some of the structural, biological, and socio-technical elements of the HAT ecosystem. I began by searching for 'the sickness at the end of the track' (Regnier, 2017).

CHAPTER FOUR

Where the sickness sleeps

Enhanced passive surveillance in an elimination setting



“Artefacts only have significance in the hands of people”

- Whyte, van der Geest, and Hardon, 2002

Diagnosing Human African Trypanosomiasis (HAT) is complicated, requiring the alignment of clinical suspicion with serological, parasitological, and molecular confirmation to determine appropriate treatment. Classically HAT is diagnosed via a three-step approach: the identification of clinical and serological suspects, parasitological confirmation, and disease staging. This

chapter concerns the first two steps which can be broadly classed as 'case detection'. It begins by describing a mobile screening, a now rare event that once characterised the state's public performance of HAT intervention in the historically T.b. gambiense endemic West Nile. Participants problematise the new strategy, foregrounding the chapter's exploration of how HAT is detected syndromically by patients and health workers amidst a changing referral landscape.

Specifically, this chapter focuses on the treatment seeking trajectories of syndromic patients in pluralistic landscapes of state, self, and private care. Where these intersect with state health infrastructures of surveillance, HAT is then 'read' (Umlauf and Beisel, 2016) and 'translated' (Callon, 1980) by serological diagnosis (via the presence of trypanosome-specific antibodies in the blood). The chapter then focusses on the trajectory of patients who are serological suspects as they navigate the new decentralised referral system to receive their confirmatory diagnosis. Interviews with 20 RDT-positive HAT suspects who had failed to complete their follow-up referral reveal that the diagnostic landscape and treatment-seeking pathways navigated by patients are not as linear as the Intensified Sleeping Sickness Elimination Programme (ISSEP) assumes. Communication at the point of testing is identified as a factor in determining referral non-completion, as suspects were largely unaware of the need or importance of having their RDT result confirmed by microscopy, or in some cases unaware that they had even been tested positive for HAT by a rapid test.

Introducing an RDT-based passive surveillance system is innovative in being a cost-effective approach to placing diagnostic technology within the 'material proximities' (Fontein, 2011; Brown and Kelly, 2014) of patients at the primary healthcare level. However, this case study suggests the diagnostic assemblage is held together by important relationships of trust and communication that are sensitive to change, and highlights the importance of social proximity (Chandler et al., 2011).

Previously, HAT diagnosis has been carried out by mobile lab teams which confirmed cases in village screenings and transported patients for treatment. Since cases have declined however, expensive active screening campaigns have become less effective. As a result, these have been phased out and replaced with passive, symptom-based algorithms. Without early treatment HAT is fatal, yet timely diagnosis in regional referral hospitals is difficult to access for many of the remote, rural communities predominantly affected. Rapid Diagnostic Tests (RDTs) are designed to be affordable, portable and easy-to-use; desirable attributes in resource-poor settings, and favourable in disease elimination conditions where case numbers are low and highly localised.

Testimonies from RDT-positive referral patients depict the historical and social phenomena that shape the ‘therapeutic’ landscape in which individuals seek care (Gesler 1992, 1993; Gesler and Kearns 2002; Street and Coleman 2012; Winchester and McGrath 2017; Cross and MacGregor, 2009). They describe the local “ecologies of testing” (Umlauf, 2017), and the management of expectations and anxieties, illustrating how patients navigate and frequently deviate from the diagnostic landscapes imagined and constructed by the national HAT control programme.

Bringing the laboratory to Ewanyati

James claps his hands in jubilation at our arrival, “It is here! Stop the car,” he announces as we pull up into a clearing. After three hours of navigating pot-holes and impenetrable fields of elephant grass and cassava, we finally come upon Ewanyati. The village is too far from either Yumbe or Omugo, the two closest health centres with level IV laboratory facilities, for us to transport patients back for their microscopy tests, so today we must bring the lab with us.

While active screening is no longer the norm here in the West Nile, specific projects and reactive screenings are still conducted sporadically, though not as part of a concerted large-scale surveillance programme. In recent months, the Liverpool School of Tropical Medicine has been conducting active screening across the region where it has just introduced a widespread network of insecticidal treated nets called *Tiny Targets*, in a bid to significantly reduce the tsetse fly population and interrupt transmission of human infective *T.b. gambiense* HAT. By actively searching for cases in these areas the programme sought to establish a baseline of prevalence data from which to measure the impact of the targets on human cases in the region. When I join the team in November, the screening programme is moving into its second phase. People who had tested positive using the CATT (Card Agglutination Test for Trypanosomiasis) and the new RDT during mobile screening must now be “rounded up”, as the regional programme officer Oliver puts it, and brought to the closest lab facility where they can undergo further tests to determine if their initial serological diagnosis can be confirmed via parasitological demonstration by microscopy. In circumstances where this is not feasible, such as today, the capacity to perform these tests must be brought from the clinic to remote communities.

After this first round of active screening follow-ups no more mobile teams would be deployed, and patients would be expected to present themselves for any further follow-ups at their nearest microscopy centre (as per the passive surveillance system). Ewanyati is approximately 40km from the nearest microscopy centre, compared to the average distance between peripheral RDT sites and referral facilities, closer to 12 km (Wamboga et al., 2017), and so any confirmed suspects assembled before us here today faced travelling considerable distances to complete follow-up or treatment if needed.



The Omugo Hospital mobile screening team test their first patient in Ewanyati, Yumbe District

Those who have arrived already queue patiently to be seated and have their CATT and RDTs repeated, and venous blood samples taken to be centrifuged, prepared, and inspected. Technician David takes the samples and drips them carefully onto individually numbered CATT cards and RDTs, assembling them neatly on the table in a line. Meanwhile, Jacob is

performing the mAECT (mini Anion Exchange Centrifugation Technique).⁴

Jacob crouches over a chair, whirring capillary tubes in a handheld centrifuge device not dissimilar to a mechanical whisk, and prepares blood smears onto glass slides. Chief lab technician Albert has positioned himself and his microscope at the end of the production line, where he relays his results to Oliver, who is recording them on his clipboard.

Given this kind of mobile screening is no longer the norm and has been replaced by the new RDT-based referral system, I'm curious to learn how much participants know about the new rapid test for HAT, and I approach a congregation of people while they wait for their results.

"Now that we know they [the RDTs] are there, I could ask for a test, yes" one young man responded thoughtfully, "but I don't know how the health worker would react to my question [...] I don't know whether the health workers in our unit here will respond to our call saying we want to be tested for this though" (Active screening positive suspect 2). The significance of this uncertainty would become pertinent later on, though given how referral-non completion had been framed in earlier conversations with programme staff, I anticipated my questions regarding the new referral system to elicit generic complaints about long journeys and transport, as I had been told to expect. Instead these open a new discussion altogether.

"We would find all possible ways to go, because it is a bad disease which needs to be treated seriously."

- *Mobile screening positive suspect 2*

"Our worry is if we are told to come again and be tested again after 3 months. I wonder if we will need to go to Omugo, or Yumbe, or if the team will come here again like they have today."

⁴ This consists of separating the trypanosomes from venous blood and concentrating them in the bottom of a transparent tube by low speed centrifugation. After centrifugation, the tip of the transparent tube is examined under the microscope for the presence of mobile trypanosomes. The large blood volume (350 µl) allows detection of less than 100 trypanosomes/ml resulting in high sensitivity (Büscher et al. 2009).

- *Mobile screening positive suspect 1*

“If we have to come every 3 months, how long will this take? How many months before someone tells us that we are positive or negative?”

- *Mobile screening positive suspect 2*

“My worry is treatment. The areas they go to for it; Omugo and Yumbe are very far. Now we have information about RDTs in the units that is okay, but also bring the drugs to the unit too!”

- *Mobile screening positive suspect 4*

Others join and jeer in agreement. James our mobiliser, a former ‘Sleeping Sickness Attendant’ (SSA) with over 20 years of experience with the MSF screening teams, interjects to explain the referral process at more length, responding to questions and elaborating on the specificities of follow up procedures. The group eventually settle, seemingly satisfied, and conversation resumes.

“There are two main things, major problems. First, to go to hospital we need money, which we need to find money ourselves before we go. Also, we have the problem of leaving family who we need to support. We also need to also find a member of family to support us at the hospital when we go, so who will then be left behind to manage?”

- *Mobile screening positive suspect 3*

“That is a very big challenge, as I would be leaving the family to suffer, but if I don’t go then I am sick, then I must get the treatment. This is a very big challenge to us”.

- *Mobile screening positive suspect 1*

“I am worried, the first test we were told to be followed up after three months, and if today again it is positive they say to go again after 3 months. This gives us worry, why does that happen?”

- *Mobile screening positive suspect 2*

James attempts again to assuage their concerns, but the disjointed nature of referral and follow-up continues to raise apprehension and confusion among the group. The perplexity this system poses to those seeking diagnosis

passively may be more problematic than anticipated, particularly where there will not be an experienced team of staff on hand to guide them through the complexities of this novel and unique process at length.

My sub-study on RDT referral non-completion had been conceived in response to the problem of referral drop out, or 'defaulting', whereby serological suspects failed to present for follow-up microscopy tests to have their diagnosis confirmed by parasitological demonstration. Reasons for drop out were generally assumed by the elimination programme to be logistical, and staff had been quite adamant that the only real challenges facing suspects reaching follow-up and completing referral were poor attitudes and the distances involved in travelling to health facilities for microscopy.

“People give distance to the microscopy centre as the reason for not coming. Sometimes it can be up to 45 km to travel to get to the microscopy centre, and Koboko Hospital is the only one in the county”

- District programme supervisor 3

“People are not willing to get tested, there are some negative attitudes [...] Because some [suspects] have a negative attitude to going, I have to counsel them and assure they will not have to pay”

- District programme supervisor 1

Meanwhile, one District Supervisor seemed confident that - providing the technology and capacity are present - there is no problem of case detection to speak of.

“Case detection is not a problem – there are no challenges. So long as RDTs and health workers are there then they will detect cases”

- District programme Supervisor 4

Nevertheless, the experiences described above and subsequently by RDT-positive suspects in this study deviated from the control programme's vision of the landscape it imagines its target population to be navigating. Namely,

that people would get sick and go to their local health centre and be comfortable asking staff to test them for HAT, and that this request would be met and they would be tested with an RDT. It assumed that the health worker there would give their results with clear instructions, and that those who tested positive understood those instructions and would comply with them unhesitatingly should they be practically able. What it failed to envisage is the collective memory communities have of past HAT epidemics and the mobile screening teams that came with them. Nor does it acknowledge the relationships of trust in local healthcare services, or the multiple confounding social and personal factors that make accessing care not merely a matter of physical presence of locally available tests, but complex relationships and socially embedded diagnostic cultures.

Environments of uncertainty: making the national elimination strategy work in local practice

The troubling dilemma of losing patients to follow up is one shared by many of the ISSEPs District Supervisors. A case, having left the confines of the health facility transforms from a visible, monitored, knowable body, into an unknown, potentially infectious agent. This patient outside of the follow up cycle is reimagined, from once being a victim of HAT (or potential victim in the case of serological suspects), to a potential vector and infectious reservoir in the community (Battin et al. 2009). One ISSEP supervisor expressed his concerns about losing patients in West Nile to follow-up and the 'environment of uncertainty' this creates;

"It is important to reach every RDT+ suspect and make sure they reach microscopy, We want to avoid an environment of uncertainty. Each person must come to be declared by microscopy. We don't want to create room for people to be living with Trypanosomes [...] We don't know if they are positive or negative, so we pray that they haven't gone on to infect others in South Sudan for example where the health system is weak".

- District Supervisor, Koboko

Here, 'at risk' and 'vulnerable' patients are re-configured as non-compliant bodies by referring to the threat they pose to others, as they continue to go about their daily activities while potentially infected, thus posing a risk to the wider community around them. In framing the issue of referral-non completion in this way, it is possible for programme managers and policy makers to detract from other socio-economic and cultural drivers of HAT under-reporting, and instead problematise individual, deviant, 'defaulting' bodies that threaten targets being met.

Their 'status', as many patients and health workers referred to, is ambiguous outside of the physical constructs of the surveillance infrastructure; the penetrability of the control programme being limited to the material confines of the lab. However, in the same way the state can be brought into the clinic (Hutchinson et al, 2016), the clinic too can move through space and extend the ISSEP assemblage to reach remote communities and deviant bodies. These environments of 'epidemiological uncertainty' propels new forms of evidence making and surveillance (Biehl, 2016). For example, the ISSEP District Supervisors (DS) had each come up with their own tailored solutions to some of the logistical challenges to patients completing referral. In Koboko district, this consisted of following up patients through local Village Health Teams (VHTs) with whom the DS has contact with. As the home village of the suspect is often (but not always) recorded in the patient register, by referring to the record books of the receiving facility that performed the RDT, he could find their Case Report Form (CRF) and subsequently the VHT that cover their village and their contact details. Where they had access to motorcycles, sometimes VHTs would pick patients up from home and bring them to their microscopy appointment, though "generally the intervention is counselling to convince them to come under their own volition" (District Supervisor, Koboko). Liaising through local networks in this way often resulted in much higher adherence, as it was mediated through trusted local VHTs and allowed them to relay important information which may have not

been communicated effectively at the point of testing. However, even VHTs require support to carry out follow-up.

These strategies, while largely effective in keeping the programme functional on a day-to-day basis, come at the expense of the unremunerated personal time of District Supervisors (and other support staff) which is already stretched across a multitude of other responsibilities. Koboko's DS suggested that if he didn't keep on top of doing follow-ups himself, those patients would have never come to their appointments, saying "it has become a necessary part of the programme". Elsewhere, one DS who had 17 outstanding HAT suspect 'defaulters' at the time of study told us how he could not follow them up himself because of other commitments, and that before he got his motorcycle (provided from the government's NTD programme) it was very difficult to trace suspects to follow them up at all.

"It would be easier if the Ministry of Health had budgeted for the movement and commitment involved in following up defaulters. I have to work around my budget given to me with many other projects and commitments, but they are making more cuts all the time".

- ISSEP District Supervisor, Yumbe District

Another DS devised an even more extensive strategy, bringing laboratory capacity to suspected patients to their home;

"We take the lab person to take blood samples when they visit as they know how to best handle them in transit. They take these to the microscopy centre and repeat the RDT, then prepare microscopy samples and filter paper samples for LAMP".

- ISSEP District Supervisor, Maracha District

At the time of writing, a pilot study not too dissimilar to this approach had been formalized and carried out in Bandundu Province in the Democratic Republic of Congo using 'mobile equipe' (or 'mobile mini') teams on motorcycles (Reed, 2017). These teams, comprising three 'scouts' and one

person to confirm diagnosis, travel by motorcycle to make house-to-house visitations, extending the reach of HAT clinical services and improving coverage of Gambiense HAT detection and follow up in difficult to reach populations.

The screening capability of a mini-team is similar to that of a conventional mobile team, but is more flexible, reaches more people in remote villages, and takes into account the activities of communities. This 'fast and light' approach to active screening and follow up has so far proved successful owing to its flexibility. However, despite its relative simplicity it remains no less expensive than the traditional truck-based mobile teams as the cost of human resources and tests etc. still must be accounted for (Boelaert. HAT modelling meeting, 2017). The primary weakness of the mini-team approach is that the diagnosis of RDT positive cases is only confirmed a few days after the screening, thus the risk of not being able to find those with a positive diagnosis again, i.e. positive patients dropping off referral, remains a key challenge (HAT platform newsletter, 2018:15).

Herein lies the crux for Uganda's programme. Sleek, innovative solutions can be devised and co-ordinated in the face of adverse circumstances, and the efforts made by ISSEP supervisors to simply 'make things work' is important labour that makes the RDT align with components of the decentralised healthcare system. A benefit of not prescribing a rigid method of implementation has been that practical solutions can emerge to fill locally specific problems. However, supervisors all share other leadership responsibilities within this system, come with associated costs that have to come from somewhere. Their efforts, while resourceful and commendable, ought not to be taken for granted as long-term sustainable solutions. For this reason I am reluctant to glamourise the 'tinkering' involved in trying to make new diagnostics 'fit' into local assemblages of care, as it panders to the unhelpful trope of the 'innovative spirit' of African practitioners "turning obstacles into opportunities" (Van Houten, 2018) in global health media. This

serves only to detract responsibility from the power structures that allow conditions, whereby implementation staff at the sharp end of interventions must undertake such 'noble struggles' to make programmes work amid a constellation of local priorities. Approaches such as mobile motorcycle labs and VHT follow up teams do make confirmation testing both more physically and socially proximate. However, the current referral system at both entry and exit points is disjointed and difficult to navigate for patients. Re-configuring this landscape to a more 'user-friendly' one requires facilitation from HAT referral support structures. However, the responsibility of devising and funding these changes need to come from the spaces of policy and programme design, and not placed on overstretched and under-resourced staff at the implementation end of interventions.

In the following sub-study, the testimonies of serological suspects in this system complicate a prevailing narrative of global health; that diagnostics equate or lead to diagnosis, and that cheaper more accessible diagnostics create greater and more equitable access to care. It centres human interactions and the importance of communication at the point of testing over the presence of devices, where discordant results reveal discordant priorities between programmes seeking cases and patients seeking care. This lays bare the gap between the objectives of the elimination programme with those of the health system with which it has ostensibly integrated. Finally, it suggests the material proximities of diagnostic technologies to target populations is less significant than their social proximity; through structures of support, trust, and communication.

Referral non-completion among RDT-positive suspects

Between August 2013 and February 2014, Uganda's Intensified Sleeping Sickness Elimination Programme (ISSEP) introduced three diagnostic technologies across different levels of the public health system. All of the 212 health facilities in areas of West Nile believed to be at risk of *T.b. gambiense*

HAT transmission were supplied with HAT RDTs (Wamboga et al. 2017). Nine well-maintained and staffed facilities in the project area were also given training and equipment to perform parasite confirmation techniques. Three of these facilities were also upgraded to perform the sophisticated molecular LAMP (Loop-mediated Isothermal Amplification) testing. For this kind of referral-based intervention to succeed, patients need to be able to navigate the referral step easily and trust programme supervision structures which guide patients between them (see figure 14).

At each of these levels, relationships of trust and power between patients and health providers is a key dynamic to understand programme compliance (Horter, Kerschberger et al. 2016), with trust built partially on what people see and hear about technology (including diagnostics (Beisel, Umlauf et al. 2016)) and institutions (Ostegaard 2015). Thus, referral completion involves not only technical and organisational considerations, but also expectations and emotions (Bossyns and Van Lerberghe 2004). Many studies of the referral process therefore conclude that low referral compliance reflects more about the health system than the patient, since “every non-respected referral is an unsatisfied patient with an expressed need but with an inadequate response of the health service” (Peterson, Nsungwa-Sabiiti et al. 2004, Bossyns, Abache et al. 2006, 56). For a referral-based intervention to succeed, patients thus potentially need trust in both referring and receiving facilities as well as programme supervision structures which support patients to move between them.

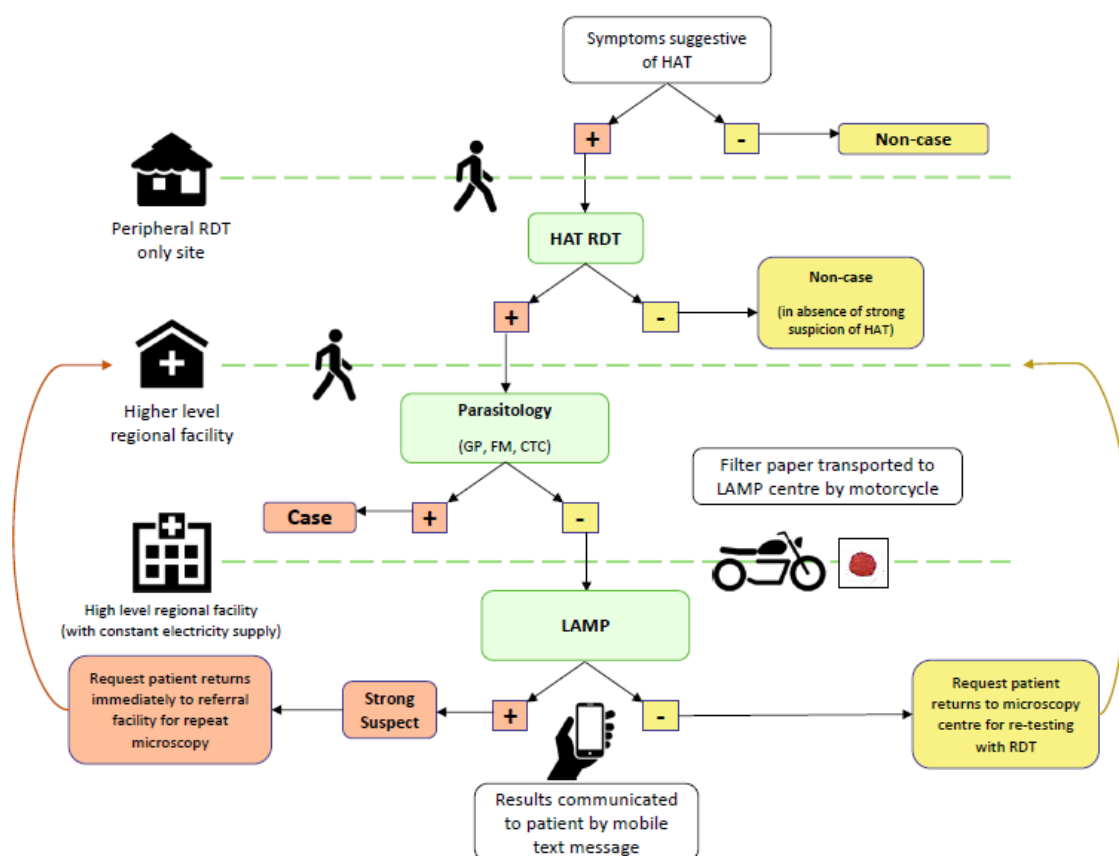


Figure 12: The *T.b. gambiense* human African trypanosomiasis diagnostic referral algorithm implemented by the ISSEP in Uganda.

Adapted from Wamboga et al. 2017: 7.

In this sub-study I examined patient experiences and perceptions of HAT, HAT tests and the referral system in relation to HAT testing, to identify systemic challenges to referral completion by HAT screening suspects. I interviewed a total of 20 serological suspects (RDT+) who had not completed referral. Of these, 4 had returned for one follow-up microscopy examination, but not returned for repeat follow-up, indicated in the text as 'RDT+MS-' for 'microscopy negative'. Of the 20 RDT+ suspects I interviewed, the majority (15/20 or 75%) were female, (see Table), the median age was 40 years (range 8-76), and the median time between first screening RDT+ and interview was 13.6 months (range 3.0-26.3, 13.5 for the 16 RDT+ suspects and 16.6 for the four RDT+MS- suspects). Participants had been screened at 13 frontline facilities across four of the seven districts covered by the ISSEP (see figure 15). The median distance from respondents' RDT screening sites

to the facility they were referred to was 15.0 kilometres (range 5-48 km), slightly further compared to the whole sample (13.0 km, range 1-50). All the suspects completed their outstanding microscopy examinations after interview; no parasites were identified and all were dismissed from further evaluation.

Table 2: Demographic profile of all outstanding RDT+ suspects in four districts and those interviewed.

		RDT+ suspects outstanding	
		Total identified, n (%)	Interviewed, n (%)
Total		94	20
District			
	Arua	30 (31.2)	9 (45.0)
	Koboko	22 (23.4)	2 (10.0)
	Maracha	20 (21.3)	3 (15.0)
	Yumbe	22 (23.4)	6 (30.0)
Gender			
	Male	34 (36.2)	5 (25.0)
	Female	60 (63.8)	15 (75.0)
Age (years)			
	Median (range)	30 (3-79)	40 (8-76)
Time referral outstanding (months)			
	Median (range)	12.9 (1.2-26.2)	13.6 (3.0-26.3)
Distance to referral facility (km)			
	Median (range)	13.0 (1-50)*	15.0 (5-48)

*n=92 as data on the referring facility was missing for 2 patients.

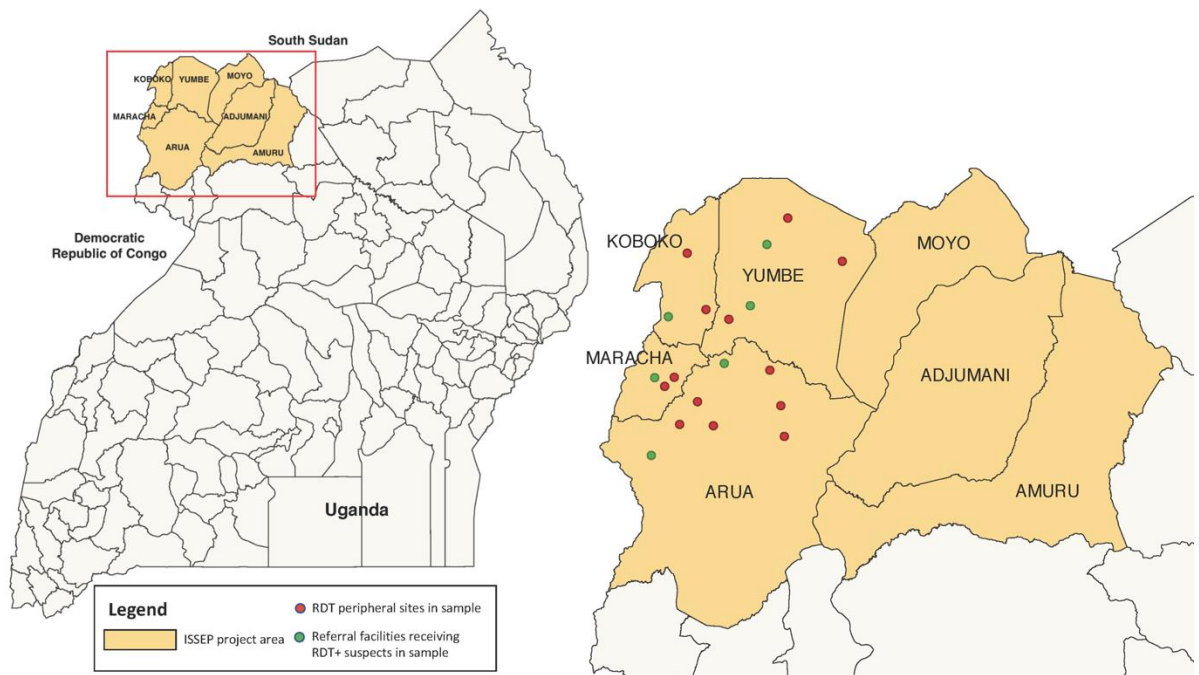


Figure 13: Map of West Nile region in Uganda showing locations of HAT-endemic districts included in the ISSEP and locations of referring (red) and receiving (green) health facilities included in the study sample.

Findings

Awareness and perceptions of risk

While patients may not have suspected HAT themselves before being tested for it, most patients I interviewed appeared to take the disease seriously. This included an awareness of their own risk from HAT, particularly after receiving a positive RDT result. Almost everyone interviewed had some personal knowledge of HAT, having known relatives or people in their village who had suffered or died from it during outbreaks in previous years. Other key sources of knowledge included community sensitisation campaigns associated with medical active screening programmes or LSTM's tsetse fly control intervention using insecticide treated targets. At the time of interview, nearly all respondents claimed to feel there was a risk of HAT in their area. Peoples' perceptions of risk were discussed in terms of their proximity to tsetse flies near rivers, 'the bush', and dark, densely vegetated forest areas. Risk was also interpreted in relation to the presence of HAT interventions,

with comments such as, “We have that fear because the screening teams came to our village” (RDT+MS- suspect 1, Arua) and “I have fear in my hut, I have seen tsetse fly nets being hung up [nearby]” (RDT+ suspect 19, Maracha).

Despite a moderate local knowledge of HAT, awareness of the RDT for *T.b. gambiense* on the other hand was extremely poor, and so knowledge about the test and its position in the referral system was similarly limited. Given peoples’ lack of awareness of HAT RDTs, their presence in frontline facilities did not seem to have had a similar influence on suspects’ perception of HAT risk prior to testing. Like mobile screening teams raising risk awareness, comments about not personally feeling to be at risk *until* testing RDT+ such as the following, however, suggest that the process of screening RDT+ may have heightened some suspects’ perception of personal susceptibility to HAT: “from the result of my blood I have that thought that I have sleeping sickness” (RDT+ Suspect 21, Maracha).

By the end of this sub-study I concluded that very few participants had been aware that HAT control in the region had been handed over to government services, and were still under the impression that this was still co-ordinated by MSF through mobile screenings. Prior local knowledge about HAT among RDT positive suspects in the West Nile were largely based on collective memories from past epidemics which were managed by MSF.

Knowledge of the referral process or treatment of HAT was also very low across both active and passively screened patients, and only those with experience of either having been treated before or having known a close relative who had also suffered from the disease had been aware of what the staging process or treatment involved. Some knowledge was based on rumours or stories from past epidemics when MSF was operating in the area. Some expressed fear about the infection staging process, such as the lumbar puncture, or the perceived excessive blood withdrawal during follow

up. Others were concerned about the side effects of treatment and the impact on their productivity and livelihoods.

“In previous years the first people who came to treat, they told us that when you are vaccinated with that vaccine you cannot work”. (RDT+ suspect, Arua District)

In all cases, the decision to use HAT RDTs was initiated by health workers, rather than on the request of patients. “The technician health worker started just removing blood and testing, and told me they have found sleeping sickness in my blood. It wasn’t my previous idea that I am coming to test for sleeping sickness” (RDT+ suspect 17, Koboko). Low awareness of the HAT RDT among respondents before testing may partly explain why self-referral was not as common as reported in other studies (Palmer, 2014; Palmer, Surur, Checchi et al. 2014b). Only two people (both from Maracha District) had previous knowledge that the RDT was available at their local health centre through sensitisation activities. One respondent in Koboko District knew they were available in the main referral hospital.

This was the ISSEP’s first faulty assumption; that syndromic patients, on suspicion of their own symptoms or after ruling out malaria, would know they could request to have a rapid test for HAT at their local primary healthcare facility. In this regard, the introduction of the RDT to bring diagnosis closer to communities had been, at the time of study and among my respondents, a practically invisible intervention. Indeed, many respondents were still under the impression that in order to be tested for HAT they must either wait for a mobile screening team to visit their village or travel to Omugo Hospital. This would explain some concern among respondents that active screening for HAT had not taken place in their area for some time, and sentiments that MSF or the state had somewhat abandoned them. In a place where sleeping sickness interventions have historically been “the most visible expression of

the state” (Lachenal, 2017), active screening is taken as a signal that the government is proactively taking HAT seriously.

I found that people in remote areas generally fell into one of two groups; those that felt reassured that the withdrawal of screening teams meant the area was no longer at risk, and those who felt concern that ‘they’, [MSF or local government], had lost political will to control the disease, leaving communities ‘behind’ and vulnerable to further epidemics. Very few respondents were aware of a national sleeping sickness control programme, the availability of local free tests, nor of on-going efforts to eliminate the disease. Thus, despite attempts to sensitise communities during the initial phases of the ISSEP (Wamboga et al. 2017), the introduction of RDTs into health centres appeared to have transformed the state’s HAT diagnostic algorithm without altering the populations’ perceived treatment seeking landscape at all. This mismatch renders the main feature of the enhanced passive surveillance strategy - accessibility (a key trait of the rapid test design) - futile, as the device remains out of sight and out of reach to the remote populations who need it. Elsewhere outside of my study districts, despite fears that refugees were at particular risk of disease and posed a credible threat to elimination (Picado and Ndung’u, 2017), based on low RDT performance figures ISSEP coordinators switched to a sentinel surveillance strategy in areas hosting the highest concentrations of refugees from South Sudan. This meant that RDTs were removed from most refugee-serving facilities, ultimately exacerbating the existing inequities in access to HAT surveillance (Palmer, Robert, and Kansiime, 2017). As the following section explains in more detail, placing RDTs in government health facilities already situates HAT diagnosis outside of local testing ecologies and treatment seeking pathways.

Patient pathways to testing

At the time of interview, most suspects reported having experienced symptoms consistent with HAT, particularly headaches, fever, or excessive sleeping during the day. HAT-like symptoms were commonly described as part of a long-term, difficult to diagnose or treat illness that some patients reported suffering from for years. While peoples' symptoms matched the HAT syndromic screening profile, however, only one person, who had a family member previously treated for HAT, had ever considered they might have had the disease before being tested. Everyone else assumed that they were suffering from malaria or typhoid, or were unsure of what could be causing their symptoms, so sought diagnosis and treatment from local health facilities and drug shops. Some additionally considered whether they might be affected by witchcraft or a common flu, and so took herbal treatment.

“It started like malaria. From there I took a step and went to the clinic. I bought a drug, tablets. I took the drugs for two to three days, on the third day this thing threw me down, I was bed ridden [...] from there they told me this is not malaria, what is detected it looks like sleeping sickness”. (RDT+ suspect 19, Maracha)

Of those who suspected malaria or typhoid, the majority reported to have sought treatment from local drug shops in the first instance. Here they would not be tested, but after describing their symptoms would be advised by staff how much of a certain drug they should purchase. Many respondents reported buying drugs for typhoid or malaria, and taking these for one to three months on average, or up to one year in some cases, before being prompted to seek help at a health centre after symptoms had failed to improve.

“I started buying drugs from a clinic called Adrayo. I would also go to clinic at Ochodri. I would only explain what I am feeling, and the attendant would only give what drug they thought I needed. I would also give money and they would give me the drug up to the amount of money I have given. I took them for one year”. (RDT+ suspect, Arua District)



'Hope Medical Clinic' in Rhino Camp refugee settlement, Arua district. Many shops of this kind serve as an informal treatment provider in rural communities, including where government health facilities are equidistant.

While many acknowledged their significant role in a pluralistic health system, drug shops were widely cited by health workers as a key challenge to detecting HAT patients at the point of care.

"The problem is though, some people do not even go to the facility; they will go to a clinic where they don't have the RDTs [...] these are just places where people go to get drugs. They are drug stores [...] some people prefer going to clinics instead of health centres. They want treatment, so [...] they will just go straight to buy the drugs from a clinic. Also the clinic might not be so far to travel".

- Lab technician, Omugo Hospital

Some respondents also sought healing through religious faith, relying on continuous prayer and visiting their church and church leaders. Only after no improvement in their condition would they then seek help from a health facility. In other cases, individuals would treat themselves with herbal remedies, either prepared at home by themselves using family recipes, or using herbs prepared and purchased from people locally who sell them. These would be used to treat flu-like symptoms, or in some cases where the patient felt they had been suffering from some 'traditional curse', which required herbal treatment. The distinction between biomedical and 'local' illnesses is drawn frequently, as supernatural causes of disease, as opposed to biomedical origins, would likely render conventional drugs ineffective.

"I also heard that this treatment would take long in your body and you would fail to recover, especially this treatment will fail to treat you because curses are attached to your life".

- RDT+ suspect, Yumbe District

"I was becoming insane and so I could not clearly figure out which disease was disturbing me. I possibly thought this was typhoid. I also thought there was also traditional curse following me, whereby the treatment is you have to wash your body with some herbs".

- RDT+ suspect, Koboko

Where patients felt these alternative treatments improved their condition slightly and allowed them to continue their work, this would further postpone their presentation at health centres.

"I was taking herbs, I would drink them. They [relatives] instructed me how to make, so I would make my own [...] I thought it was flu that is causing all that. I continued taking the herbs for flu, but the pain persists so this influenced me to go for the test". (RDT+ suspect, Yumbe)

These responses suggest that seeking treatment is not necessarily dependent on or directed by biomedical diagnostic technologies, as patients circumvent formal health facilities and testing procedures to access drugs. Furthermore, they suggest treatment success is not determined by diagnostic

tests that 'clear' them of their infected status either, but by the alleviation or absence of the symptoms that initiated their treatment-seeking journey. Amid the discordant priorities between biomedical systems that seek to confirm or clear people of diagnoses and patients seeking to alleviate their symptoms, those who were tested and found positive by HAT RDTs then had to face pulling together resources and support to undertake follow-up referral to have their serological suspicion confirmed.

Socio-economic challenges to completing follow-up referral

Given that many other RDTs like malaria and HIV are generally free of charge, and that in many cases the HAT RDT was performed alongside these other free tests, most respondents correctly assumed that the RDT for HAT is also free of charge. Those who expressed concern at having to pay for a sleeping sickness test appear to have been reassured by health workers at the time that this service is free. In a few cases communication appeared to have broken down, where some patients believed health workers were charging them for HAT testing. This had discouraged them from coming for further follow-up tests, such as this young man who was deterred from attending a follow-up microscopy appointment, believing he could not afford it;

“When I was taken to Arua, I was to be tested of sleeping sickness but these people charged me 20,000 shillings. Because I did not pay the 20,000 they did not test sleeping sickness, I had to come back home. I had already got the [RDT] result that I have sleeping sickness in Sirpi [health centre] but I was referred for further tests in Arua. They charged 20,000 because they said they could not do the second test from there”.
(RDT + MS- suspect, Rhino Camp, Arua)

On top of the added costs of transport to reach hospital to have these tests, expense is a big barrier to patients coming for referral appointments.

Furthermore, in the experience of some respondents where free RDTs for

other diseases such as malaria have been performed and positive results given, health workers would then instruct them to go and purchase the treatment elsewhere. Knowledge about the treatment involved for HAT is very low, and so none of the participants knew whether the treatment would cost money, or how much this would be. There is also added associated costs to coming for follow up referral appointments every three months, which in this sense (despite tests being available for free) in fact make the referral process relatively expensive. The vast majority of patients I interviewed were very willing to come for follow up tests once the importance of confirmation was made clear to them, but for various economic and logistical reasons many still could not attend the appointment given to them. Barriers to reaching referral appointments unassisted remained consistent, though not necessarily those anticipated by the ISSEP. As expected, matters of distance or lack of access to transport and funds to that end were cited frequently.

“Because of transport we would not come [...] if we are to be followed again then we will need to be picked from our places like today”.

(RDT+ suspect, Arua district)

“I had prepared to come and test for sleeping sickness here in Omugo, but this shortcut there is water, that always floods there so I was waiting for dry season to come”.

(RDT+ suspect, Yumbe district)

For others, though, including many who had already cited transport, other challenges to referral completion were also given, including the length of time spent away from home which entails further complications such as needing to arrange support for family left behind, childcare, and food. These are issues that make leaving home for one day for follow up testing problematic, and the prospect of having to spend up to two weeks in hospital for treatment posed the same problems but on a larger scale.

“This year the crops did not yield well so there is a bit of famine. So we have the problem of leaving family who we need to support. [...] Also we

need to find a member of family to support us at the hospital when we go, so who will then be left behind to manage? I would be leaving the family to suffer.”

(RDT + suspect, Yumbe District).

“I need to make sure there is money for transport and money for feeding. When you are found positive and you need to be admitted and you also need food and someone to stay around you. Since I’m just like this by myself and I have small children, they are not strong enough to look for things to help me so I could not come”.

(RDT positive suspect, Arua district)

Others complained of negative experiences of the lumbar puncture (LP) procedure, though this was generally tolerated as a necessary part of diagnosis. One suspect additionally reflected on the impact on livelihood and indirect costs of LP and treatment even after discharge from hospital, saying:

“When you are vaccinated with that vaccine [referring to the lumbar puncture procedure] you cannot work [...] I also heard that this treatment would take long in your body and you would fail to recover, especially this treatment will fail to treat you because curses are attached to your life” (RDT+MS- suspect 3, Arua).

Aside from the challenge of arranging support for family left behind at home, there is also the issue of finding a carer to accompany patients in hospital for the duration of their admittance for support. Many mentioned the need for support, either from someone to bring them to hospital, or more specifically to look after and attend to them while at hospital in case they are admitted. This individual would provide help with food, washing clothing and bathing the patient, as this is not something provided by health staff at hospitals. Without such an individual (usually a close member of family) to attend to them in hospital, many people would not come for treatment. There is also the need for support at home in their absence, usually for children which need to be fed and cared for. If such family or personal support cannot be arranged, then many felt that they are tied to stay at home despite their

willingness to come to the hospital. Therefore, it is also an issue of time and the length of time spent away from homesteads and from daily work that shape the landscape in which symptomatic patients seek care. Without such support, it is understandable that HAT patients might fear a lengthy hospital admission and the effect it might have on their family, livelihoods, and finances. These concerns are a powerful agent in determining an individual's health seeking behaviour and choices early in the referral process.

“For me I had lost interest in going for further treatment because no one helps me in my condition, in this sickness unless you have a father or a mother, but no one helps me” (RDT+ suspect, Koboko district)

“The problem would be finding care for the family members we would leave behind. We would need to look for somebody to give support to our family, maybe a neighbour. If we are to be admitted then we would come with someone to support us in hospital”.

Contrary to claims by some staff that cite access to transport (though this was a key issue) and “poor attitudes” as the primary causes of patients defaulting referral, those who reported they felt well informed about the testing process and understood the importance of confirmation claimed they were more likely to adhere to future referral appointment despite the various logistical and financial barriers to reaching hospital. This highlights the importance of communication at the point of testing to align programme incentives with patient priorities and improve referral completion. Negative experiences at the point of testing appear to significantly reduce the likelihood of suspects returning and completing referral. Close observation of the interactions between patients and health workers in the lab during testing confirmed the accounts given by my respondents, with health workers having little to no time to discuss the rationale behind testing nor the implications of results during brief interactions with patients. While I cannot say that encounters appeared to be overtly negative (which could have been on account of my presence), I could see how the brevity of point of care

interactions limited the space in which effective communication on a relatively complex post-testing referral process could sufficiently take place.

Experiences at referring facilities

At referring facilities, patients in my study appeared to have received little information about the HAT testing process. In all cases the health worker they visited had tested them for HAT alongside tests for malaria or typhoid and most patients told us they only became aware that they had been tested for HAT after they received a positive RDT result. Five people (quarter of my sample) even left the facility not understanding they had screened positive for HAT. Three of these reported that the first time they heard they could be infected with HAT was when a district supervisor, lab supervisor or village health team member followed-up their outstanding referral, as described by the patients quoted below.

“That time he [the health worker] did not tell me he has found sleeping sickness in my blood, but he told me he has found malaria [...] When these technicians from Yumbe hospital [a microscopy site] went to Kochi [an RDT site] they gave information to me at home that they have discovered sleeping sickness in my blood. I said, ‘why so abrupt like this?’ When I went for the test they didn’t tell me I had sleeping sickness. Even my husband had to pick my small patient book and went to hospital to check, and found that in my small book it was not indicated that I had sleeping sickness, but the big book had my name in the list with the names of people who have sleeping sickness, that is how I got to know about it”. (RDT+ suspect 14, Yumbe)

“I was not told I have sleeping sickness, no one in the health facility told me that until they wrote information and sent it through some guy who is doing business in this trading centre [...]. He said, ‘did they tell you about it when you went for the test?’ I told him ‘no they did not tell me’. Now they have told me that I have sleeping sickness”. (RDT+ suspect 5, Arua)

Two suspects even reported that sensitisation for our interview was the first notification they had received. Such patients therefore reported not to have

known about any follow-up appointments, nor that they were considered to have an outstanding referral by the national programme. Even when results had been given at the time of consultation, however, several people expressed confusion and even suspicion about why they were being referred. Only a minority of patients attributed the reason for referral to limitations of the test, such as the following individual:

“They told me this could possibly be sleeping sickness. Since their machine’s detective strength is not adequate I should come to Omugo [a microscopy site]”. (RDT+MS- suspect 3, Arua).

More often however, rather than questioning the reliability of the RDT itself, peoples’ confusion about referral rationale was expressed as distrust in the expertise of referring health workers who appeared to not be interpreting the results correctly:

“I did not trust them because they told me that I should come for further testing in Omugo, which means they failed to interpret the result from the first test”. (RDT+MS- suspect 4, Arua)

“It was explained, but he did not explain in a direct way. He did it in an indirect way, saying that the drug for sleeping sickness is at Omugo or Arua [another microscopy site], so you must go there to get the treatment”. (RDT+ suspect 4, Arua)

“People who are learned, they automatically use politics in their speaking. He [health worker] did not tell me exactly the way you have said, but he showed me the way so that I can come and discover from this side” (RDT+ suspect 17, Koboko).

“When these people told me that I could be having sleeping sickness I felt they are not being open to me, I was trying to force them to be open. I thought that if they know that it is there, they should tell me I have sleeping sickness, so I was trying to force them. I knew I had sleeping sickness [because] I would be among other people and I would fall asleep during the day. That is the symptom I knew meant I had it”. (RDT+MS- suspect 2, Arua)

As evident from the last quote, patients' own interpretations of their symptoms influenced their trust of test results and health worker interpretations of them.

While some were sceptical that they could have HAT because their illness experience was inconsistent with what they had heard about the disease, others trusted RDT results because they were "feeling it inside [their] blood" (RDT+ suspect 10, Yumbe) or in some other way, saying, for example: "My swollen legs did not change, and the signs and symptoms I experienced continued, so I believed I had sleeping sickness" (RDT+ suspect 2, Arua). This corroborates earlier suggestions that diagnosis is more strongly attributed to lived illness experience beyond the diagnostic test result.

Before receiving their results at microscopy centres, patients reported that they would likely trust the second round of tests more than the first, associating more reliable tests with being conducted in larger hospitals:

"Because I think this is the biggest hospital that can bring out the truer result than the previous one" (RDT+ suspect 12, Yumbe)

"It can differentiate between truth or lies. So if the first test may say it is true I have sleeping sickness, while today it might say it is false, or the first test might say I don't have, while here it will say that I have; I will prove from here". (RDT+ suspect 17, Koboko).

Only one patient expressed distrust of the motivations behind the referral rationale and having to attend larger hospitals, telling us she had declined to come for further blood tests because of family members' suspicions about blood theft:

"I got false information from people that they had come to steal my blood, so I was not in a position to come. I spoke to my people at home, but my husband was not pleased so I would not have come by myself" (RDT+MS- suspect 2, Arua).

Other characteristics associated with receiving facilities, besides trust in the tests they offered, thus appeared to influence most peoples' decisions not to present, particularly financial concerns related to referral. While a frequent concern in many interventions that require blood drawing (Deconinck and Palmer, 2017; Fairhead et al, 2006; Geissler and Pool, 2006) reports of rumours pertaining to blood theft and blood draw refusal were few in this study (only 2) except for the RDT+ MS- suspect quoted above, and the father of one CATT+ mobile screening suspect in Ewanyati, Yumbe district, who refused microscopy on the grounds that "he listened to these stories about how much blood they take, and is fearing that someone will take it back to your country, that they will steal it" (James, active screening mobiliser). As the following vignette illustrates, the taking of venous blood samples for confirmatory testing is not only a biomedical procedure, but a socio-technical practice attached to expectations established by the performative enactments of previous interventions.

The bleeding

Maracha is a very large and impressive level IV facility on first impression, a plethora of signs picketing the entrance inform visitors this is a private hospital funded by a European NGO. The laboratory is a large and airy room, the open space accentuated by how sparsely equipped it appears to be. I count two microscopes on entering, and a small centrifuge under some plastic sheeting tucked away in the corner of the work bench. Dull ivory coloured tiles line the walls adorned with posters, referral flow charts, standard operating protocols, stock lists, and various useful phone numbers of local VHTs. I note a diagnostic algorithm for HAT RDTs, and a sleeping sickness awareness poster, sun-bleached and curling at the edges. Maracha hospital has one of a small handful of laboratories across the West Nile with the capacity to test for and confirm cases of HAT, and so this is where patients from across the entire district (and border regions of neighbouring districts) who have been identified as suspected cases travel to have their diagnosis confirmed.



Members of the lab team analysing HAT microscopy samples in Maracha Hospital laboratory

A charismatic young man in a white lab coat then introduces himself as Tom, one of three technicians. He is taking bloods today he informs me eagerly; "I am the best man for the job" he chimes, his colleagues laughing in retort, "He is not the best! He is the fastest. That one is not always the best", his fellow technician David teases.

Dr Oliver had been keen since I came to Arua that I come to the lab and be present for what he ceremoniously declares "the bleeding", when RDT-positive suspects have their samples taken for follow-up microscopy, and today was the first of many I would spend in Maracha and Omugo labs observing the daily enactments of diagnosis.

Patients file in one by one and sit down at Tom's instruction in silence. Some wince as he jabs and pins down the needle with his thumb, most fixate resolutely on the ceiling while he fumbles with his remaining free hand to locate a fresh capillary tube in his pocket. He pushes it in with a sharp tug, and waits for the blood to trickle into the glass receptacle. A few seconds later the procedure is done. He slides the needle out quickly replacing it with a small wad of cotton wool, then bends the patient's arm up and instructs them to hold it in place before waving them off back outside to the waiting area. No words are exchanged, only gestures. Instructions given and observed in total silence. The formality and expediency of the procedure is impressively brusque.

His last patient of the day, an elderly man, peers in and shuffles through the door sheepishly. Yellow rosary beads dangle from his open collar, which he rolls between his fingers anxiously as Tom begins tugging up his sleeve to locate a vein. By this point he has gotten into of a rhythm of sorts, and is taking up the procedure like an assembly line worker in the full flow of production. Pulling the man's arm down in a swift, automated motion, he wraps a latex glove around the bicep in one seamless manoeuvre. I'm beginning to understand his colleague's jest; he is certainly efficient to the

point of abrupt. His patient's free hand clutches at a trembling knee, his feet shuffle agitatedly. Tom pushes the needle in and waits a few seconds for the blood to come, the man's eyes bulging as the tube fills with his substance. Tom smiles and shakes his head, persevering until the tube is full before finally withdrawing his needle. The man immediately clenches his hand around the puncture. Visibly irritated by this interruption in his routine, Tom grabs and pulls away the patient's hand to replace with his cotton wad. "There is always a difficult one!" he chuckles. The man turns to me, rasping in protest, *"Too much! You took too much blood. Why did you take so much?"*

When I later interviewed the individual that Tom had taken "too much blood" from, I referred to this exchange and asked him to elaborate on his experience.

"Yes! I complained to you. There is too much blood taken for this test. It is not like the other test where they just take a small amount from your finger. Today they fill a whole glass. Look at me! I am so old and have no blood to give. They should not take so much. They should at least replace it [...] with soda."

Several studies have documented blood draw refusal from participants stating that too much blood was being taken by trial or programme staff. Explanation for this concern largely relate to the concept of blood as a valuable, indispensable necessity of life which cannot be easily replenished (Deconinck and Palmer, 2017; O'Neill et al, 2016). As for the suggestion his blood ought to be replenished or compensated with 'soda', there was general agreement among other patients I spoke to after testing that this exchange was an unfulfilled expectation of theirs also. James later explained to me that during past MSF screening campaigns, it would not be uncommon for patients undergoing blood draw for microscopy to be given a bottle of soda, not for any biomedical reason as such (as some participants had come to associate it), but as some token of compensation for their time. Watkins and Swidler describe a similar routinisation of practice, in their description of "an

untheorized consensus of what an HIV/AIDS programme should look like”, in which they describe the ‘choreography’ of training sessions, constituted by a ritualized set of practices. As with the choreography of HAT diagnosis, they describe how certain objects and exchanges become entangled in the enactment of trainings, where flip charts, ample lunches, and mid-morning and mid-afternoon Fantas become a “ubiquitous social practice [...] performed jointly by donors, brokers, and villagers” (Watkins and Swidler, 2013). This was one of a host of expectations that previous interventions and referral models had impressed on the collective memory of ‘reflexive communities’ (Mackian, 2004). The memory of these typical exchanges between healthcare providers and those undergoing testing had become part of the diagnostic narrative in the West Nile, and gone on to form part of patients’ collective expectations of the procedure and its outcomes. Patients bring diagnostic expectations from mobile labs into the clinic, where they continue to be negotiated and managed between patients and health workers during the diagnostic process.



Drawing blood from an RDT-positive HAT suspect for microscopy in Koboko Hospital Lab

Discordant results at follow-up

For treatment to be given, multiple diagnoses must be 'aligned' (Mol, 2006; Street, 2014). Such misalignment, where RDT positive and microscopy negative results (which can be caused by cross-infection, sensitivity, or low parasitaemia) prolongs this period of uncertainty before a person can access treatment. Receiving discordant (RDT+MS-) results at labs in receiving facilities caused some patients to revise their understanding of which tests could now be trusted to give the 'true result'. As one patient described:

"I thought that Omugo [Hospital, a microscopy centre] has to be the one to give the true result [...] but they told me it takes a long process to come up with a result, so I have to come back and they will send the result here and the technician will tell me if I am truly sick" (RDT+MS-suspect 1, Arua, referring to the process of further testing via LAMP)

For others, confusion was expressed as distrust in the health staff that performed their microscopy. This was especially true for RDT+MS- suspects who again received negative results but were asked to return for another quarterly follow-up appointment. One patient said: "since they did not cure me, I am not sure of their profession, I'm not sure of their work [...] the health worker, the one who tested me did not discuss the result with me, instead they discussed it with another health worker" (RDT+MS- suspect 4, Yumbe).

Realising the financial implications of more travel associated with conflicting results not only gave patients the impression that confirmatory testing would become a very expensive process. Many patients also highlighted the unfairness of their compliance with HAT programme referral rules but not, in return, being taken care of by the same system. One person, for example, demanded to know, "Now that you have brought us, after testing, will they give us treatment straight away or not?" (RDT+MS- suspect 2 Arua). Another suspect explained: "First I came there and was found positive, and from here I was told the disease is not there so was told to come after three months, so I was taken to the other unit and was on some medication. I took all those

drugs, but still there is no change” (RDT+MS- suspect 1, Arua). Such suspects, who believed that they did indeed have HAT, were dissatisfied that HAT treatment could not be given at the moment of testing, as for other diseases such as malaria. During this sub-study I observed only four instances of serological suspects receiving further clinical investigation for symptoms after microscopy or repeat RDT testing. While clinical staff appeared dedicated to the ethics consent counselling process, their time was limited and a full syndromic examination and exploration of alternative diagnoses did not seem to be part of their usual routine. Moreover, long outpatient queues of up to two hours required to see clinicians after testing negative meant that many patients preferred to return home and (for RDT+ patients) wait for LAMP results by phone.

This highlights where programme objectives diverge from and override those of patients. Given the priority of patients is to seek treatment and alleviate their symptoms, failure to receive alternative diagnoses after receiving discordant results negatively effects relationships of trust in the referral system, and potentially wider aspects of the system such as local health staff. Where the explanations behind frequent outcome of discordant results are not communicated, this can understandably lead to frustration.

Discussion

Local socio-technical ecologies of HAT testing

The socio-technical interactions described by many patients in my referral study may help to explain why many initially seek treatment outside of the government healthcare system. As my daily observations in the lab and account of blood drawing in Maracha Hospital lab demonstrated, communication (regarding which tests are being conducted, rationale for testing, discussion of results, and the importance of follow-up henceforth), is

largely absent from the health worker-patient consultation. Meanwhile, within a diagnostic ecosystem that prescribes the passive acceptance of professional or ‘expert’ clinical opinion, patients with limited information at hand (i.e. no awareness of HAT RDTs or understanding of how confirmatory diagnosis works) rarely asserted themselves in these exchanges.

This partly elucidates why alternative spaces and services are often sought outside government health frameworks, where individuals feel they can articulate their symptoms and desires more freely on a more ‘customer-provider’ oriented exchange (Chandler, et al. 2011: 939). In stark contrast to the “palpable power imbalance between health workers and patients”, community members are aware of the power they hold over drug shop workers in providing their income. This contributes to a sense of agency in the process of seeking treatment, including asking for advice and purchasing or rejecting treatment, thus clients are empowered by the relative ‘social proximity’ of the relationship with informal providers such as drug shop workers compared with health workers in public health facilities (*ibid.*) This is more suited to the ‘trial-and-error’ diagnostic culture which drives the private drug shop market in Uganda (Mboye et al., 2010: 2), yet is at odds with the test-result driven method of clinical decision making that the HAT referral system must ensure. Having said this, shortly before the time of this study in September 2015, 16 private drug clinics in Koboko and Yumbe towns were enrolled in the project under a pilot scheme, while 3 facilities serving refugees in Adjumani that had been dropped were re-engaged (see Palmer, Robert, and Kansiime, 2018). Of 13 HAT cases reported in the project area from the ISSEP’s implementation up to December 2015, 1 was identified from one of these enrolled private clinics (Wamboga et al., 2017). The implications for placing RDTs in socially proximate settings such as private clinics on HAT case detection therefore warrants consideration, and highlights the need for a more critical discussion of relationships of power between patients and health workers, structural barriers to care, and the

positioning of resources and diagnostic technologies, both physically and socially.

Assimilating HAT RDTs into ecosystems of surveillance

Community perceptions of HAT control programmes are not only influenced by historical memories of past interventions, but shaped by how new methods are introduced. To expect that community perceptions will unreservedly accommodate new interventions without thorough information dissemination which includes two-way communication between communities and programmes is unrealistic (Kovacic et al. 2016). Innovations are made compatible not only through deeply embedded cultural values and practices, but also with previously adopted ideas (Rogers, 1995: 225). Existing ecologies of testing are the mental apparatus by which individuals assess new technologies, to compare against what is already familiar and known (Rogers, 1995). As the elimination programme area for the RDT intervention is also endemic for malaria, staff at all facilities were already familiar with performing malaria RDTs (Wamboga et al. 2017). This familiarity prefigured the implementation of an RDT for HAT and it was assumed the test could be absorbed seamlessly into a pre-established diagnostic routine. Malaria and HAT RDTs have shared aesthetic features, but how similar are their social lives? Post testing, the diagnostic processes they initiate significantly diverge.

Owing to the potentially toxic nature of HAT drugs, treatment cannot be administered based on clinical suspicion or RDT results alone, and patients must travel to hospital for follow-up tests (microscopy, lumbar puncture, PCR). This can be disappointing for patients, and confusing when negative follow-up tests contradict initial positive RDT results, the most common outcome in elimination settings. Unattractive aspects of the culture of care at receiving facilities such as long waiting times, dismissive or harsh treatment by health workers, language barriers and recurrent drug stock-outs can dissuade patients from completing referral (Bossyns and Van Lerberghe

2004, Peterson, Nsungwa-Sabiiti et al. 2004). Even if patients manage to reach facilities they have been referred to, there can be problems with patient processing and lab service unavailability (Palmer, Surur et al. 2014), compounded by poor communication about referral linkages and poorly integrated recording and monitoring systems (Heunis, Wouters et al. 2011) that prevent referral consultations or tests from being carried out. For patients contemplating the costs and benefits of completing HAT referrals in a place where cases are low and therefore unlikely, the implications are profound. Falling short of expectations set by the malaria model it sought to assimilate, the HAT RDT not only fails to eliminate the need for a laboratory, but introduces additional layers of diagnosis, bureaucracy, and travel for patients and health workers. In contrast to the mobile team-led system which preceded the RDT, the diagnostic algorithm for HAT is divided across different levels of the health system and geographic spaces, requiring patients to travel between institutions by their own means. This raises the question, that given the teleology of testing differs between programme definitions and patient priorities, where in this system does diagnosis occur exactly? Is it where a trace antigenic signature of HAT is 'read' in the window of an RDT, or where parasites can be seen by the human eye and 'counted' by microscopy? (Umlauf and Beisel, 2016). By the biomedical gold standard definition happens at a point in the referral algorithm that takes time and unseen work for patients to reach.

The HAT elimination surveillance programme is primarily (and understandably) interested in optimising sensitivity, since any missed case can be a potential source of infection from which epidemics can start to build (i.e. District Supervisors' concerns about leaving room for environments of uncertainty). On the other hand, this chapter has drawn attention to the human cost of imperfect test specificities in a context of low disease prevalence. Moreover, that so few patients in my sample left microscopy facilities with an alternative diagnosis or treatment for their ongoing symptoms raises an important discrepancy between meeting the objectives

of an elimination programme and meeting individual patients' needs. Despite the vision of those who designed the HAT elimination programme that the HAT RDT would integrate seamlessly into the existing malaria diagnostic ecosystem, this was premised on a presumed similarity between the two RDTs that in fact did not extend beyond the physical features of the device itself. However, diagnosis cannot be reduced to the binary result displayed in the RDT window. It is a spatially and temporally distributed process that comprises a dynamic assemblage of infrastructures, comprising health information systems, supply chains, and clinical expertise. Diagnostic ecosystems are as fragile as they are dynamic and complex, and new technologies can have unpredictable and destabilising effects on relationships between diagnosis and care.

Conclusion

Parasitological demonstration by microscopy remains the epidemiological gold standard for HAT diagnosis, yet the passive surveillance system relies heavily on suspected cases being detected at the point of care, and subsequently completing referral to determine their 'true' infection status. Thus, the processes and environments by which patients reach the point of detection and trajectories thereafter are critical to understanding why some suspects do not complete referral or go undetected altogether. However, HAT is located and defined in the practices of the patient, and "comes into being differently according to what people feel and self-diagnose, where they go for support and how they (get) treat(ed) themselves" (Umlauf and Beisel, 2016: 9).

In the West Nile region of Uganda which has recently decentralised its passive surveillance system, I examined patient experiences and perceptions of HAT, HAT diagnostic tests, and the referral system to identify systemic challenges to referral completion by RDT-positive suspects. This chapter has described the diagnostic landscape that patients must navigate forging

pathways to treatment. By investigating experiences among a minority of suspects who failed to complete referral under the new algorithm, differences between the landscape imagined by the state and that experienced by patients have been revealed, thus allowing the social proximity of RDTs and their agency in local testing ecologies to be explored (Chandler et al, 2010; Umlauf and Beisel, 2016). This chapter demonstrates how current case detection strategies fail to reflect local treatment seeking strategies and diagnostic cultures, and that far from simplifying diagnosis, introducing RDTs can introduce complications of their own with potentially iatrogenic effects on the health system by eroding important aspects of trust in both diagnostic technologies and referral structures. Medical historians have shown that elimination success depends on strong health systems (Stepan, 2011; Birn, 2009) but this relationship can also work the other way around, whereby inappropriate elimination strategies can potentially harm health systems (Stepan, 2011). The breakdown in communication between health workers and patients at the point of RDT testing, and disappointment at receiving discordant results at follow up with no alternative explanation or treatment undermines important aspects of trust in referral support structures.

RDTs are ultimately social objects, entangled and embedded in social practices, and the agency of diagnostic technologies is determined not only by their physical accessibility in terms of mobility and cost, but also by their social proximity to target populations and the diagnostic cultures that govern their positionality within local testing ecologies. Despite achieving relatively high referral completion (85%) under this strategy, the RDT-based enhanced passive surveillance system could do more to make itself more culturally acceptable and effective to the local context to which it has been implemented (Panter-Brick et al., 2006). Effectively addressing health provider communication about the meaning of HAT test results could avoid future mistrust of HAT referrals as programmes in Uganda, and elsewhere, mature. I further argue that the RDTs have been somewhat paradoxical, in that they fail to solve the problem that they purport to; namely eliminating the

need for a laboratory, even requiring corroboration and legitimisation from more sophisticated tools and laboratory infrastructures. Thus, the clinical gaze supposedly extended by RDTs is actually limited to those spaces where patient diagnostic landscapes and state structures intersect. More than this, the programme forces patients out of their preferred treatment-seeking landscapes and into state structures which place the responsibility and costs for their own diagnosis onto economically vulnerable populations.

These testimonies give us insight into how the transposing of biotechnologies can present unexpected complications, exposing steep global health power imbalances (Sariola et al., 2017) between national programme objectives and the delivery of acceptable local care. Many of these challenges are intensified in the laboratory space where diagnostic encounters occur, and as such the following chapter seeks to describe these and the accounts of staff working in these spaces. It is here that I shift my analysis, from where I have thus far described the conditions and processes by which patients navigate the pathways that leads to this space, to the infrastructures of surveillance that produce the epidemiological landscape of evidence.

CHAPTER FIVE

Infrastructures of surveillance

Socio-ecologies of testing in the public health centre laboratory

“Infrastructures cannot be built into boxes”

- Street, A. 2014

From seeking out cases in the community using point of care devices, this chapter shifts from a patient perspective, to where HAT is brought into the clinic and under biomedical scrutiny through confirmatory diagnostic procedures by health workers. It is important to note the location of study has also shifted, highlighting key policy and programme differences between the different strains of HAT. Here, although there are more HAT cases in central northern Uganda, there is less programmatic priority for human case detection because there is no such PPP for eliminating rhodesiense HAT as there is the ISSEP for gambiense. The previous chapter showed that for the socio-technical ecosystem of HAT surveillance to detect cases, components must not only be positioned physically, but aligned socially in practice. This conclusion turns out to be as true for healthcare workers as it is for patients, as I describe a precarious distribution of health workers struggling to align protocol with practice, and juggle multiple programme objectives where HAT is a low priority. Data collected from a survey of 15 health centres in central Uganda is drawn upon to explore the structural apparatus of surveillance and interrogate the concept of infrastructure beyond “staff, space, stuff, and systems” (Farmer, 2014). The testimonies of health workers provide an additional perspective of the diagnostic ecosystem, one that encounters the restraints of a decentralised healthcare system, the demands of target driven

vertical programmes, and struggles of delivering care with little resources or structural support. This phase of study moves from an elimination setting of *T.b. gambiense*, to a region where zoonotic *T.b. rhodesiense* is reportedly increasing.

As in the previous chapter, attention is drawn to the flaws of passive surveillance where awareness is low. Here however, focus shifts to the implications of this in a setting where HAT may be spreading into new territories. By describing the material components of the health system on the frontline, infrastructures are reimagined, stretching beyond technological capacity to encompass the relational aspects of diagnosis and care. Whether the introduction of a discrete new diagnostic tool, the digitisation of information, or the wide-scale structural decentralisation of health services, changes are not implemented onto a passive system. They interrupt, destabilise, reconfigure, and adapt to an existing diagnostic ecosystem, and in turn this system is re-shaped to accommodate these changes.

Meeting Serena

My first few days in Dokolo town are hosted by Dr Frederick Odongo, a local veterinarian and founding member of the 3V Vets network. He has brought me to Dokolo Health Centre IV to meet who he calls the region's 'focal sleeping sickness person', Serena Akello. Prior to arriving in Dokolo, I had spent quite some time at the COCTU office in Kampala consulting with the national HAT control programme to compile a list of key individuals involved in HAT in the area; the District Health Officer, District Veterinary Officer, Vector Control Officers, entomologists, and so on. Like Frederick, Serena had never been mentioned while mapping out the regional HAT network, yet here were two individuals who were apparently central to the local

assemblage of HAT management and control. Frederick beckons her to join us in the Clinical Officer's office which is currently unoccupied, he is seemingly familiar and quite at home here. Serena sojourns across the courtyard and enters the room with an infectious warmth to greet us both – her and Frederick appear well acquainted as she asks after his children and how business is going. Taking the rare opportunity to rest her feet from her ward rounds she pulls off her plimsoll shoes, and at Frederick's invitation delves into stories about patients whose treatment she has overseen throughout her time here.

Serena wears many professional hats in her work but appears most heavily invested in her role managing sleeping sickness cases, and despite being the hospital's most qualified clinical nurse she also oversees HAT cases management in Dokolo District. She emphasises the struggle of juggling multiple responsibilities and not having enough time to carry out all of the tasks required of her. Later during my time at Dokolo HC, one of the nurses recalled in admiration how, whilst in theatre performing an emergency C-section, Serena was called to attend to a HAT patient who had become unresponsive. "She then had to leave theatre mid-operation to go and save their life, then return to finish the operation, and save another!" This is apparently typical whenever they have a HAT admission as she becomes overstretched in her duties, though not through necessity but by virtue of her experience and knowledge of HAT.

"Even though there have been several other members of staff trained, when I am absent they call on me for advice or to return to the hospital."

During my time in Dokolo, it became very clear that – despite not being recognised as such in any formal manner – Serena was in fact the lynch pin to the entire local HAT network. Were it not for her being on call to manage cases and deliver treatment at a moment's notice, there was a very real chance case management would falter and patients would need to be transferred to Lwala, or even Lira hospital much further away. Aside from

highlighting the very severe fragility of this network and infrastructure, it also begged the question – what would happen were Serena to leave and be removed from this unstable ecosystem? How would such a significant actor in this network, with such a high centrality of agency, come to be accounted for or replaced?

“Now I just put myself in situation where, when I leave, are they going to close the treatment centre? When I’m on leave they call me back for tryps patients. You know I want to go back to school outside Dokolo, what will happen? Now when they brought this new HAT patient yesterday they started calling me when I was at funeral rights in the village! There were people here trained, and yet they call me while I’m on leave. People want this [rubbing her fingers together] – money – because some NGOs assist, they come and people are used to them paying them. I don’t know what the DHO wants to do about it, because some time I want to leave Dokolo”.

In terms of plugging this capacity gap, there had been very little health worker training or community sensitisation in the region until 2014 when they received upward of 20 cases. In response, the National Control Programme’s director launched active screening and a sensitisation campaign broadcast over local radio. However it is difficult to know what, if any, lasting affects this has had on the community’s awareness, or indeed the suspicion index of health workers who Serena claims will not turn up to training while there is no financial incentive (unlike other disease control and elimination programmes, sleeping sickness training does not offer payment for attendance).

“People are so money minded and don’t think about the patients. Even just last year there was training by the Ministry of Health, but now here there is nobody. Those who are in their work for money will not go. For me, my call was not for money but for my work” [...] People are used to this kind of work that either you are paid or at the end of some month. For sleeping sickness there is nothing. That is why people have not picked interest. Even those who were trained previously before me, people have not picked up. They come and get their allowances and go back”.

Others at the various levels of programme co-ordination and delivery often expressed similar concerns, referring to a lack of support or financial incentives contributing to difficulties in building capacity.

“Transport is a challenge. There are three different organisations that support our work – stop malaria, pathways, family planning, all gave me a bicycle, but none of them work now, they need repairing. The other [challenge] is that we are not trained regularly. Also when you have these meetings people have to sign their name and then after that they are expecting payment for attending. They won’t come to the sessions with no money on offer.”

- VHT worker, Kobulubulu Subcounty, Kaberamaido

My relationship with Dr Serena proved to be one of the most insightful from the health-worker perspective, and offered an open and candid account of the difficulties faced by those working at the nexus of HAT control on the ground. It became starkly apparent throughout my fieldwork in the region that Serena was arguably one of the most important agents in the region’s HAT ecosystem, and alongside a handful of other key individuals like Frederick, her tireless work is pivotal in holding this fragile assemblage together. Throughout our time together, she frequently reflected on the struggle of juggling multiple responsibilities with little time to carry out all of the tasks required of her; *“If I am not here then nothing happens for sleeping sickness patients”*.

Serena’s concerns about capacity centred on a lack of financial incentives deterring other health workers from taking up the responsibility of HAT case management. However, this potentially masks some of the underlying structural problems that discourage her colleagues from taking up her place. For instance, Serena’s reputation as the ‘focal sleeping sickness person’ places her in the unenviable position of being the authority on managing HAT cases. Although there may be other sufficiently trained health workers to undertake the responsibility of overseeing HAT treatments, while Serena is in Dokolo the default course of action will frequently be to defer to her expertise. Indeed, health workers at facilities I surveyed who had any knowledge of how to act on a suspected case told me they knew only to send them to Dokolo where Dr Akello was based. Being the acute form of HAT, rhodesiense is associated with particularly alarming connotations and

notoriety for being difficult to treat, given the “toxicity and complex administration” of currently available drugs (WHO, 2018). It could also be the case that some health workers simply did not wish to have the responsibility of administering drugs like Melarsoprol with a history of adverse side effects and fatalities and, seeing how dependent the local HAT assemblage is on Serena, are reluctant to take her place once she has gone.

The strong imagery associated with past outbreaks of HAT filling treatment centre beds is an image HAT programmes have tried to transform in endemic settings, by reintegrating HAT patients into regular medical wards, renaming ‘treatment centres’ and ‘HAT wards’, and re-shuffling staff responsibilities to integrate HAT management with routine inpatient management. Dokolo Health Centre IV, despite still being widely referred to as ‘the Dokolo HAT Treatment Centre’, houses HAT patients in the same wards as other admitted patients. WHO guidelines do not require patients to be treated by particularly trained personnel or in a specialist unit, however the collective memory of HAT management lingers. One retired medical officer from COCTU recalled the 2014 outbreak, saying the wards at Dokolo “looked just like the old days”, with rooms full to capacity by row upon row of HAT patients. The effect of recent outbreaks on the perceptions and confidence of local health staff to take on the responsibility of HAT management may be considerable, and easily dismissed as idleness or financial interest.

Mapping capacity across Uganda’s health system

It is worth noting that elimination monitoring, underpinned by the HAT Atlas (Simarro et al., 2010), defines passive surveillance coverage in terms of an ‘at risk’ populations’ distance from “facilities with capacities for HAT diagnosis and treatment” using time-distance analysis (Franco et al., 2017: 4), whereby the cumulative travel time is calculated from any location to the nearest health facility (*ibid*: 5). Diagnostic capacities for HAT are categorised as

'clinical' (DxC), 'serological' (DxS), 'parasitological' (DxP), and 'stage determination' (DxPh) for gambiense HAT (Simarro et al., 2014). As a serological screening test is not available for rhodesiense HAT, the categorisation is only for DxC, DxP, and DxPh capacities (Franco et al., 2017). Importantly, only travel time is calculated. The economic costs of travel (something that respondents in both my gambiense and rhodesiense patient studies described as a key factor in referral completion) are not considered in these analyses. How 'capacity' is defined beyond devices, and at what level facilities actually conduct HAT testing however is not monitored. This illustrates the elimination programme's diagnostic landscape in geographic terms, but tells us very little about how HAT diagnosis actually occurs in these landscapes.

Health Centre Survey and laboratory staff interviews

To dig a little deeper into this material notion of 'capacity' I visited health centres to gain some greater understanding of how the presence or absence of key elements of diagnostic 'infrastructures' facilitate diagnostic practice (table 3). Of 13 government health facilities surveyed across Kaberemaido (6), Dokolo (5), and Lira (1) districts, only 7 employed a laboratory technician, while 8 relied on a lab assistant to conduct laboratory tests. 2 facilities had no lab, being level II facilities.

Table 3: Basic diagnostic capacity of 13 government health centres in rhodesiense HAT affected area

Health Centre	Level	District	Staff	Lab Tech	Lab Assts	Clinic Officers	Nurses	Records Officer
Ocero	III	Kab	15	0	1	3	3	1
Kwera	III	Dokolo	17	1	1	2	2	1
Kobulubulu	III	Kab	21	1	1	2	4	1
Kangai	III	Dokolo	16	1	0	2	3	1
Kalaki	III	Kab	20	1	1	2	6	1
Kaberamaido	IV	Kab	59	1	2	3	18	1
Boroboro	III	Lira	22	1	0	2	3	1
Bata	III	Dokolo	17	0	1	2	2	1
Awiri	II	Dokolo	7	0	0	0	1	0
Amwama	II	Dokolo	3	0	0	0	2	0
Alwa	III	Kab	17	0	1	2	3	1
Lwala	IV	Kab	22	2	2	3	13	1

Of these, 11 facilities were equipped with a working microscope and a member of staff trained to operate them, while nearly all (12) were equipped with malaria RDTs (see figure). The types of tests available generally reflect the most frequent health complaints affecting local patients, which ranged (in order of most common) from malaria, HIV, diarrhoea, Sexually Transmitted Infections, cough, respiratory tract infections, TB, and pneumonia. Skin diseases, brucellosis, and intestinal worms were also given as less common but notable health complaints among the local population.

Knowledge and awareness of HAT symptoms was variable, but generally high. Most health workers interviewed could identify key symptoms, but admitted that without a history of being bitten, few would suspect HAT if patients presented with them even in the case of testing negative for malaria. Some (5) said that they would refer cases thought could be possible HAT suspects to high level IV facilities. No respondents considered HAT to be a local health priority, and the vast majority (with the exception of those working at level IV facilities) considered HAT not to be an issue locally given the low profile of cases. Seven members of staff, all based in the higher HCIV facilities, were identified as having received formal HAT training, four

receiving training in 2012, three in 2014. However, even among those who received training, this was considered to be 'limited' and confidence to act on the knowledge gained from this was low.

Informal health providers

During my interviews health workers regularly expressed distain for drug shops and their use by patients. While recognising their centrality in local community treatment seeking networks, many generally regarded private clinics to be unregulated and illegitimate, and problematic to their everyday practice in multiple ways.

“Sometimes you find they [patients] have been taking medication – you might find a neonate being given very strong antibiotics, or a pregnant woman being given a drug that could affect the pregnancy, and some people come claiming they’ve been getting treatment, but when you ask which kind the documentation it is not there. So for us health workers it becomes very difficult to determine what kind of drugs this person has been on, whether it was correct or not, so it effects the treatment plan – you can’t intervene and know what kind of treatment to give this patient. Some they come with serious conditions and have been given the wrong treatments”.

- Clinical Officer, HCIII, Dokolo

“The biggest challenge is these people who are handling these drug shops, they are not properly trained, someone goes and asks “I have a cough, what can you give me?” No underlying cause is explored and the diagnosis is not made, they just treat a symptom. These people end up getting treatment for symptoms and signs, but the real cause is not discovered. So they are not trained”.

- Nurse, HCII, Lira

“They are just drug vendors, they just sell them. People from the NDA (National Drug Authority) pass through these big trading centres, but deep in the villages they have not gone there. But even if they pass through here at a big trading centre, you find people are well co-ordinated. The moment they know they are coming the information has already circulated, those selling drugs illegally close their shops and disappear. So when the NDA go back they just open again. Those operating illegally tend to be very cheap, so you find instead of people going to the clinics which are expensive, they dash to the cheap ones

where people are not qualified and sell at low prices. They are situated in the communities, so it is not so far for people to travel as the health centre. The whole time the NDA have no realistic data on where clinics operate and how many. It is very difficult for them to determine. The data they have will be of those that are legally operating only”.

- Clinical Officer, HCIII, Kaberamaido

These comments pose some particular challenges to introducing new products, such as drugs, diagnostic tests, or HAT awareness training to private clinics. Firstly, this appears to back up my findings from the West Nile, that patients primarily visit informal providers to bypass ostensibly unnecessary and potentially costly diagnosis and gain immediate access drugs. The likelihood of a patient going to a private clinic to purchase drugs for their suspected malaria induced fever is unlikely to be interested in paying to undergo a stage of testing in order to gain access to treatment. This removes incentive for informal vendors to provide these products and encourages presumptive treatment. Secondly, if many private clinics are indeed operating outside of regulation, then the logistics of introducing and rolling out diagnostic devices and being able to monitor their usage and results would be highly challenging given their ‘off the radar’ status in the local health infrastructure. Reporting mechanisms utilised by state facilities, such as the mTrac, are not mirrored in the informal sector, and therefore local and national data on rarer diseases like HAT would likely be skewed or unrepresentative. Given that the elimination targets requires careful monitoring and accurate data to be paramount, it seems incorporating private drug shops into the elimination assemblage would be highly divergent from the programme’s priorities.

Health staff training and capacity

An under-detection model developed by Odiit and colleagues calculated that for every reported death of HAT, 12 deaths go undetected (i.e. 92% of deaths are not reported). Furthermore, a deterministic model based on the possible routes of a HAT infection to either diagnosis or death (via the health

system or outside of it), showed that of a total of 73 undetected deaths, 62 (85%) entered the healthcare system but were not diagnosed, and 11 died without seeking health care from a recognized health unit (2005). Notably, mortality rates in newly affected districts in central Uganda (See figure 17), - in which diagnostic and treatment delays are higher, and from where an increasing proportion of HAT cases are originating- have also increased from an average of 5% in the early 2000s to approximately 10% in later years (Berrang-Ford, Wamboga, and Kakembo, 2012).

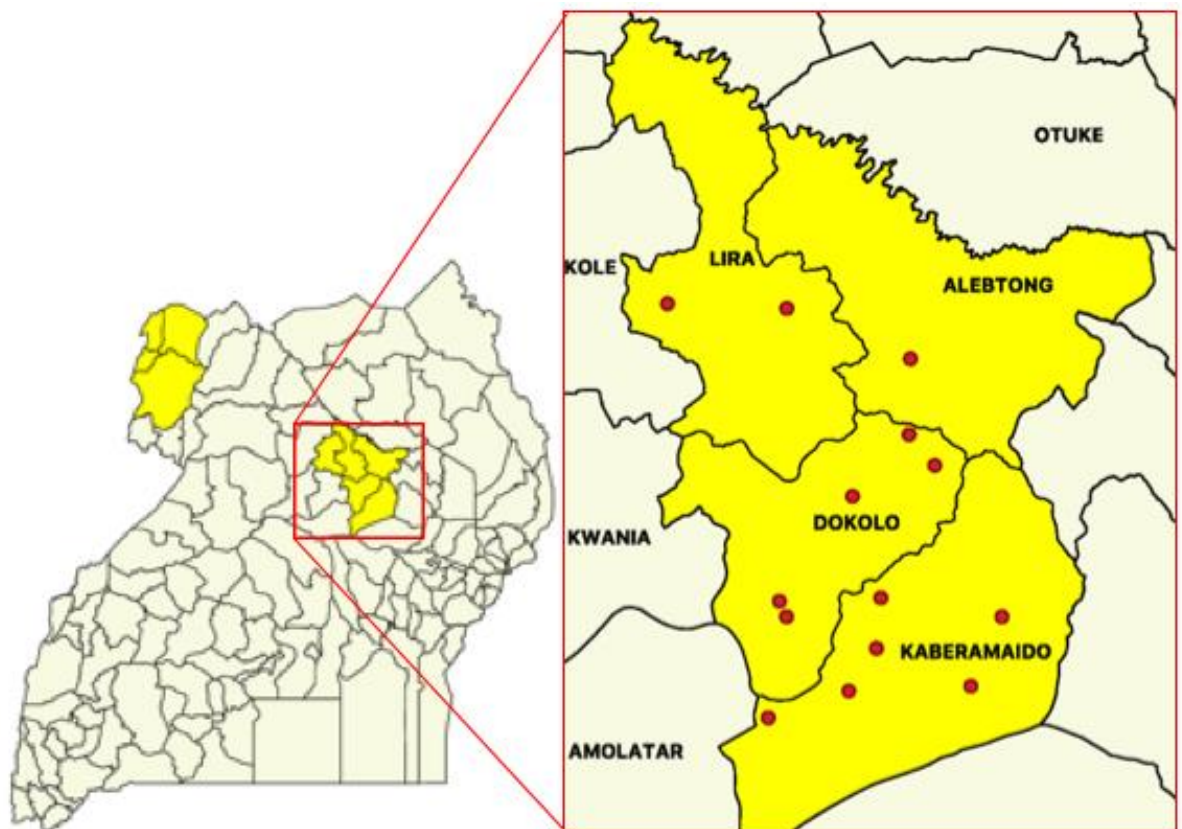


Figure 14: Locations of Health Centres surveyed.

Kaberamaido and Dokolo districts have experienced outbreaks of HAT with reactive screenings and sensitisation in the last 10 years, whereas Lira and Alebtong districts are newly affected by rhodesiense HAT cases. Shapefile and point data retrieved from Ministry of Health and Uganda Bureau of Statistics, ArcGIS depository, 2018.

Two hypotheses are considered to account for under-reporting of sleeping sickness in central Uganda. The first is that infected individuals do not present at hospital, meaning cases are not detected and therefore not reported. This has primarily been addressed by actively seeking out cases

from high transmission areas using mobile medical teams. As discussed in the previous chapter, in the absence of active screening, patients take many pathways to diagnosis outside of the formal health sector before presenting at public facilities.

The second is that people are going to hospital but are not being diagnosed when they present. As rhodesiense HAT has a severe onset of symptoms, presentation at hospital may be sought more quickly, but immediate diagnosis is not guaranteed. The knowledge base for sleeping sickness among health workers, and the capacity to manage cases determines whether cases are diagnosed and reported (Acup, 2013). Based on my findings described in chapters 1-3, I suggest that both explanations contribute to under-detection, but that 'capacity' ought to extend beyond laboratory diagnostic equipment to the people expected to utilise them in challenging environments.

My own encounters with health staff across the public sector revealed a shared resolute pragmatism displayed by staff in the face of biomedical uncertainty in a fragile system (Street, 2014). Most of the health workers I interviewed claimed they had not had the opportunity to attend HAT training, and so the lack of remuneration cited by Serena and others was not raised as a practical issue by those in my study. High staff turn-over is however a frequently cited problem underlying the sensitisation of health workers in the region, as many claimed that of the few personnel who had once been trained at their facility, very few remained. Those who left had not passed on their knowledge from their HAT training to others at their facility before leaving. Of those who had been invited to attend this training, all had gone voluntarily, but none of these individuals had gone back and carried out CMEs (Continued Medical Education) to pass on this knowledge to anyone else at their facilities. Additionally, most who had attended any form of training claimed it to be of limited use.

“When you look at the number of these staff, we are about 8 or 9, out of them it was only 2 who attended that [HAT] training I mentioned before, and the sessions are not in depth, they are about identifying the patient initially. After coming back from the training the staff are supposed to train the other staff, but the health information changes from time to time.”

- Clinical Officer, HCIII, Kaberamaido

“When we used to be in Lwala they trained the staff in the lower health units, but of course we have had new staff who have not been trained. Staff are transferred in the district, so there is a high turn-over [...] There are new staff – sometimes every three years new staff arrive. Because of the new recruitment, others were transferred to other facilities. We need to be trained all the health staff should be trained, they know the Sleeping Sickness is a large topic, just one to two weeks of training. We know the symptoms but we need more knowledge, because misdiagnosis for malaria is so common the symptoms are so similar”.

- Nurse, HCII, Kaberamaido

Decentralisation and healthcare delivery

The distribution and frequency of funds and resources delivered to primary health care facilities was regularly cited as an on-going challenge to delivering adequate care at the local level.

“With medicines we always get stock outs because what we receive is just a push system, they just send us [drugs], we don't order, so what they bring is not enough. What happens is there is a fixed budget for each health centre levels, so if for HC III or HC IV, they are going to receive the same amount of drugs. These places vary in terms of populations and you find the consumption rate may not be the same, some other places drugs get through faster than the other side. The state we are in there is nothing we can change because the budget is fixed”.

- Nurse, HCII, Dokolo

Furthermore, budgetary allocations of public funds may not always reach the intended facilities as expected due to competing priorities at various levels of government or in some cases misuse of public funds (Ablo and Reinikka,

1998). The central government is mainly responsible for the salaries of health workers, the majority of whom are central government staff. Most (non-wage) funds for health facilities are largely transferred in the form of drugs and other supplies. At the district level, locally recruited health workers are paid out of the district's own resources, while health units are directly supplemented with funds and in-kind resources (in terms of equipment, materials and drugs) from donors and the government (Acup, 2013).

“Stock outs is a big complaint from patients. Medicines come, and when communities know the medicine are there like today they come in big numbers, when they run out they go away again. There is a specified quantity we supply but whether it's enough or not is the issue. Also training issues come again somewhere, because you are having very many people managed by very few staff. When you run out you prescribe and tell them to go and get it themselves. Even if you explain that to them you always feel so bad, they say we steal drugs! They don't know there is a specific quantity to be delivered to the health centre”.

- Enrolled Nurse, HCIII, Dokolo

While a handful of respondents (5) claimed they were relatively well supported as a facility, all of them went on to describe what they saw as deficient infrastructural necessities in order to function properly as a facility.

This rarely related to particular objects or equipment per se, rather more the underling conditions and spaces in which such objects could be made possible, such as buildings, new labs, or having a constant electricity supply.

“We need infrastructural improvement, we have machines now like our microscope uses electricity and then we have the pima machine, we also have the audio visual equipment to help with health education, but what we are lacking is power, so we need electricity even for light. We have solar system but it's not very reliable. It is very difficult to manage patients in the dark”.

- Clinician, HCIII, Kaberamaido

“If there was a way of getting a separate laboratory block, the examination room there is now part of the ward. That plan was for those days when

the population was still very small, but now the number has gone up and general attendance. There is no space for mothers, they just sit in the corridors and we get worried about infections, even TB is also high in this area. We have a fridge here but the gas maybe for one month is not there. We supplement the lack of electricity with gas sometimes, we try to make it happen”.

- Lab assistant, HCIII, Alebtong

Circumventing microscopy

Throughout my survey, I noted two facilities in particular that drew me back for regular visitations. One, a HCIII in Dokolo district, the other a HCIII in Kaberamaido. These both had what would generally be considered to be functioning laboratories, but were notably understaffed - comprising of one lab technician (Dokolo) and one lab assistant (Kaberamaido). Only the technician in Dokolo had received formal HAT specific training in 2014. The assistant in Kaberamaido had only “learned about HAT on the job”. Over several visits to both facilities I would spend part of the day in the lab to observe their daily interactions with patients and record keeping practices. By 10 am each day patients would be forming long queues outside the lab, and by midday I would find myself clambering through swathes of people gathered outside the laboratory door, some laying on the ground or propped up against the wall.

On one such morning at the Kaberamaido clinic, I reclude into a corner while things are reaching a crescendo outside. The lab assistant, Jacob, is working his way methodically and briskly through a pile of patient test slips issued by the clinician on duty. He bellows down the corridor the name of the next patient in line, and there is some commotion as a young woman hauls herself up off the ground and tries to make her way through the crowd balancing two children on each hip. Jacob takes her patient booklet, and after deciphering

the clinician's instructions he swabs and takes a pin to the infant's finger. Before the child is barely aware of this and begins to wail, Jacob drops the sample onto a small white rectangular pallet and ushers the woman back out into the conundrum outside. After a few minutes of shuffling through papers and test request slips he looks over at the small queue of RDTs lined up on the workbench. "Ah! These are all negative except one." He scribbles the results in the patient note books and calls out their names down the corridor to come forward and retrieve them. Meanwhile I've been pouring through and noting the number of malaria RDTs performed each week.

"Do you get much time to discuss the results with the patients?" I ask.

Jacob laughs, nodding to the growing crowd outside, an absurd notion.

As the day trudges on, the stream of patients coming and going seems relentless, and Jacob hasn't had a break for several hours. I'm resolved to enduring the shift with him, but am visibly beginning to falter in the afternoon heat and he is taking some professional pride in watching me founder. "You are glad you do not have my job, eh?" he chuckles.

By around 6pm the crowds have ebbed away, and Jacob begins to tidy his work space. I seize on this lull to follow up on some observations I'd made throughout the day. Opening the lab record book, I point to one of a few examples I could have chosen at random.

"The malaria test result here is negative, but the microscopy column on this entry is blank. The first few lines have zero entered, but the rest are blank...does that mean microscopy wasn't performed, or it was and the result was negative? Are positive results recorded elsewhere?"

He cranes his head over my shoulder.

“Yes. This is our form from last week. See, the date is there, I even signed it. That means no microscopy done. I just stopped entering the zeros eventually” he remarks nonchalantly.

I hesitate for a moment considering the numbers populating the other columns.

“It says here 153 malaria RDTs were performed last week, of which 92 were negative?” I point to the corresponding column.

“Mmmhm. That’s right” he nods.

“So of those that were negative, what was the next step for these patients?”

“I cannot say” he shrugs, “these people will have been tested because they presented with fever, so many of them may have been sent home with Coartem.”

Being an endemic country, malaria is widely treated presumptively in Uganda, but research has raised concerns that this had led to its over-diagnosis, the over-prescription of malaria medication, and the under-diagnosis of other infections (Reyburn et al., 2004). This was the first time I had considered its very real potential impact on HAT case detection.

“So even though they tested negative with the malaria test?”

Jacob looks uneasy now, as though I am trying to catch him out.

“I’m just trying to understand under what circumstances a microscopy examination would take place, theoretically”. His shoulders fall back and he smiles.

“Ah, well now! Theoretically it should be when there is a negative malaria RDT, but *practically*...you saw how many we have of those in a week, can you imagine” – he leans over to re-examine the entry – “doing 92

microscopies that week? It is just me here - that would be back breaking! It would never get done”.

“So how often would you, on average then, manage to perform microscopies?”

“I do them, it is just malaria is the most common here, so it is easier to treat and send away, and it makes the patient happy. If we *suspect* sleeping sickness then I will do blood smear yes. Of course.”

I ask if they have recently had any such incidences. Jacob shakes his head. “It is not really a problem in these parts, we don’t see cases”. I inquire how this can be known if no symptomatic cases are ever tested for HAT. He reflects for a moment. “That is true, but this is the problem. We do not expect cases here because we have no data to suggest it. But there will be no data if we are not looking for cases. It is really up to us [health workers], but what can I do?” He gestures at our surroundings. “It is just me here”.

Microscopy performance and HAT data

Aside from the obvious parallels regarding point of care interactions and communication with the previous chapter, Jacob’s lab gives us additional insights into the patient-health worker relationship. Patient’s bring expectations of treatment, and this is something staff want to help them fulfil, sometimes by contravening protocol and overriding negative malaria RDT results. This feeds into a wider collective perception of the local health priorities, one where HAT features very little. Similar to findings from a study in South Sudan, few health workers in my study performed microscopies of made routine HAT referrals, either because diagnosing HAT was perceived as something that should be done by larger hospitals and mobile screening teams, or because they did not realise the magnitude of the problem in their

region, and hence would not suspect HAT as a possible diagnosis (Palmer, Surur, Checchi et al. 2014).

My few days spent in Jacob's lab were early on in my study, and so I was able to explore this further throughout the health centre survey. By the time I had concluded my survey of 13 health facilities across four districts (see figure), 11 had working lab facilities (level III). Of these, 8 reported to 'rarely' carry out microscopies on malaria negative patients, while 2 responded that they 'never' performed microscopy. Aside from the implications of this under-usage of microscopies on HAT case detection, respondents highlighted a the problem of test sensitivity, and inconsistencies in RDT data within the existing system that potentially muddies the epidemiological picture.

“People will think they have malaria, they will not even come and ask to be tested now. Now they just come and they say “I have come for the anti-malarials”. But most of the time it is just malaria so we give. Sometimes we test malaria and it comes back negative, but I might still suspect and just give the treatment for it anyway, and they improve. I think those RDTs are not so sensitive, they miss a lot of cases [...] the data can be misleading. We might perform a number of tests, some will be positive, some will record negative, but really that will not be the real case. Sometimes we see cases and treat them, but don't record a diagnosis even - you can't record a case of malaria without a positive test result. So the numbers do not match reality”.

– Lab Technician, Health Centre III, Dokolo

“The challenge with this system in Uganda is that the RDT they are using is not perfect; we have patients who have been negative then turned out to be positive. Also they are just specific to p. falciparum, but not the other malarias. There are how many...five now? Our tests will only react to falciparum I think, so they miss people who are infected with other strains”.

- Lab assistant, HC III, Dokolo district

At the HCIII in Dokolo, I found the same issue of over testing for malaria arising out of the RDTs convenience where insufficient and overstretched laboratory staff are under pressure to serve a large population. While juggling the everyday constraints of operating in an under-resourced environment

with little support, the RDT has been convenient, but has ultimately re-shaped diagnostic practices to the extent where previously routine protocols such as microscopy have become marginalised.

“The RDT issue is making the use of microscopy disappear, every month we get very many RDTs, those kits, over 200 you find they accumulate. Even the lab person, you might order for blood smear and they do an RDT instead, but they have not enough time to do regular microscopies, most of people who come here present with fever. It is much quicker for them to do an RDT for malaria, then if it is negative we can go from there in suspecting other things. Patients get treatment from home first, when they come here they want a test. So you find the number who come for a test at the lab is too big for one staff to get through. It just goes back to staffing numbers and the number of patients and how many of those tests you need to do in a day. The majority of patients come here with fever. We only identify suspected cases [of HAT] and refer to Lwala hospital”.

- Clinical Officer, HCIII, Kaberamaido

“To identify Tryps you have to use microscopy, but then the MOH recommended for malaria you use RDTs, so we may find that sometimes because of the many patients at the facility you may be driven for going for the RDTs and end up missing the haemo parasites because so few microscopies are being performed”.

- Lab assistant, HCIII, Lira

One technician at a level III facility in Lira tried to explain what was unfolding in more detail, producing a weekly report sheet from a pile of papers on the desk. The number of RDTs performed three weeks ago is shown as 52, of these, 15 are negative. I follow the line along to the column for ‘microscopies performed’ – 0.

“You see? How would we find the Tryps, even if they were there if no one does the right test! The main problem is our health centres usually receive high volumes of out-patients and you find it may be very hard for the lab personnel to conduct microscopy in one day you can have 100 people, you can’t make those 100 slides and examine them, someone might collapse! [...] It is not common to routinely test patients with fever, headache, joint pains etc. for sleeping sickness – we mainly request for malaria tests. In most cases the moment the patient is suspected to have malaria even Tryps is supposed to be suspected, but now the biggest

challenge is the work load for the lab, so many come with fever and we only have one lab assistant and a small lab. So unless the patient was treated for malaria and has come back with no improvement then that is only when we might start thinking of sleeping sickness”.

- Lab technician, HCIII, Dokolo

The protocol described in the last quote enunciates the algorithm they use in practice to think of rhodesiense HAT as a possible diagnosis. This aligns perfectly with the gambiense RDT protocol which stipulates a HAT RDT be performed where malaria diagnosis is negative or malaria treatment fails. Therefore there is an existing diagnostic culture among health workers which prefigures the introduction of a rhodesiense RDT.

Overall, routine performance of microscopies at facilities was determined largely by staffing levels, and therefore time constraints which were strongly associated with the level (and subsequently the resources) of the health facility in question, and the demands of the local population, in terms of patient numbers and number of trained staff available. This is resonant of the work of Chandler *et al.* that describes the ‘juggling exercise’ health workers must perform while enacting malaria throughout the diagnostics process, as they try to realise their own medical aspirations and reputations whilst managing the expectations of their patients in constrained settings (2012). This had led some of the staff I spoke with expressing wishes that their facility would soon be ‘upgraded’ above their current level in order to gain access to more resources, drug stocks, and staff. On average, Health Centre II facilities reported having anywhere between 900-1500 patients on average per month to attend to, figures frequently cited while justifying health workers’ wishes to upgrade their facility. Most Health Centre staff reported they could not cope with the sheer numbers of patients they have to serve, and that this burden has a profound effect on staff morale as well as health service delivery.

“We’ve been told by the district they can’t provide any more, that the ministry only has the power to do that. There’s too few staff here and it makes them depressed, you can work for 24 hours and you have to rest, and yet they need to work all the time. And yet the only way to get more staff here is to promote this HC from II to III. Whenever we ask the district people there is no way they can help us. They say it has to come from the ministry. According to our numbers of clients we see and report, when you compare the numbers it is beyond the level of HC II”

– Nurse, HC II, Dokolo District

Implementing *mTrac*: information infrastructures and reporting mechanisms

During my survey I would also ask who would collect data on tests performed and how often this would be collated. The lab personnel or records officer would usually then produce a book at this point, flipping pages and displaying the entries for each tests and the results. Initially my interest was primarily in seeing if they kept a register of HAT testing, but it soon became apparent that outside of the large referral hospitals and HAT treatment centres, no facility considered a need for any such HAT specific data entry system, owing to its low standing among a plethora of more pressing local health priorities. I asked one lab technician how they would usually report their data, and if I could see a copy of the report forms they used for this system.

“In terms of management of data when you come to analysis, we don’t have IT materials, we just do it manually and it makes it a delayed process. So we thought if there was a computer, printers, work would be made faster. It would help us process, and draw graphs, when that data is being sent by everyone, someone can say ‘why are we doing it like this? What are we lacking? How should we move forward?’ and so on. If it is manual sometimes you aren’t motivated to move on”.

- Lab technician, HC III, Dokolo

Convenience is not the sole benefit of digitising surveillance reports. The role of information technologies in this case are not limited to streamlining the data collection and management process, but also of facilitating feedback

and sharing experiences between colleagues. Feedback from facilities was repeatedly cited as something that health workers felt would be useful, particularly where suspected cases of HAT had been forwarded to a referral hospital and received no communication regarding the result.

“We never got any feedback about any patient from Lwala. If someone maybe was identified from this sub-county and treated in Lwala hospital we have never got any feedback concerning that”.

- Clinical Officer, HCII, Kaberamaido

One records officer in Kaberamaido described some of the practical challenges associated with implementing IT infrastructures for data sharing.

“Of course the computers are not there, but if they were then the other challenge is the connection part of it – like modems, if those ones are there then it is easier to share just within a click, without other expenses like fuel just within a second you are sharing information and it can be so helpful. At this facility we have no specified transport means, we just have to hire to move the destination you are ending at, maybe you are taking the monthly report – or you have realised you have a stock out so we want to cover that gap. We have to just hire a vehicle, so still we have that gap of transport, some expenses to and from with motorcycles, the problem is fuel which is not all there. Some report forms we are using the phones to send – the weekly surveillance reports and mTrac.”

He promptly produces a two page document headed ‘*mTrac Health Centre Surveillance Report Form*’. The mTrac system had been described by records officers at a handful of primary healthcare facilities I had visited as a surveillance system for general health comprising a range of common diseases, though HAT does not appear to be captured in the form. I peruse the entry columns as he talks me through his weekly routine of texting the lab’s test results to the system.

“We started implementing mTrac in 2013. There are many challenges - it’s about commitment, you need to make sure the reports are ready on a Monday by midday to send, and you may have other things that need doing and finding the time is hard, but it got easier as we got used to the

*new system. We still lack so many things on that, we face challenges on network [coverage]. **Then there are gaps whereby you find only one person has most of the knowledge, in case that person is missing for one week then you find you cannot send your report, the whole thing breaks down***".

Unlike the paper based system, the report is sent in a coded format and forwarded to the database where it is collated by the Ministry of Health and reviewed alongside reports from other local facilities. This is then collated into a report which is used for accountability and feedback during quarterly regional performance meetings.

"We can all see each other's results and say 'why is it like this, what happened here? How can we make this such and such better?' It prompts me to work harder and help me to supervise the screening for malaria or whatever. It is a motivation thing, it motivates you to work harder and manage the data, it helps you to move forward. If you don't pull up your socks how are you going to appear on the ground? That kind of thing".

Funded by and coordinated through UNICEF, FIND, and the Ministry of Health, the mTrac (Mobile Tracking) system was conceived in response to complaints about shortages of medical supplies at its health facilities (Cummins, 2012). The system was designed to replace the slow and cumbersome paper-based reporting system and "allow electronic data capture at the community and lower health facility levels without the need for investment in heavy IT infrastructure" (Uganda Ministry of Health, 2011). The weekly 'HMIS 033B Form' health workers must submit form their mobile phone captures indicators on notifiable diseases, malaria treatment, and ACT/RDT stocks. Currently there is no mechanism to report unusual cases such as HAT in these reports.

The programme claims to "create accountability for response and action by empowering each level with the information they need to effectively carry out their duties" (ibid). My interaction with the records officer whose motivation to

'pull up your socks' suggests mTrac has had a positive effect in this respect. However, despite the programme's aims to circumvent gaps in 'heavy' IT infrastructures, staff in my study widely expressed a desire for more investment in the structural and relational apparatus of information systems at the local level. Problems of network coverage, purportedly resolved by the programme in a pilot report by UNICEF (Cummins, 2012) persisted at the time of my study. Meanwhile, the supposed streamlining of data reporting via an SMS-based system does not appear to have significantly addressed the workload of health workers as many reported they still struggled to find the time to submit timely reports to the district. The observation described above that when one person with 'most of the knowledge' is absent, 'the whole thing breaks down' raises important questions regarding the destabilising effects of the mTrac on the surveillance infrastructure which seemingly excludes HAT. As with the RDT which claims to fill a gap in laboratory diagnostic infrastructure, novel mobile reporting systems like mTrac risk creating more labour and bureaucracy for health workers, who still need to report other health data and compile reports on other health outcomes as well. This is another example of where technology, supposedly designed to circumvent gaps in infrastructural paucity, end up inadvertently creating more work to make it fit in the wider ecosystem.

Discussion

Devolving surveillance to the district

Throughout affected regions, only certain hospitals are capable of diagnosing and treating HAT owing to the difficulty and training required to confirm diagnosis by microscopy, and potentially fatal nature of the treatment. In addition to physical infrastructure, a lack of trained staff can also be a major obstacle. One study found that 50% of rural health centres in Kabarole

district had microscopes, but only 17% had a trained technician that was able to use them (Tumwebaze, 2011). This problem is echoed, if not amplified when considering diseases such as HAT, which require specially trained laboratory staff to carry out lengthy and expensive diagnostics procedures. If the elimination of HAT is to be achieved, not only do frontline health facilities need to be equipped with dependable diagnostics, but must also be able to reliably recognise early clinical signs and symptoms of HAT, and understand the disease management and referral systems to manage diagnosed cases.

Partly owing to the focal nature of sleeping sickness epidemiology, HAT control has always been closely entangled with disease mapping, with detailed maps of HAT distribution in Uganda published as early as 1903 (Christy, 2013; WHO, 2018b). That elimination progress is measured using the HAT Atlas to calculate merely the distance between health centres equipped with diagnostic tools and 'at risk' populations is revealing of how the programme conceptualises the elimination landscape. It imagines that the geographical and material proximity of facilities to people increases the likelihood that symptomatic patients will follow treatment-seeking trajectories that align their symptomatic uncertainty with diagnostic capability to produce a case. However, as the previous and following chapters show, patients do not trace these predicted pathways to treatment. Nor (as the following chapter demonstrates) does presenting at an equipped centre necessarily lead to HAT tests being performed or a correct HAT diagnosis reached. This observation alludes to Farmer's (2014) "Staff, space, stuff, and systems" idiom that captured the crux of the health infrastructures discourse surrounding the Ebola outbreak in West Africa. The alignment of necessary factors for this to happen requires more than the physical presence of diagnostic devices being closer to people. More than this, it needs to be culturally compelling (Panter-Brick et al., 2006) within local testing ecologies (Umlauf, 2016), and socially proximate (Chandler, et al., 2011).

Measuring performance in a fragile assemblage

The implementation of the mTrac system is a useful insight into how the bypassing of old physical infrastructures through technologies are increasing the reach of state programmes throughout digital health infrastructures in novel ways. Mobile technologies and data reporting mechanisms create digital mirrors to hardcopy networks, allowing information to flow not just unilaterally and upstream, but between other actors within the health network. As one respondent pointed out however, the presence of technologies like computers are only one part of the ecosystem, and that in order to gain traction and have agency, connectivity is key. This it is the relational forces between technologies and people holding infrastructures of surveillance together stable enough to function. For example, mTrac reporting relying on the knowledge and timely actions of a single person make the surveillance assemblage extremely fragile and unstable, or as our respondent put it, “the whole thing breaks down”.

While this supposedly creates a more open distribution of information between stakeholders, it also allows for state and vertical programme managers to hold individual actors and facilities to account. Through the socio-material relations of health workers, patients and medicines (Rose, 2007), the health centre, the laboratory, and the private clinic emerge as sites of governmentality upon which the state seeks to install particular regimes of diagnostic practice (Dean, 2010). Through learning and performing these socio-material enactments as are introduced into the surveillance infrastructure, they establish themselves as new technical modes of ‘truth telling’ (Foucault, 1988; Besley, 2005). However, as the introduction of the mTrac surveillance system demonstrates, such interventions rarely transpire to be the ‘seamless bio-political disciplining project’ (Geissler, et al, 2012) that the Ministry of Health may have striven for, as East African healthcare contexts rarely allow for such a perfect implementation (Hutchinson et al, 2016).

The overlaying of new, digital, information infrastructures opens avenues through which data can be democratised; through sharing, feedback, and learning. However it also opens channels through which progress and performance can be monitored, and become a tool of promoting accountability through public, mutual scrutiny. Indeed, 'accountability' has become a buzzword in international development discourses. Policy makers in government and NGOs acknowledge that infrastructural developments, drug provisions, or introducing diagnostic tools are not enough to save lives unless clinical staff in contexts like Uganda are held accountable for doing their jobs. But where health staff struggle to meet the demands of large populations with little support from central or local government, with whom should this accountability really lie?

While such motivations for self-improvement and accountability are noteworthy, the potential consequences of implementing such a system of surveillance onto already struggling facilities may have unintended consequences, as staff struggle to meet the demands of patients, and increasing pressure from the state to deliver national targets. Health systems and staff working under the pressures of reporting positive results therefore can result in the production of poor quality data about what is happening in at the ground level. Although the mTrac system promotes transparency and accountability through real-time reporting of drug stock and case data, it is not invulnerable to the unpredictable pressures this kind of performance measurement places on a decentralised health system. Furthermore, by prioritising only the most common health conditions such as malaria, there is less incentive to use the system to report conditions such as HAT, reinscribing its status as a neglected disease even further through socio-technical practices of evidence production.

Social proximities of surveillance

In Uganda, around two thirds of medicines are procured from the private sector, mostly from drug shops (Chandler et al, 2011). Testing needs to be available where patients currently seek treatment, and HAT RDTs have been introduced into many government health facilities in *T.b. gambiense* affected areas of the West Nile. However, policy makers recognise the limited reach of such activities, given that much treatment is sought outside of public health services. The introduction of HAT RDTs at drug shops therefore has been suggested as a way make a significant contribution to targeting HAT in many hard to reach communities (Kovacic, 2015). This had been piloted in the West Nile with encouraging uptake (personal communication, 2016), and the identification of one HAT case in 2015 (Wamboga et al., 2017). However, for *T.b. rhodesiense* affected areas where there is no such rapid test currently available, it is difficult to know how well such an approach would translate from one local setting to another, or even be received initially by the individuals running these outlets, given how they are perceived and treated by the public biomedical sector. The malaria RDT has already undergone this process in Uganda before, and so some precedent exists that can be looked to. Indeed, even in the case of introducing the ubiquitous malaria RDT into private clinics laying on the peripheries of the regulated health infrastructure was not without its challenges. Drug outlets are seen by different actors as both a biomedical clinic and an unregulated vendor at once; legitimate and illegitimate; trusted and distrusted (Chandler et al, 2011).

A number of patients treated at Dokolo had reportedly been referred from private drug shops where the staff had suspected HAT. It had been suggested to me by some clinical staff, most notably by Dr Serena Akello, that a sensible option would be to expand training to the individuals managing these private clinics where the majority of patients tend to present at initially, in order to expand the suspicion index beyond the boundaries of the formal health sector into the community via these pre-established links. Understanding the potential consequences of attempting to tap into a parallel

network that largely operates 'under the radar' of state regulation requires a critical analysis on what constitute these networks.

In seeking to intervene upon the daily mundane practices of health workers, patients, and drug shop owners, state HAT control and elimination programmes could introduce a new technology of surveillance into an even more unstable, unfixed, and fluid infrastructure than which it already exists. The location of drug stores physically, being closer to remote villages and high risk populations is an attractive feature of this option. Moreover they are more topologically proximate too, being so close socially to sick individuals whose treatment seeking pathways tend to overlap far more frequently with these outlets. However the remit of the programme by definition is to render these connections and nodes visible, and integrate with them. The intentions of the programme and the system it seeks to tap into diverge in this respect, as many drug outlets that would be most accessible to patients would also be illegal and therefore unlikely to enrol into an exercise of state governance and monitoring. The quote describing how many stores communicate with one another to evade detection by the authorities illustrates the ephemeral nature of the private drug store infrastructure which inherently makes it a difficult landscape upon which to overlay interventions. It is an interesting if not paradoxical situation, where on the one hand health staff in the formal health system are lobbying to be seen by the state to access more resources, while the informal network of private clinical spaces operating parallel to this infrastructure actively seek to remain 'beneath the radar'.

Meanwhile, the national HAT Control programme aims to extend its reach into difficult to reach populations by inserting technologies into these controversial social hubs. Incorporating informal health providers into programmes would increase their social proximity to the public, particularly in remote regions. However, given the sentiments expressed by health workers in my study, integrating informal health providers into the biomedical ecosystem would require a challenging, if not unlikely cultural embrace.

Formally acknowledging the plurality of health providers questions authoritative claims on expertise and knowledge, and would require programmes to re-imagine infrastructure as a socio-material assemblage beyond the physical bounds of state health facilities.

Impact of RDT culture on microscopy performance and HAT detection

Surveillance relies on the awareness and training of health workers, and the resources to enact on clinical suspicion where potential cases present themselves to the clinic. Although microscopy is considered the gold standard for malaria diagnosis (World Health Organisation, 2010), it has been found to be impractical in many remote and resource-poor settings due to its requirements for trained personnel, equipment, regular supply of reagents and continued quality assurance supervision (Chandler et al. 2012). Investment in developing new rapid point-of-care (POC) tests provide particular appeal in health systems like Uganda's, owing to their easy mobilisation and use. RDTs are designed for places with weak public infrastructure and laboratories networks, power outages and staff shortages, and as such are expected to enable quick diagnosis without needing to invest heavily in training, equipment or infrastructure associated with the development of laboratories (English et al., 2014; in Hutchinson et al. 2016). They are, in short, what Peter Redfield calls 'solutions in a box' (2012); a substitute for absent infrastructure (Street, 2014). Small, nimble, modest-looking technologies, such as the RDT for *T.b. gambiense* can detect antibodies in just 15 minutes, and embody the 'promise of healthier, more economical and more equitable futures' (Street, et al. 2014) that ascribe to the *frugal innovation* narrative of tackling complex problems with stripped down, simple technologies (Radjou and Prabhu, 2015).

Diagnosing HAT is not just a biomedical procedure. More importantly in this setting – where practice frequently diverges from protocol owing to localised constraints and contexts – it is a social practice (Pool & Geissler, 2005).

Through these socio-material practices, assemblages of technology, policy, training, health workers and patients, and medication come together and create new meanings and relationships (Ong & Collier 2005). The diagnostic process as described by the health workers I met was one of struggling to reconcile policy with practice in the face of overwhelming patient loads and ever dwindling stocks. Managing expectations of care – both of the patient and programmes– in this environment led many health workers to opt for what will conveniently close cases and satisfy patients at the time of consultation, and donors in evaluation reports.

The malaria RDT is just one example of how vertical disease-centric programmes which focus on magic-bullet solutions to seemingly isolated problems can exert unintended negative impacts on the health systems they seek to improve. RDTs were promoted as a solution to these diagnostic challenges in settings with no or poor quality microscopy, and as a result of their convenience have become the primary diagnostic tool in the vast majority of facilities. An unintended consequence of this of course, is that microscopies are no longer performed as a general rule, not least due to staff and resources constraints (hence the utility of the RDT), but now also because there is a preferred option for the patient as well as the health worker. RDTs have created -or at least greatly contributed to- a diagnostic ecosystem whereby microscopy is no longer performed, thus case detection is dependent on the suspicion index and vigilance of trained health workers, and appropriate referral to high level treatment centres.

At a workshop on Global Health Diagnostics in Montreal, Canada in June 2018, the crux of this particular issue arose during a panel on diagnostics for antimicrobial resistance, after one panellist remarked that, while centralised referral labs and trained staff were once commonplace in many Low and Middle Income Countries, the devastation wrought by HIV and the move to single disease testing ‘destroyed’ the central lab. However, as one representative from the diagnostic device industry who was present pointed

out, the climate created by global health agendas and donor missions limited the scope for industry to explore central lab strengthening; *“The impact has been done by influential groups saying we need to do point of care, but not lab testing. So companies like us have had to de-invest in building lab infrastructures because it’s all RDTs, point of care, ‘in the bush’ diagnostics. So now we’re going back to regional labs, and people are coming to us saying ‘so where are your [lab] tests?’ Well we de-invested in those tests because you told us to focus on RDTs!”*

An audience member then interjected and countered the point with a sharp rebuttal; “So did HIV kill the lab, or Bill Gates?”

Focussing on the ‘local’ level of implementation as I have done can risk obscuring the structural factors shaping these issues. Donors and funding structures that have driven global health crusades have played a major role in transforming the diagnostic landscape today (Street, 2018). Much emphasis has been placed on developing high end technologies, but Point of Care testing and RDTs have come at the expense of investing in central labs in many countries that need them. Systematically focussing on RDTs has pushed investments in lab support to the margins. Even in 2018, cheap point of care tests continue to be framed as the solution for all low and middle income countries. We still think labs are too expensive, difficult and impossible to invest in, consequently pushing the issue into the future (Engel et al., 2016; Pai, 2018a; 2018b).

Re-imagining infrastructure and the role of the centralised laboratory

During each visit to health centres I would be taken on a ‘tour’ of the laboratory. Some of these would be large and well equipped, perhaps a run-down but broadly recognisable as a working laboratory. Others would appear to be no more than a small box-room, bearing little resemblance to conventional western conceptions of a lab. While I found these spaces

notably 'basic' and 'poorly equipped' as I blithely remarked in my notes at the time, these transpired to be the far more effective examples to draw from, as by documenting the features which they lacked, I unwittingly found myself describing those necessary elements by which the laboratory is held together and can function across varying levels of capacity and accessibility. What was it about these seemingly deficient labs that allowed them to continue to work and meet the demands of the local population they serve? The space itself and how it was used possessed certain transposable features that determines its capacity to function as a 'working laboratory' (the function being to make disease, or the causative agents of disease, visible to the biomedical gaze). For example, the presence of certain items of equipment to conduct certain diagnostic procedures is expected within this clinical assemblage. Other physical elements; equipment through which to connect the subject of biomedical enquiry to these technologies such as rapid tests kits, syringes, capillary tubes, and glass slides are arguably necessary for these technologies to perform these diagnostic enactments in this system, but by all means are not always available. Not only is the presence of certain artefacts imperative for these relationships to hold meaning, but people and their interactions with these objects are equally critical (Whyte, van der Geest, and Hardon, 2002).

Drawing on Farmer's useful, albeit somewhat tick-box style formula of staff, stuff, space, and systems (2014), if health infrastructures are to be subject to scrutiny and targeted for intervention, then they must no longer be conceived of solely in material terms. The presence of material diagnostic technologies such as microscopes does not infer increased capacity for case-detection, where lack of staff (or lack of training), or diagnostic cultures introduced by RDTs create disincentives to perform microscopy and find cases in peripheral health centre facilities. Within the wider system of HAT referral, the clinic cannot be considered in isolation any more than the pot-hole ridden or flooded road that separates it from the patient, nor can RDTs or mobile reporting be conceived of as being introduced into a stable system of

surveillance practices. Each and every element within the wider assemblage of the health infrastructure, from pathogen to patient or from laboratory to homestead, are entangled in the same complex ecosystem of dynamic socio-material relationships that govern the likelihood of a case being detected and treated. For these complicated regimes of surveillance and control to work, certain physical structures must be in place, but rely on these elements being held together as an assemblage recognisable as health infrastructures. In other words, "*Infrastructures are relational*", they are "neither an abstract system nor physical stuff; it is the relationships between people, stuff, and space that enables health systems to work" (Street, 2014b). These are necessary components, but insufficient parts of a complex socio-material ecosystem.

Conclusion

As shown in the previous chapter, patients entering the clinical space have to negotiate access to treatment through social and technological interactions. However, as this chapter has shown, health workers too must navigate these interactions and seek ways in which to make themselves visible to the state to gain access to resources whilst managing patients' expectations of care. Meanwhile, it is difficult to estimate how much information can be realistically communicated at the point of testing where health workers are limited by time and resource constraints, are under pressure to meet program targets, and while managing numerous tasks and associated workloads.

Decentralisation has led to a slow degradation of public health infrastructures in Uganda, where health workers must strive to reconcile standardised biomedical practice in contexts of 'institutional instability and medical uncertainty' (Street, 2014a. p.11). In the face of a dynamic population the local healthcare system is conceptualised to be static and outdated by health

workers. The notion that facilities need expanding, and 'stepping up' in the face of rapid population expansion has led to many workers lobbying to have their facilities upgraded to higher levels in order to access more resources, equipment, and buildings. The decentralisation of the health system has removed HAT as an item of national importance, and relegated it's threat to a low priority for districts where it is not perceived to be a risk, therefore little training or resources are mobilised to these areas. Staff regularly find themselves having to manage the expectations of health service and disease control programmes, while being held accountable by their peers and local population whom they serve and treat on a daily basis amidst budget and resource constraints. Delivering satisfactory care – both to the expectation of the patient and the clinician's standards - within faltering infrastructures becomes a daily struggle against a backdrop of increasing demands from multiple vertical programmes. Without the substantial financial and material capacity to accompany them, the reality of achieving many of the objectives set out by such programmes becomes a Sisyphean task.

Infrastructures –and as such, strong or weak health infrastructures- are not solely determined by the technical and material capacity that form their physical composition. Many HC IIIs are well equipped with working microscopes, but few have trained staff to operate them. Even where staff had the tools and training, few felt they had time or confidence to accurately perform microscopies for HAT. A study among diagnostic laboratories in the Democratic Republic of the Congo found that performance of blood parasite microscopy, including Trypanosoma was poor, and that recent training were associated with better performance, being higher among those trained less than 2 years previously, compared to those who were not (42.9% versus 26.3% respectively) (Mukadi, Lejon et al. 2016). Before the introduction of malaria RDTs, staff still had to rely on knowledge and clinical suspicion of HAT to look for it as they do today. The crucial difference however is that they would have been routinely performing microscopies and more likely to detect trypanosomes. Today in the RDT era where the routinisation of

practice has been transformed to circumvent microscopy, few health workers have the training or confidence to identify trypanosomes by this method.

The pressures of time and high patient demand have been compounded by the introduction of RDTs. The culture of rapid testing that has grown up around the malaria RDT has negatively impacted on the HAT diagnostic ecosystem, weakening passive case detection for *T.b. rhodesiense* by reducing the performance of microscopies. Few staff had received any form of formal training for identifying or dealing with HAT cases, while many were unclear where referrals should be made and whether referrals should be followed up or reported elsewhere. Understaffing, high turnover of staff, and infrequent or limited training have created a low index of suspicion among health workers, further reducing the likelihood of microscopies being performed in frontline health facilities. Few regarded HAT to be a problem in their local area, though some admitted that local prevalence data could be skewed due to lack of microscopy. Meanwhile, digital reporting methods like the mTrac system have facilitated a mechanism for data collection and accountability to be built into local health services reporting to the district. However, poor communication between lower health facilities with larger regional hospitals suggests information is not fed back up the referral stream.

Through enactments of HAT diagnosis, hospital infrastructures emerge as relational assemblages that, while on the whole appear large and monolithic, remain fundamentally fragile. The testimonies of health staff give a different perspective to the surveillance ecosystem, one that encounters the restraints of a decentralised healthcare system, the demands of target driven vertical programmes, and struggles of delivering care with little resources or structural support. Decentralisation has put HAT on a low priority setting for districts where it is not perceived to be a risk, therefore little training or resources are mobilised to these areas. Many health workers wished their facilities to be upgraded to a higher-level to receive more resources and support from the district. Here, the presence of material diagnostic

technologies such as microscopes however does not infer increased capacity for case-detection, where lack of staff (or lack of training), and diagnostic cultures introduced by RDTs create disincentives to perform microscopy and find cases in frontline health facilities.

Given the emphasis on case detection as the primary challenge in contemporary HAT control efforts, it is reasonable to assume that once a case is correctly identified and diagnosed, that treatment and discharge is a relatively straightforward and stable process. However, as the following chapter illustrates, this too is a fragile and complex part of the HAT ecosystem that faces possible disruption from new technology.

CHAPTER SIX

After HAT

Managing post-treatment referral and environments of uncertainty

“The hospital was not particularly bad, but my life was hard there”

- Patient 7, Apac District

While remaining in the clinical space, this chapter shifts from finding cases to managing them. Here, patients have been re-configured from clinical suspects to confirmed cases through the alignment of diagnostic practices, such as parasitological demonstration in the blood and cerebrospinal fluid, lymph node examination, and in some limited settings, DNA amplification. With a confirmed diagnosis the infected body is transformed and subjected to violent biomedical intervention with potent drugs, and monitored throughout and after to confirm the success of treatment. Strict monitoring guidelines once required discharged patients to return for quarterly follow-up tests, with failure to complete referral posing similar dilemmas for those trying to reconcile epidemiological certainty with clinical pragmatism in the ISSEP.

This chapter draws on data from a study exploring the diagnostic, treatment, and referral experiences of 25 HAT patients (24 treated *T.b. rhodesiense* survivors discharged from Lwala and Dokolo treatment centres, and 1 in-patient admitted to Dokolo treatment centre at the time of study). It reveals the frustrating and iterative pathways many take before finally receiving a

HAT diagnosis, the financial and social burden of long periods of hospital admission throughout treatment, and asks how potential novel oral drug regimens could transform this landscape. Drawing on testimonies from patients and health workers, this study reveals the fragility of the HAT case management ecosystem, and raises questions over the potentially destabilising effects of introducing new guidelines and treatment regimens.

Treatment and referral experiences among *T.b. rhodesiense* survivors

The first cases of rhodesiense HAT were reported in Kaberamaido and Dokolo districts in 2004, and the continued presentation of new cases indicates active transmission in both districts (Bardosh, 2016). In 2014 an outbreak of zoonotic *T.b. rhodesiense* HAT in Dokolo, Kaberamaido, and Lira districts prompted a national response co-ordinated through the Ministry of Health and COCTU. This included a number of public sensitisation campaigns which highlighted signs and symptoms of HAT to look out for, and encouraged the continual spraying of cattle with pyrethroids to tackle the outbreak. Around 18 months later, I arrived in Dokolo to explore the lasting effects of the outbreak and the subsequent public health campaign in the region. During this time, I conducted a study to examine survivor's experiences and perceptions of HAT, HAT testing, treatment, and post-treatment referral to explore the scale of referral completion and perceptions of new therapeutic regimens due to be brought onto the HAT market.

Participant characteristics

13 out of the 25 (52%) patients interviewed were male, representing an even sample between sexes. The median age of people interviewed was 30y (range 12-80). Only 10 could recall how long the period between the onset of symptoms and finally receiving their HAT diagnosis was. Of these, the

median time reported was approximately 1.5 months (range 1 week – 5 months).

Awareness of HAT and perceptions of risk

Rashid leads us under the shade of a long timber framed shelter where he makes bricks for a living. He dumps his heavy load, two buckets of murky brown water he has scooped up from the river bank, onto the ground and reclines into a restful crouch.

“You know I heard something very interesting. I remember we had some missionary who came early in Uganda, and that person was killed within Busoga. In this time they believed because they killed him, the Europeans now decided to bring those tsetse flies to come and torture us and give us that disease. Actually the way they killed him, it was communication problem, they consulted the Buganda king and he instructed them ‘you go and leave him’ - you say ‘mu-te!’ (leave) - but in Busoga that word means killing, so instead they killed the man! So they believe because of that mistake it brought that very dangerous disease and is torturing us”.

He laughs and pours some water into his hand and rinses the residue of clay from his face.

“It’s just a story, because the disease is there, you know? I know it is the normal way of transmission. The tsetse fly, they like the places where cattle go to take water, and the swampy areas” - He gestures to the embankment he has been filling his buckets from- “My work is majorly based in swampy areas where you can get water nearby and mix the mud and make the bricks, so I believe during that time when I was in Gnkwalakwala I may have gotten that disease that side. But also on my observation, generally the tsetse are many in this community also.”

When Rashid fell sick in September 2014 he attended his local health centre III in Lira district. When the malaria drugs that were prescribed to him failed to work, he feared that he had contracted HIV. At this time he had been preparing bricks for a member of lab staff, who suspected he may be infected with HAT and took him for testing at Lira Hospital. After several failed attempts to find parasites in his blood, the persistence of the lab worker’s

suspicion paid off, and his sixth microscopy result was found positive for HAT. He was transported straight to Lwala Hospital, where after a painful lumbar puncture he was admitted for 10 days with early stage HAT and treated with Suramin. *“They gave a certain period to go back, but during that time I felt so well, and also I was fearing the lumbar puncture, so I didn’t go back. I feel I am completely healed!”*

HAT awareness among my sample was generally high (only two respondents claimed to have no prior awareness of HAT before diagnosis), due to repeated outbreaks in recent years. Most respondents expressed good knowledge of symptoms and understanding of how HAT is transmitted. The majority of those interviewed had some personal knowledge of HAT, having known relatives or people in their village who had suffered or died during previous outbreaks. Both collective memories of past deaths from HAT in the community, and personal experiences among close social networks of friends and family accounted for most HAT awareness.

“I had heard about it but I did not know about how it presents. I heard that the disease was transmitted by omele (tsetse fly) from a friend who had a bite once and was told to get tested. They advised me to go for other tests for Sleeping Sickness”

- rHAT patient 3, Dokolo

“Yes that been information was parading around, and we had some relative who had died of that, but people only realised later on what it was, when we saw also other people suffering the same way. In the clan down there, people thought they were bewitched, only after they died we heard of other cases of this sleeping sickness and realised that was what it was”.

-rHAT patient 20, Dokolo

Radio campaigns also contributed, but these messages were rarely delivered in local languages. During one interview outside a patient’s homestead in Lira we overheard one such radio broadcast, in English, describing the signs

and symptoms of HAT and promoting the clearing of tsetse habitats. When asked what the interviewee thought about the message, they replied “I do not know what they said, it is not Lwo”. Those who could follow broadcasts and cited radio as a source of HAT knowledge (6) did so alongside circulating knowledge among community members and personal social networks as a key source of knowledge.

“Yes I used to hear about it but didn’t know about how the disease would take you. I heard from here [points to radio], and because even my grandfather had a bite. They are speaking Kumam sometimes, mostly English though which I do not speak”.

- rHAT patient 24, Apac

It is reasonable to assume that some of the circulating community knowledge about HAT came from sensitisation campaigns initiated by the Ministry of Health in response to local outbreaks, however only two cited HAT sensitisation activities by medical or veterinary professionals as a source. Even during testing and treatment for their own infection, some claimed to not have learned anything about HAT throughout referral.

“From the community and through radio talks. I used to hear that it is transmitted from person to person by a tsetse fly. But I do not know exactly how you catch it. Health workers at Dokolo did not explain it to me”.

- rHAT patient 25, Dokolo

At the time of interview, nearly all respondents claimed to feel there was a risk of HAT in their area. Peoples’ perceptions of risk were discussed in terms of their proximity to areas with high densities of tsetse flies, such as rivers, swamps, and uncultivated bushy areas where *lantana camara* (locally known as *obelewinyo*, or ‘tick berry’) grew. Others referred to these habitats and particular social or occupational habits that placed them in proximity to risky environments.

“You used to cut the grasses for roofing the house, during that time I could see the tsetse flies coming and eating on me”.

- rHAT patient 18, Dokolo

“The tsetse fly that brings the disease are very many here and the place is bushy and we are very close to the swamp. People are keeping cattle, and then these children they go for fishing in swamps, those are the risks. Then also going to fetch water from there because it is near to the swamp”.

- rHAT patient 9, Kaberamaido

“I fear I got it from the bush. I feel I maybe had the bite from the bush because I used to go and collect firewood from there”.

- rHAT patient 13, Kaberamaido

Despite most (17/25) saying they felt they were exposed to risk of being infected with HAT, none claimed to have suspected HAT when they first became sick, although as shown below, some later developed suspicion following treatment failure and rapid progression of symptoms, leading to 5 individuals eventually requesting to be tested for HAT.

Pathways to treatment

All interviewees reported having experienced symptoms consistent with HAT, particularly headaches, fever, or excessive sleeping during the day prior to their diagnosis. Many also complained of muscle weakness or ‘paralysis’ and difficulty walking, as well as cognitive impairment.

“He had a headache for so long. He would be looking at someone from a distance as if there are two people. The boy complained he would be seeing very big animals with red eyes, and he was talking in an un-coordinated manner. We continued from the private clinics until November when he got his diagnosis at Lwala at our second try there”.

- Parent of rHAT patient 9, Kaberamaido

While all described symptoms matching the HAT syndromic screening profile, most assumed that they were suffering from other locally endemic or high profile diseases such as malaria (9), HIV (3), Brucellosis (2) or typhoid (2). 5 individuals suspected they had been bewitched, as described in the following responses.

“Before this onset one night as I was sleeping something landed on the roof of my house, then I picked a spear and pierced the thing from inside and it fell down, I came out and there was nothing. Then from there all the signs and symptoms started, so I thought that somebody sent for me something, and because I tried to pierce the thing, it turned against me and from there the symptoms set in and my sickness started”.

- rHAT patient 5, Dokolo.

“Because he was studying I thought maybe some jealous person had bewitched the boy, I thought it could have been somebody from within this place bewitching him”.

- Father of rHAT patient 6, Apac

“Some people were saying maybe some person has bewitched me, or maybe it was myself, my own witchcraft disturbing me. But the issue of witchcraft stopped when the medical workers made the diagnosis of Trypanosomiasis.”

- rHAT patient 18, Dokolo

Others were unsure of what could be causing their symptoms and attributed them to kidney problems, possible infection from the tsetse bite (chancre), or in one case symptoms of pregnancy.

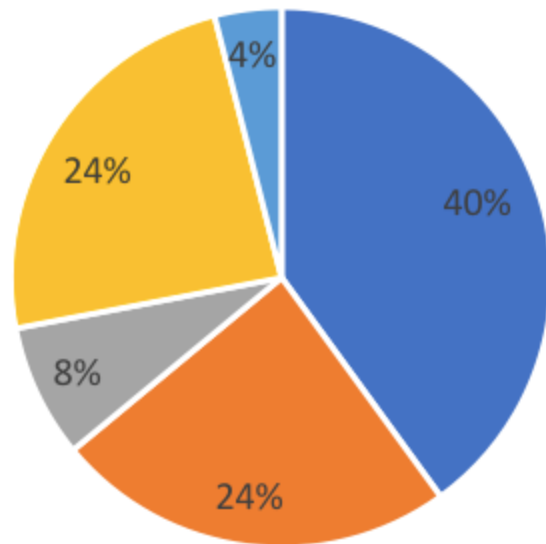
Patients took a variety of pathways leading up to their HAT diagnosis (see figure 18). The majority of respondents initially presented at local health facilities (16/25). This is likely to be motivated by the rapid onset of severe symptoms described by many. Others visited private ‘clinics’ (6), attended church for prayer (2), or self-treated with herbal remedies (1).

“10 am they [symptoms] started, I started feeling the headache [...] By 10pm the thing worsened and it started affecting all the joints, all my joints were paining me. I lost consciousness by that time. Then I was carried out by the children, they took me outside and bathed me but now I was not aware of what they were doing, I had lost consciousness. I even went and called the catechist to come and pray for me, I thought I was on my way”

- rHAT patient 18, Dokolo

“We tried these malaria drugs before we took him Dokolo, but there was no improvement. That’s why we took him. We had taken him to the clinics, the clinic tested him for malaria but it was negative. After this we were very worried we did not know what was happening, he was becoming weaker and weaker. He got worse very quickly

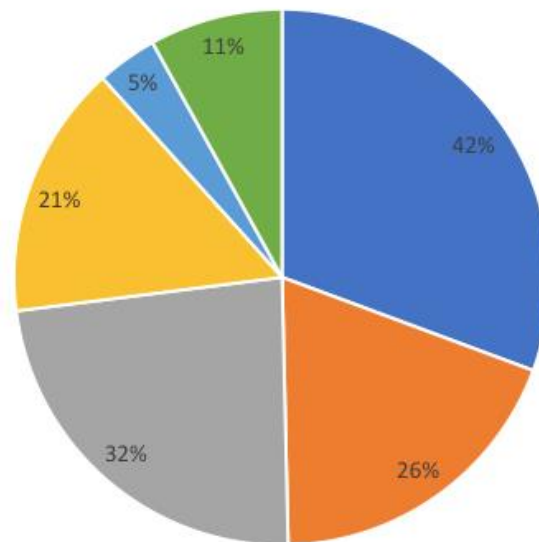
- Father of rHAT patient 20, Dokolo



■ HC IV ■ HC II/III ■ Church ■ Private Clinic ■ Ajok

Figure 15: Places first visited seeking treatment for symptoms by Rhodesian HAT patients.

Patients reported presenting at public health facilities (blue and orange) immediately owing to the severe and sudden onset of symptoms. 'Ajok' is a local term often translated as 'witchdoctor'.



■ Antimalarials ■ Painkillers ■ Unknown tablets
 ■ Unknown Injections ■ Typhoid Injection ■ Herbs

Figure 16: Treatments taken by patients prior to receiving HAT diagnosis.

Nearly half of those who took treatment before diagnosis were taking antimalarials, most frequently identified as Coartem, often given alongside the painkiller Panadol. All 'unknown injections' were performed by private clinic personnel, while unknown tablets were prescribed by both private vendors and health centre staff.

Most individuals (19/25) reported having taken treatments before being diagnosed and treated for HAT (see figure 19).

“We were buying drugs locally from a private clinic within this place, the kind of tablets we don’t know. But there was no improvement so eventually we took the boy to the health center.. After this treatment there was no improvement and the boy stayed home for more than one week and we had to take him back, and from there he was diagnosed”

- Mother of rHAT patient 6, Apac

“I was being given drugs, some people were saying I had a disease of the meat (brucellosis). Tablets, even injections, but no improvement. Then I was taken to Lwala Hospital, I was about to die”.

- rHAT patient 7, Apac

“I was given some injections from the private clinic, but I don’t know what. Then from Lwala first they removed some water from my back, but they didn’t find anything”

- rHAT patient 11, Kaberamaido

Some health workers reported that witchcraft is widely held to be a common cause of sickness in the region, and many sleeping sickness patients will initially visit the ‘shrine’ of a witchdoctor, only presenting at a health centre during the late stage or when it is “too late”. Suspicion of being the victim of witchcraft was more common among this sample than in West Nile, with 5 individuals reporting they initially attributed their symptoms to ‘bewitchment’ or being ‘charmed’. However, only 1 respondent (the mother of a young patient) had claimed to have gone to several traditional healers before presenting at a public health facility. In addition to the deviation toward drug shops observed in the West Nile, treatment seeking pathways among Rhodesiense HAT patients also included consultations with what were locally termed ‘Ajok’, or ‘Ajoki’ (pl), commonly referred to as ‘witchdoctors’. Treatments given by these practitioners ranged from providing herbal treatments in the form of liquid drinks, or therapeutic cutting procedures.

Piercing the body to introduce healing substances or remove sickness, through making cuts or several incisions to the skin to rub in medicines is still a widespread practice in many African settings (Whyte, van der Geest, and Hardon, 2002).

The popularity of consulting with Ajoki appeared largely due to their local ties within the community, their ease of access, and their suitability in treating symptoms considered to be supernatural or spiritual in nature as opposed to biomedical. These consultations and treatments are often financially costly, and were widely criticised by local health staff for significantly delaying in patients presenting at public health facilities. In contrast to the West Nile, where traditional healers rarely featured as part of the diagnostic landscape, many rhodesiense HAT patients were forthcoming in describing their experiences in seeking therapy from such practitioners.

“My body started swelling, then the first place for help was the witch doctors and they did the cutting because I was swelling in the legs, then I was brought back in some improved state. But suddenly I went back to all those other symptoms and I was not able to walk [...] There after I was taken to Dokolo health centre IV after failing with the traditional way [...] until then I was purely on herbs”.

- rHAT patient 5, Dokolo

Of those who visited Ajoki and drug shops for a long time before presenting to a health centre, many spoke of the high financial cost of paying for treatments outside the formal sector prior to being tested and diagnosed with HAT.

“We thought maybe the child was bewitched, we took her to four different Ajoki. One was in Kaberamaido, another in Amolatar, another was around 4 km away in Abalang. But we were defeated with traditional, so eventually we took the child to Dokolo HC. They [Ajoki] move around, they are mobile. When they are coming they advertise over the radio and you go to the place when they say they will be there. There is one we took her to though who is settled. The one in Amolatar district, he is called ‘Agwech’. My brother in law told me about him [...]”

They were giving her traditional herbs for oral taking, and doing these therapeutic marks, cutting where you cut the skin using razor blades, and applying local herbs over the wound [...] It cost close to 300,000 shillings [approximately 80 USD] all together, for all four”.

- Mother of rHAT survivor 22, Dokolo

While community perceptions of ‘tor omele’ (the fly disease), or ‘tor anino’ (the sleeping disease) were mostly grounded in biomedical, mostly symptom or tsetse oriented explanations, some recalled how circulating beliefs that HAT had some supernatural aetiology or mechanism played a role in their treatment seeking decisions.

“The people here, the feeling is they fear the disease that is so terrible and at times they feel it is caused by some traditional behaviours like witchcraft. For example when I was taking him to the health centre and he was mentally confused, someone said “is that the sort of thing you take to be treated at the hospital? Take him to the witchdoctor and he will be out with it”.

- rHAT patient 2, Dokolo

However, even where patients mostly chose to go straight to a public health facility and were tested for HAT, it is not always guaranteed that health workers will immediately suspect HAT and test for it. Even then, a low parasite load in the blood may prevent trypanosomes being detected even by microscopy at first.

“After failure we went to Dokolo HC five times without detecting the parasite in blood, then the last 6th time they detected the parasites in the blood of [x] and also the other boy [x’s sibling]. All these five times they were testing for sleeping sickness but they failed to get a positive result until the sixth”.

- Father of rHAT patient 2, Dokolo

This pattern of being referred back-and-forth from one facility to another several times before diagnosis was common among my sample, leading to delayed diagnosis for 8 cases.

“I went to Kaberamaido HC and was negative, then to Lwala where I was told I had typhoid fever then back to Kaberamaido, it wasn't there, was negative. Again I went to Lwala that is when it was detected.”

- rHAT patient 15, Kaberamaido

“I was taken to Dokolo health centre. But there the attendants they told me I had problems with my intestines. I was referred to Lira, unfortunately people did not have enough money to take me to Lira. I was brought back that very day, but people took me to Lira the following Tuesday. From Lira hospital they got the parasite in my blood. I was then brought back to Dokolo HC IV. I was now just being carried on a stretcher, from Dokolo I was admitted and they confirmed my diagnosis and they started working on me and treating me. [...] The people doing the testing didn't do well because they said it wasn't there then shortly it was discovered from Lira. If it was just Dokolo I went to then I would have died, it was Lira who found the parasite. Even the intestine problem they spoke of at Dokolo was not even there at Lira, it was false.”

- rHAT patient 18, Dokolo

This suggests case detection can be delayed by poor access to transport or funds to reach referral hospitals, but also that in some cases poor knowledge and awareness of HAT, and thus low index of suspicion among health workers in this region contributes to misdiagnosis and delayed detection of HAT cases. As shown in the previous chapter, few health workers in frontline health facilities feel confident in recognising HAT symptoms or trypanosome identification by microscopy. Furthermore, few considered HAT to be a problem in their area, reflecting the low priority of HAT at district level and a lack of surveillance data available to staff at lower level facilities. The net effect of this is low suspicion and delayed, or even no detection, of some HAT cases.

Furthermore, while patient led referral (i.e. patient's, or guardians requesting health workers to test for HAT) was higher among this sample (7/25) compared with the West Nile, many shared the concern that health workers would not receive such requests well and feared being 'sent away'. The following quote is a particular example of how relationships of power between patients and health workers, and informal health providers produce

differential outcomes in access and care, as this patient describes her referral being made through a private practitioner who brokered their request.

“We feared the health worker would not understand if we ask for tests, and they think that we are thinking we have more knowledge than them. They might send us away with nothing. From there the other person, the private practitioner made a request.”

- rHAT patient 25, Dokolo

“When I went there Lwala they tested a blood sample from finger-tip, it was negative. Then my husband complained that we came here and we want the test for Tryps, then you say its negative. Then the nurse came and requested the doctor to take water from the back [LP], they tested and it was positive. Then they started treating me”.

- rHAT patient 23, Apac

Patients negotiating HAT tests with medical staff suggests a low vigilance of HAT among health workers, however the majority of patients reported that their diagnosis was made under the suspicion, or ‘initiative’ of health workers’ to test for HAT based on symptoms or patient history, though this only followed repeated failed treatments for malaria or typhoid for example.

The majority of health workers I interacted with during my time in this region regularly expressed dissatisfaction with the current passive system and its unsuitability for local treatment seeking contexts;

“We get few cases, but those will come in the late stage and in some cases you end up missing them. Sometimes you might not be able to treat them, it’s too late. I think the challenge is mostly two ways; sometimes they take long to seek our treatment, sometimes they are sick but diagnosis is not made early, so people are thinking of other things, after you finally find it 2 or 3 weeks have gone and the disease has progressed”

- Clinical Officer, HCIII, Kabaermaido

Admission and treatment experiences

The vast majority of patients described some difficulty in reaching hospital for admission, whether they were brought in an incapacitated state by others, or presenting themselves, many faced challenges in accessing transport. For those cognisant enough at the time to remember it, the treatment itself in some cases was uncomfortable

“The challenge was that I had problems in transport, the place is far and I was very weak so couldn’t get myself there. But eventually a woman rode me on a bicycle there”

- rHAT patient 4, Dokolo

“It’s not easy, people need to hold you in order to get the sample [CSF sample via lumbar puncture], you will never forget that, it was terrible. One day they wanted to give an IV administration but failed to get a vein, that day I didn’t get the medication because all the health workers there tried to trace a vein and it was not accessed, and it was so terrible, they tried everywhere. ”

- rHAT patient 1, Kaberamaido

While some of the experiences described by patients related to the treatment itself, the majority focused on the associated experience and knock-on effects of being admitted to hospital, from arranging child care, to raising funds for food and medical supplies after health centres had stocked out.

“Other than distance, there was frequent visiting to the hospital, we had to travel there a lot, we took things like foodstuffs, it was a challenge. It affected our studies so much, he was behind on his studies”.

- Brother of rHAT patient 6, Apac

“The hospital stay is not easy to stay there is always problems. Water is distance from the place, collecting water isn’t easy, also looking for firewood from distant places, but the foodstuffs are sold nearby the hospital. The problem of getting money for purchasing those is the challenge”.

- rHAT patient 14, Kaberamaido

“I was treated well in terms of treatment, the problem I had was leaving home for 1 month - I had left rice in the garden and the daughter in law

was struggling to harvest and had difficulties. Also raising money for the upkeep was also difficult”.

- rHAT patient 18, Dokolo

Despite the Ugandan government’s policy to provide “free care,” undergoing treatment at public sector hospitals can result in a severe economic burden to patients and their families, as frequent stock-outs and broken equipment require patients to pay for large portions of their care out of their own pocket (Anderson et al. 2017).

Fire in the veins

There is no lighting in any of the hospital blocks - the power has been out in Dokolo town for three days now and there is no back-up generator to cover these intermittent and indeterminate periods of blackout at the hospital.

David, Dr Serena’s most recent HAT in-patient is well enough to stand, though very quiet and lethargic. The Nursing Officer, Constance, saunters nonchalantly along the veranda and ushers our patient into the examination room where she directs me to a chair behind the consultation desk. Dr Serena then appears in the doorway and greets us apologetically. “*Sorry, sorry. I was in theatre. It will be a bit dark now, but we will manage*”.

Constance pulls a mobile phone from her pocket and instructs David to take a seat on the bench and roll up his sleeve. Aiming the phone’s torch for guidance, she inspects the inside of his forearm arm and straps it below the elbow, searching for a vein under the weak light emitting from the screen. Meanwhile, Serena pulls out the small glass vial of Suramin from its box and places it carefully onto the table in front of me, narrating the procedure instructively as she prepares the drug for administration.

“Suramin is given weekly over the course of one month, and the dose is given at 20 mg per kilogram of body weight for seven days. It is very important to calculate the patient’s weight very accurately”.

Serena unsheathes a syringe to draw up some saline from a plastic ampoule - a fiddly task in poor lighting – and snaps the needle in the bottle’s neck. *“Ah! This one is spoiled now”.* She throws the syringe into the sharps bin with an exasperated sigh. Constance calls over David’s wife Christina, who has been hovering attentively from the doorway, and gives her an abrupt instruction in Acholi to bring a new syringe. Christina, visibly irked, marches off to the private drug store across the road that provides most of the equipment and drugs the hospital regularly stocks out of. After a few minutes she re-appears with a new syringe and delivers the packet to Constance. Serena laughs and takes up the new syringe for the second attempt. *“This one she complains now, after spending so much money on taking him to witch doctors, that she cannot afford the 300 shillings for a new syringe!”*

Total darkness has fallen, and the three of us are now fumbling with mobile phones and torches from different angles to illuminate the scene as Serena prepares the patient and the drug. With the second syringe loaded, she clicks the needle into the cannula and resumes her clinical narration of the procedure, placing particular emphasis on how cautiously the drug should be administered. *“We need to inject very, very slowly, and carefully. Then we must flush it.”* She fills the next syringe with more water, and flushes the Suramin through David’s veins. Once the procedure is done, she scoops up the packaging off the desk and throws it into the clinical waste bin, *“We are done!”* she claps triumphantly. David looks fairly unfazed, if a little bewildered by the whole experience, as Christina lifts him up by the arm and shuffles him out and back to bed.

“That’s it, once a week for a month, then he will be walking out of here and so happy. The patients, they are so happy when they wake up and recover from it. It is very rewarding”.

I'm surprised by how relatively undramatic the procedure itself was, having heard so many accounts of painful treatment regimens during patient interviews. "Ah, that is not the one you are thinking of". Serena beckons me through to the drug store and produces another box, this one containing slightly larger vials labelled *Melarsoprol B*.

"This is the drug that is very painful, it is what you hear stories about when people complain of the pain when they are treated. David is in the early stage of disease, so we only need to treat with Suramin. That is rare! They usually come too late and we have to administer Mel B."

Melarsoprol B (or 'Mel B') is an arsenic derived compound that is only administered to patients in the late, meningoencephalitic stage where the Central Nervous System is infected (confirmed by identifying trypanosomes within the Cerebro-Spinal Fluid (CSF) via a lumbar puncture procedure). Serena goes on to explain how the Mel B treatment can be toxic and in some cases is fatal to some patients.

"The compound can also cause tissue necrosis, so you must be very careful to get the IV line right, otherwise a patient can even lose an arm [...] Suramin is just fine, there is no problem giving this, but Mel B is so, so painful for them because the drug is so viscous and thick. It's like vegetable oil, and it needs a lot of force to push it through the vein, that is why it is so painful for them. Some say it is like having fire in their veins"

David's symptoms had been scrutinised by the health worker at his local facility after his malaria RDT had come back negative. Suspecting HAT, they referred him immediately to Dokolo hospital. Upon arriving he had undergone a lumbar puncture procedure to determine which stage the infection had advanced to, a painful and miserable experience as he later recounted; *"I am glad to be cleared of that disease, but I wish to no longer have that needle in my back! I could not bend for a long time, it is so painful"*. Fortunately for David, he was in the early haemolymphatic stage of disease, which can be

treated with a 10-day course of Suramin injections to clear the infection in the bloodstream. Had trypanosomes been located in the CSF however, he would have been in the late stage of infection, whereby the parasite has permeated the blood-brain barrier. The invasiveness of the parasite in turn requires an adequately invasive course of treatment of Melarsoprol B, a lengthy two-week regimen of painful intravenous injections with a toxic and potentially fatal compound.

Aside from the unpleasant nature of treatment, lengthy hospital admission periods present further burdens on patients and their families beyond the physical debilitation caused by lumbar punctures and intravenous injections of toxic compounds. David's wife Christina later confided some of the difficulties they faced.

“David is my husband and he is sick and I am the one looking after him, so home is left behind with my siblings. Feeding is a problem for me for this long, at home we have our cassava garden and vegetables, but here there is no forest here for collecting firewood from. If we go back again we need transport which becomes costly [...] I would prefer him to be treated from here, but if there is treatment I could carry home then I would prefer that”.

Health workers too acknowledged the struggles faced by patients during treatment and expressed hope for the benefits of a potential oral treatment patients could take home

“I think that would be better to manage them from home, because the society we live in and the services we have, I think our community prefer being with their people at home, staying in hospital is an inconvenience to the patient and the family, but only if the condition can be managed from home “

- Health Worker, Kaberamaido HC IV

Fexinidazole as an emerging alternative treatment

The painful lumbar puncture procedure and potentially toxic drug regimens HAT patients currently face may soon become redundant, since new oral drugs effective against the both stages of the disease look promising (Kovacic, 2015). *Fexinidazole* (or 'Fexi' as it has come to be commonly abbreviated) is a well-tolerated oral treatment that can be given for 10 consecutive days (Torreele et al., 2010; Tarral et al, 2014; Jones and Avery, 2015). At the time of study, Fexi was in stage 3 trials in the Democratic Republic of Congo (DRC), and was being considered for trials at Lwala Hospital in Kaberamaido. Since then, although no trial took place in Uganda, the drug has completed phase II/III clinical trials in the DRC and Central African Republic, with treatment success rates of 91.2%, enabling Sanofi, DNDi's industrial partner, to take steps forward for regulatory approval through the European Medicines Agency (EMA) (HAT Platform Newsletter, 2018). With such a transformative technology on the horizon, I invited staff in my health centre surveys, and the patients in my referral study to reflect on the staging process and treatment they had described during their interviews. This explored perceptions and concerns of an alternative oral treatment, which could be given on the basis of a positive microscopy, without requiring lumbar puncture, and which potentially could be taken home.

Almost all preferred the idea of an oral treatment, though only one mentioned the appeal of circumventing these painful staging and treatment procedures; *"If there side effects are not there, yes. The pain during injection time is so painful, I would prefer getting oral treatment that I can take from home"* (rHAT patient 5, Dokolo). Interestingly, two respondents felt the tablet option would be ineffective as a treatment for such a serious condition, as *"the disease was so terrible that it just needed injection; the tablets could not do it."* (rHAT patient 1, Kaberamaido). As Whyte et al. discuss in their examination of pharmaceutical injections in Uganda, injections are widely considered iconic

of “the powerful substances and procedures of biomedicine” (Whyte, van der Geest, and Hardon, 2002: 111). Like the ‘therapeutic cutting’ procedures described by patients performed by traditional healers, injections elegantly perform a more thorough form of an already well established practice, by introducing a healing substance directly into the body through piercing the skin. As certain sicknesses are thought of as moving through the blood, then injections into the bloodstream “put medicine where it can attack the sickness directly” (*ibid*:112). This perception of bodily processes can be extended to the need for more potent and invasive chemotherapeutics such as Melarsoprol B, which can permeate the blood-brain barrier to directly attack late stage HAT infection in the cerebrospinal fluid. This ‘localization’ of illness, in the flesh, blood, or brain, as opposed to the individual as a whole, is important when considering predisposal towards the acceptance of injection, intravenous, or oral technologies. Gauging perceptions of an oral drug that could be taken home is particularly important as this is an aspect of the new drug’s features that has proved to be a particular selling point in the global health community, and one which I expected would be received positively given the widespread dissatisfaction associated with long hospital stays for patients, such as the following response:

“I would prefer taking drugs at home because staying at the hospital is expensive and even going for treatment there we had to sell land to pay for it”

– rHAT patient 3, Kaberamaido

Indeed, on the whole, almost all patients in this sub-study (23) and many health workers with whom I discussed Fexi agreed that an oral regimen would be preferable to IV injections.

“The good option would be a tablet because the injection as it is entering it burns and needs to go just slowly, otherwise the tablet would be better if they are doing the same thing. I could continue with it myself because I need my life. Also that CSF test [lumbar puncture] is so, so terrible”.

– rHAT patient 1, Kaberamaido

“You give the first treatment, they improve –but you need to monitor, you are expecting there to be some drug reactions, but the patient feels okay they want to go home, it is always hard to keep them in the facility – they feel they can be at home, they have no reason of being here, they think you are wasting time, as health workers we feel we need to observe them as the treatment is going on for some time. Oral option would be the best because if it has few side effects then they could manage it from home. The other one has been hard to manage because imagine you are the patient and you are just here every day. They say today ‘you are not getting drugs but you are around’ [having to stay]. It is frustrating for the patient, they want to go home”.

- Health Worker, HCIV, Kaberamaido

Surprisingly however, reactions to a potential oral drug treatment that could be taken home were mixed (see figures 20 and 21). Of the 25 respondents, nearly half (12) would prefer to be treated in hospital under close observation (with either the current treatment or an oral regimen). Much less enthusiasm was expressed for the proposed environment of delivery (i.e. taking treatment from home) than expected.

“I would prefer to be given at the hospital by the health workers. The oral treatment to be taken, it is possible that I will forget what time and how much I should take, but the health workers at the hospital will give the right drug at the right time. I would trust the health workers”

- rHAT patient 4, Dokolo

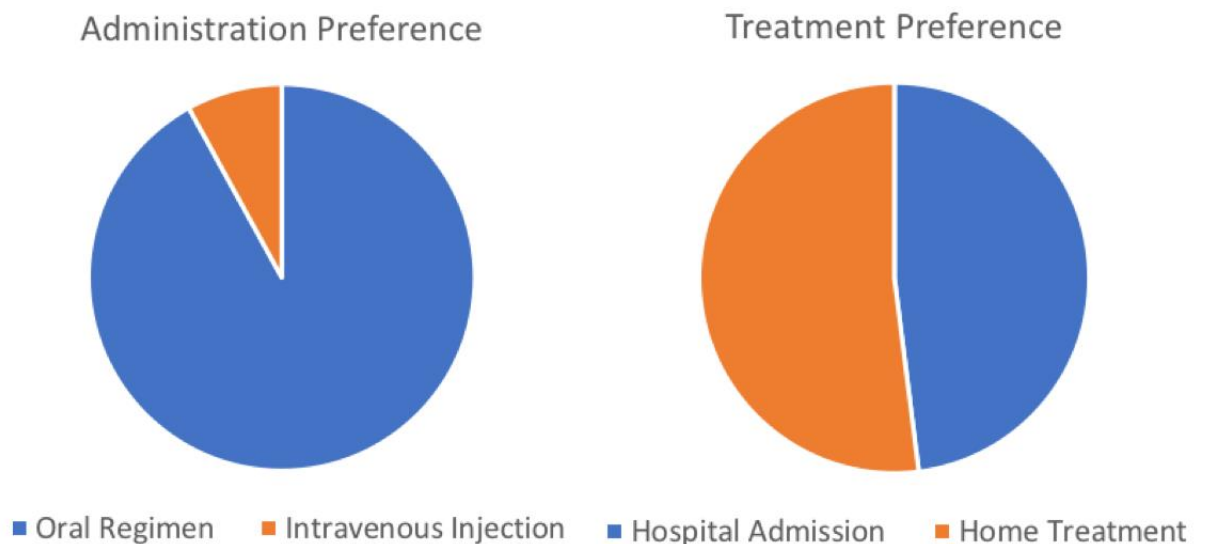


Figure 17: Patient treatment and administration preferences

92% of patients would prefer an oral drug regimen (blue) over the intravenous injection (IV) treatment they received. However, nearly half (48%) claimed they would prefer to remain admitted to hospital (blue) as an in-patient under observation throughout treatment, regardless of treatment type.

As one might expect, some patients claimed that this would be highly convenient, and circumvent some of the inconveniences and 'burden' of prolonged admission and long journeys to and from hospital. However, many health workers did not share this idea so readily, and felt uncomfortable with not being able to physically oversee the patient's treatment through to completion. Some felt it might be convenient to patients, but in order to work and not put the patient at unnecessary risk there would need to be some extension of the clinical gaze in place to monitor drug adherence. A popular model often referred to was one similar to the DOTS (Directly Observed Treatment) protocol implemented by TB control programmes.

"I think hospital for treatment is good because they can be constantly and professionally monitored, home might not be a good environment. But if they can be observed at home, like the DOTS, it would be preferred."

- Nurse, HCIII, Lira

"I think it is better they stay in hospital where they can be monitored. Also if you give patients drugs, where will they store them? They will be sitting out like this, in the sun, and say to someone 'you bring me those drugs'. They will bring them out, take one, and then they will sit there next to them in the sun. Where is there for people to store drugs properly? Something like DOTs could work I think. Although if the system of treatment were to change like that then the community would again need to be sensitised before-hand so they understand the new protocol".

- VHT worker, Kobulabulu, Kaberamaido

In spite of the associated costs and inconveniences of being admitted as an in-patient, nearly half would prefer to remain in hospital throughout the course of their treatment, even in the scenario of having an oral drug option. Most echoed health worker concerns about monitoring, and mentioned feeling as though they were being acknowledged, seen, and 'well looked after' when admitted to hospital. Some patients expressed equal concern that

they may fail to oversee their drug regimen properly and fail to get better if the onus to complete treatment were on themselves.

“I would rather be at the hospital, it is good treatment because when you are there the people there are full time. There you get regular reviews, because it’s always close to the health workers and the observation is very close. At home you might forget your time and take the treatment wrong”.

- rHAT survivor, Dokolo

In this sense, it is possible to see Fexi as a novel technology, or even a biopolitical project, through which the state HAT control programme seeks to govern the treatment of patients beyond the confines of the clinic, placing the responsibility of diagnosis through the introduction of RDTs in private drug shops and frontline facilities, and even treatment, through take-home oral drugs. However, as Brives writes in her account of phase III clinical trials for a preventative HIV drug, case trial participants, or in this case patients, must be apprehended in their multiple roles; “they are both trial participants and research subjects, and they are also subjects inscribed in domestic space” (2016: 17). Doctors in the hospital and VHTs at home may advise patients as to the correct protocol for administering Fexi under controlled conditions, but it is very clear that “the design becomes markedly more complex when one takes into account the use of therapeutic drugs in the everyday context” (*ibid*).

The struggle for patients to be seen by those around them continues beyond the diagnostic phase into treatment, where both health workers and patients alike express concern that being ‘sent away’ with drugs were symbolic of not being adequately acknowledged or taken care of by the state healthcare system.

“For me I appreciated that it was good for me to be there, because after I got the injection sometimes I could not understand myself, so I think it needed me to be near under supervision”

In *T.b. rhodesiense* affected regions, awareness is less of an issue owing to recent outbreaks and various livestock mediated control campaigns. Where Rhodesian HAT is more acute and likely to result in health centre referral, the problem lies in what happens after HAT. That is, the uncertain post-treatment phase of potential relapse where protocol, until very recently, required a series of follow up appointments to confirm the clearance of infection to be completed before clinical closure can be achieved. The following illustrates some of the frustrations that health workers face in seeking to gain clinical closure discharged patients.

Dropping off the radar

Serena invites me to review the HAT records in her office, and drops the register onto the table with a heavy thud. Serena reflects on the stories of individual patients as she turns the pages, recounting the circumstances of each case vividly. Notably, her accounts referred very little to the period of time these patients actually spent in her care, but their life histories and struggles that brought them to her and the aftermath of HAT.

“When these people fall sick, by the time they come to the health centre and by the time they are diagnosed they have wasted a lot of resources. Some have gone for witchcraft, or moved from health facility to health facility, so they have wasted a lot by the time they are finally diagnosed. And then the other thing is by the time the diagnosis is made, you find when they have been sick for so long, it means other activities could have been done. If they are a peasant farmer, that whole period when they are sick and looking elsewhere for what, there is no farming being done. Most of the time you are sleeping in the day, and awake at night, and you are sick. Then it has left orphans, because of those who have died they leave behind the children”.

She speaks at length about one case that visibly troubles her, of a child who had been brought to the hospital with what she described as “therapeutic cuts, all over his chest [...] he had been tricked into being taken to a shrine for prayers there instead of travelling to Dokolo [treatment centre]”. The boy was gravely ill by the time he had reached the hospital, but eventually received treatment and been “saved” after all.

“Well, that is a good outcome”, I say reassuringly, assuming this conclusion represents some medical, if not moral closure for Serena’s difficult work. Instead, she sighs and rubs the furrow in her brow agitatedly. Thumbing through reams of pages of the HAT patient register she eventually reaches entries for the year 2014. Sliding her finger down the column, she arrives and taps forlornly at entry no. 13. *“That is him, the boy. I do not know what happened to this one. He never came back as he should, for testing. He just dropped off our radar. I cannot follow up such patients.”*

International policy and clinical protocol has long stressed the importance of following up patients for up to 24 months after treatment with laboratory examinations of body fluids, including cerebrospinal fluid, as parasites can remain viable for long periods and cause relapses (WHO, 1998; Büscher et al. 2017). However, the challenges to systematic follow-up described in this chapter have rendered this policy intractable and forced it to adapt to accommodate the socio-material complexities of referral. In view of the fact that such patients are more likely to present themselves for follow-up examinations, systematic follow-up after treatment for HAT is no longer recommended in the policy literature; “follow-up, including CSF examination, should focus on symptomatic patients” (WHO, 2013a). Although patients should be encouraged to present themselves only when clinical symptoms of HAT re-appear, health workers like Serena continue to enact relics of policy and strive for systematic follow-up of patients.

The stabilising properties that policy and protocol instil in the HAT assemblage also make them difficult to dismantle, both in the clinic and in the community. Authors of a study in the Bandundu and Kasai Oriental provinces of the DRC found that old recommendations and rules dating from old medical textbooks from the 1970s and even Belgian colonial law had transcended over time to take on new ‘meanings’ (Mol, 2003) as social prohibitions and taboo. For example, medical advice suggesting one should rest for 6 months after treatment still circulated as common knowledge among communities, despite being a dated recommendation left over from old guidelines. This advice and knowledge went on to take on and live its own social life, the six-month period becoming socially reinforced in the community. While not the original intention of the medical guideline, because of the serious side-effects of melarseprol, an association had been drawn between side-effects and not observing the correct rest period. As a result of ‘strict social control’, patients are compelled by their close social network to adhere to these restrictions throughout treatment and the full six months post-treatment rest period. Moreover, “the community condemns a patient that violates these taboos”, and as a cohesive social network ensures that patients respect and adhere to this resting period (Mpanya et al., 2015: 9). These are the ways in which technologies (which can be structural and bureaucratic apparatus as well as discrete objects) are “an association of methods, techniques, and equipment [...] together with the people using them” (WHO, 1978, in Whyte et al. 2002: 104). They not only disrupt and transform local ecologies, but are shaped by the ecosystems they are introduced into, and once socially embedded into practice, technologies like protocols and algorithms take time to adapt or dismantle.

Post-treatment referral experiences

Of the 24 participants who had been discharged from follow up (one, David was still an in-patient at Dokolo HC IV at the time of study) the vast majority of patients (19/24) had been given a follow-up appointment and attended at

least one referral examination. 5 of these had returned for multiple follow-ups; *“I kept on reporting and reporting and they performed negatives every time”* (rHAT patient 20, Dokolo). Two had, per the new protocol, been advised not to return unless they experienced symptoms again; *“I was told if I am not getting improved then I should go back but if I am improved then there is no need”* (rHAT patient 3, Dokolo). Three patients had been advised to return for follow ups, but had not since undergone any follow-up examination. In two of these instances, a break-down in communication between health services and patients appear to have led to confusion over appointments.

“I was given a date but I went back and did not get a doctor and no one attended to me”

- rHAT patient, Dokolo

“We have never taken him back. We were told we would be informed when to take the boy but they did not inform us”.

- Mother of rHAT patient 6, Apac

Most of those I interviewed (14) claimed to be fully recovered and symptom-free after treatment, with one citing this as a factor in their decision to not present for further follow up tests; *“They gave a certain period to go back but during that time I felt so well, and also I was fearing the LP so I didn’t go back”* (rHAT patient 1, Kaberamaido). Meanwhile, the persistence of symptoms also prompted one patient’s wishes to continue follow-up examinations; *“I was given a date twice and I went, but now I still want to go because I’m not feeling well so I feel I should go and be tested again”* (rHAT patient 14, Kaberamaido). Even in the absence of symptoms however, some wanted to be re-tested for peace of mind.

“I feel that I still don’t have the thing in my blood, but still I want the test to confirm”.

- rHAT patient 14, Kaberamaido

“I don’t have any problem after the treatment, my concern is that I still want to go back to re-test. There are no symptoms, but the first time I

didn't even have any symptoms, so still I may have no symptoms and the thing is there still".

- rHAT patient 19, Dokolo

One respondent claimed that their granddaughter's follow-up examinations had been positive after treatment (contrary to our records), which had led the family to believe she had not been treated properly at Dokolo and were considering taking her to another hospital.⁵ This suggests some possible miscommunication at the point of testing.

"She took a lot of time there. The other challenge is the child is being taken there to detect the parasites and even now they are saying it is there. The treatment hasn't cleared the infection. We are thinking of taking her to Gulu hospital because she is not being treated properly at Dokolo"

- Grandmother of rHAT patient 22, Dokolo

Even with such a high referral completion rate as observed in this sample, the vast majority still faced transportation issues and additional healthcare service charges. This made referral completion, particularly in the absence of motivating symptoms, a challenge.

"I went so far for four times. All these subsequent reviews through testing, and they were all negative!"

- rHAT patient 18, Dokolo

"She was given appointment date, she went but had transport challenges, but we struggled and went on the exact date"

- r HAT patient 22, Dokolo

"It's about 15 km, it disturbed me a lot, we had problems with transportation"

- Father of rHAT patient 2, Dokolo

⁵ The patient was subsequently taken with the research team for testing at Dokolo and found negative by microscopy.

Like RDT-positive gambiense HAT suspects in West Nile, the financial costs of returning for further tests become burdensome when individuals must anticipate associated healthcare costs and travel, particularly when results repeatedly come back negative. However, while it is true for many that follow up is a costly and challenging part of referral, it is clear from patient testimonies that, in contrast to the sample in the West Nile, confirmatory examination was understood to be important and complied with. The gravity of the experience of being infected and treated for HAT is likely to be a key factor in motivating patients to be sure of their 'status'. However it was also apparent that, contrary to respondents in the West Nile, health workers had communicated the importance of returning for follow up, even though this is no longer required in the absence of symptoms.

Finally, it is evident that, as Kovacic et al. have pointed out, communities 'remember' certain socio-material practices performed by programmes (2016), from compensating blood samples with soda, to enacting dated policies out of habit. They have become routinized and left their mark on the collective conscience of those old enough to recall them, and it became apparent at the end of interviews in this study that one such 'memory' prompted some patients to inquire after the financial assistance they had heard was offered at one time.

"People said there is some kind of assistance given to people with this disease, is this true?"

- Father of rHAT patient 2, Dokolo

"It used to be back in the days when people were treated at Serere [hospital] that those who were treated for this disease were given support. When did this change?"

- rHAT patient 7, Apac

"I have been hearing people treated for this disease are being given support. The people at the hospital, they said that they are giving money".

- rHAT patient 11, Kaberamaido

The policy of paying HAT patients during and after treatment to compensate the losses incurred by travel and admission expenses has been implemented during past outbreaks, but have long since ceased. However, the 'memory' of such financial schemes have persisted to circulate and influence the expectations of HAT patients across the region today.

Discussion

Diagnostic landscapes and pathways to treatment

This chapter corroborates and provides further evidence for some of the key arguments made thus far; that the landscapes of care imagined by the HAT programme are different to those navigated by patients, that the social proximity of care shapes treatment seeking decisions and diagnostic pathways, and that effective communication is an important factor in referral outcomes. Many patients in my study presented at health centres, but are not diagnosed with HAT for a long time, often not until infection has progressed to an advanced stage. National figures for HAT have historically been greatly underestimated in Uganda (Odiit et al., 2004; Odiit et al., 2005; Acup, 2017), with an estimated 30% of HAT cases dying undiagnosed (Odiit et al., 2005). This chapter demonstrates a number of factors influencing under-reporting of HAT in Uganda. Firstly, under the passive surveillance system, patients often fail to recognise symptoms of HAT and do not present at a hospital where they could obtain a diagnosis, thus are not detected or reported. Those that do attend a lower level health facility will likely be assessed for malaria and may only be referred to a higher-level facility if severe malaria, or in some cases HAT is suspected. Secondly, cases that do reach hospital often fail to receive a diagnosis, "depending on the knowledge, attitudes and practices of local health workers at the point-of-care, and the capacity for disease

management at the centre” (Acup, 2017:231). My findings suggest the latter plays a more significant role in HAT under-detection in this region.

The spread of HAT places a significant burden on local health systems in affected districts, and have had a major impact on human health and economic development in central Uganda. Acute rhodesiense HAT has been introduced to 9 new districts in as many years (Welburn and Coleman, 2015), with many being ill prepared to diagnose cases and deliver the necessary specialist and complex clinical HAT management. Symptoms of cognitive impairment from damage to the Central Nervous System (CNS) associated with late stage HAT can motivate patients to seek solutions from herbal practitioners, with sufferers believing they may be bewitched, thus further delaying early recognition of disease (Bukachi et al. 2009). While many respondents in my study presented to a public health facility first, it was evident that a number had initially suspected bewitchment to be the cause of illness, and had received advice from members of their community to enlist the help of traditional healers and medicines first.

The stage of HAT infection at the time of diagnosis can be a good indicator for how effective healthcare systems are in recognising cases (Acup, 2017). High numbers of patients presenting in the late stage of infection indicates a low awareness of HAT in the community, or a reluctance of patients to seek state biomedical care until the illness has become severely debilitating. In a rural context of material poverty, as in most HAT-endemic areas, patient motivation to continue treatment seeking or complete referrals can be significantly diminished by high transportation costs, direct health care costs of recurrent treatment-seeking, and competing family and agricultural responsibilities (Hasker, Lumbala et al. 2011, Palmer, Surur et al. 2014). Thus, treatment seeking is both an economic and social process (MacKian et al., 2004), and it is important to examine decision-making processes occurring in the social landscape. Good (1987) found that patients in Kenya turned to ‘significant others’ - a social network of parents, relatives, or

neighbours - when their initial choice of treatment turns out to be ineffective. Many of the participants I interviewed in this study, and in my RDT referral study, reported having been influenced by the advice of family or loved ones when making treatment-seeking decisions, such as the father of one HAT rhodesiense patient who had been cajoled by his community to take his son to a traditional healer rather than hospital (patient 2, Dokolo). My findings speak to models of treatment-seeking that place emphasis on social networks and the significance of such lay referrals. Such a model corroborates my own observations and acknowledge fluidity among various treatment pathways, where informal health providers are substantial features in the diagnostic landscape.

However, diagnosis at late stage of infection is not only an outcome of 'undesirable' treatment seeking behaviours from a biomedical perspective. It is also indicative of a low index of suspicion among health workers, leading to failure to identify early stage symptoms at lower health service levels. Many in my study reported being referred back-and-forth between facilities for weeks and even months before finally receiving a HAT diagnosis, sometimes to the point where patients were incapacitated and close to death. Poor surveillance has been framed as a function of unskilled medical staff, poorly equipped and functioning diagnostic laboratories, and gaps in the knowledge of clinical staff (Odiit et al., 2004; Bukachi et al., 2009; Acup et al. 2017). However as the previous chapter has shown, it is important to recognise that 'unskilled' staff are also often unsupported and untrained, and the efficacy of diagnostic facilities does not solely rest on the equipment they house. Therefore, strong surveillance - passive surveillance in particular - relies on awareness and communication, both among and between health workers and communities. Technological capacity at frontline facilities is important for confirming and referring suspected cases of HAT, but dialogue between programmes and communities can bring this capacity closer by making the connection between symptoms and suspicion.

Introducing Fexi: a quick fix for case management?

Regarding the difficulties patients in this study faced in being admitted to hospital for treatment suggest that the potential introduction of a new oral drug for HAT may address many problems with current case management, particularly if they can be administered at home, and without the need for lumbar puncture, a painful procedure which deterred many patients from returning for follow-up. Other studies have also reported that with fear of repeated lumbar punctures during follow-up, most patients stay away from post-treatment controls (Robays et al., 2007; Tong et al., 2011). However the introduction of Fexinidazole into the therapeutic assemblage will likely be disruptive in other ways in terms of how different types of treatments are perceived (such as between oral and injection administration), and how existing home-based drug taking practices may affect the safety and adherence of a new HAT drug. In a recent review of the anthropology of pharmaceuticals, Hardon and Sanabria approach pharmaceuticals as being never finished, and as “always on the way to becoming something else” (Ingold 2011: 3). This approach follows the ‘matter flow’ of pharmaceuticals (ibid, 433), in that ‘matter’ is “always in movement, being molded and transformed by human and nonhuman processes and practices” (Hardon and Sanabria, 2017:119). As Craig says in her study of Tibetan medicines, “one cannot really know whether a medicine or therapeutic approach is efficacious until a practitioner makes and/or prescribes it, a patient uses it, and then reacts to its use” (2012, p. 7). Pharmaceutical practices continue to be actualized, modified, and re-actualised in care settings, stabilising the treatment assemblage. We see this where communities in the DRC continue to enforce post-treatment ‘rest periods’ for patients, and health workers continue to enact old guidelines that require quarterly referral examinations, and feel their failure to do so creates ‘environments of uncertainty’.

Guidelines made by international organisations, governments, district offices, and vertical programmes aim to regulate and stabilise treatment practice and

to discipline patients. However, many ethnographic studies have shown that these sites of stabilisation can simultaneously become sites of innovation in response to patients' health concerns. I have found health workers echoing and advocating patients' concerns about being 'sent away' home with tablets, suggesting a direct observation treatment model to ameliorate patient concerns about not 'being seen' by medical staff or not taking their medication properly. Similarly, Kyakuwa & Hardon (2012) describe how HIV positive nurses in Uganda resist biomedical guidelines that advise against the use of traditional medicine by teaming up with patients to incorporate a traditional cream into the AIDS program to alleviate side effects of antiretroviral treatment. Integrating biomedical innovations into the pluralistic ecosystem of healthcare is a part of the daily struggle health workers navigate to provide locally adapted, patient-centred care in their communities.

The likelihood of HAT cases being detected early and managed effectively is largely dependent on the social proximity of diagnosis and care. Kamat and Nichter (1998) argue that pharmacies serve as primary care providers, where pharmacists position themselves as first-line carers with pharmaceutical expertise. Indeed in my sample, informal health providers such as traditional healers and 'private clinics' offer a much more socially proximate source of care to that of public health facilities. Global health technologies are never introduced as discrete objects into static, passive systems of care, but as ongoing projects of expertise and governance into a dynamic set of complex and fragile ecosystems. As the following and final empirical chapter demonstrates, the social lives they take on and live beyond this point is largely a matter of where they are positioned topologically, and how socially embedded they become, with profound implications for the sustainability of 'community-led' interventions.

CHAPTER SEVEN

Tsetse trails

Tracing social proximities of community-led vector control

This chapter presents my final empirical case study on the actors and networks involved in implementing two tsetse control interventions; the '3V network' of mobile spray teams across central Uganda, and the mass deployment of small insecticide impregnated nets called 'Tiny Targets' in the *T.b. gambiense* endemic West Nile region in North west Uganda. Qualitative data compiled from 25 in-depth interviews with entomologists, veterinarians, and community animal health workers, alongside responses from 9 community focus group discussions with smallholder subsistence farmers explored: knowledge and awareness of HAT and transmission; local history and perspectives of tsetse control amid other human and animal health priorities; collaboration between key stakeholders; and prospects of programme sustainability.

Drawing on the testimonies of programme managers, implementers, and farmers, these encounters reveal how discordant priorities between programmes and the communities whose behaviour they seek to change inhibits sustainability. They also show how the precarious One Health assemblage of veterinary, entomological, and public health staff breaks down, as decentralised and under-resourced district offices struggle to maintain operational cohesion amid competing health priorities . It reveals

the vulnerability of implementation staff facing uncertain funding futures, and their centrality as gatekeepers of local knowledge and trust in social networks.

This final chapter highlights the social proximity of interventions as key determinants of sustainability, and the empirical value in approaching global health interventions as evolving 'social experiments' (Bardosh, 2016). This problematises how technologically sophisticated but socially distant interventions shift the responsibility and costs of referral, treatment, or of preventative spraying, onto poor communities in post-conflict subsistence settings. Introducing interventions and expecting vulnerable communities to continue their implementation long after using their own resources is shown to be unsustainable, and questions the extent to which community 'engagement' or 'participation' is centred in programme designs.

Driving Data: intervention informed evidence on trial

We arrive at Kibuku secondary school in Pallisa district just before 8am. Schools are a logical location for holding mass spraying activities, being located more centrally to multiple communities and more accessible by road, having water points to constantly supply spray mixtures, and of course plenty of room to host hundreds of cattle descending on them at once. Many farmers have arrived before us, and Robert, one of the freshly graduated young vets from Makerere University recruited by the *Stamp Out Sleeping Sickness* programme, estimates 100 cattle are already roaming the school field as we pull in. A row of faces peer out from windows overlooking the courtyard, while those not in class gather curiously around the cattle crush now being hastily dismantled as we arrive on the scene.

“This is no good” the field team manager sighs, defeated. “We came here last week, and we showed them the dimensions, the height, everything!” He gesticulates with theatrical dismay. “We gave them the tools and the nails, everything to build the crush for us coming today. But they have not done it correctly. You see this” – he grabs a loose post standing at the exit of the crush, jostling it from side to side within a wide and shallow hole in the ground – “This is no good! The first cow will come and just push it over, the whole thing will collapse the moment they step in”. Part of the mobilisation plan, meant to sensitise communities and increase turn out on treatment days, had been to mobilise villages to build their own temporary crush. The lack of permanent crush structures across rural Uganda meant the responsibility of preparing the infrastructure needed for the arrival of treatment ‘brigades’ were to be placed on hosting parishes. Today, the standard of the crush had been such that treatment is postponed, and so everyone – including farmers, programme staff, school teachers, even pupils – were pitching in to rebuild the crush and make up for lost time.

The spraying methods being tested were optimizing the technique of selective application of insecticides known as RAP (Restricted Application Protocol) (Muhanguzi et al, 2014). As research had shown tsetse flies preferentially feed on the legs and belly of cattle, restricting treatment to these areas is considered more cost-effective (Torr et al, 2007). RAP was deployed by SOS as an evidence-based, efficient and cost-effective alternative to pour-on application, or all-over treatment of cattle (Welburn and Coleman in Zinsstag et al, 2015).

When I accompanied the programme in September 2014, nearly a decade on from the first intervention, SOS was conducting a feasibility study for a proposed third phase of mass treatment and insecticidal application. The style and approach of the campaign was militaristic in its organisation, rigid in its implementation and, owing to the justification it needed to demonstrate to investors, highly data-driven. I had been invited to participate in the

'treatment trials'; field experiments comparing the efficacy and throughput of two methods of mass spraying, either by guiding cattle through this temporary 'crush' structure to be sprayed and injected in batches, or by moving around and spraying individual animals in situ as they were tethered to a fixed point or held by their owners. Treatment in Kibuku eventually got underway around 10am, and soon hundreds of cattle were being herded into the 'boma', a wide opening at the entrance of the structure where farmers heaved, flogged, and pushed their apprehensive animals into the mouth of the crush.

"Why are they only spraying the legs!" one perturbed farmer berated Robert, as he collected the owner's registration ticket for his cattle. Robert recites the rationale behind the RAP method, and how it was proven to save the amount of spray being used by focussing application where tsetse preferentially land and feed. This did not appear to satisfy the farmer, whose primary concern was not for tsetse, but the ticks that visibly riddled his cattle. "But you are not even treating half of the cow, what is the use? The ticks are there [waving his hand over the spine], under the skin, on their back". This was not an isolated complaint, as many farmers throughout the trials in other areas expressed discontent, largely at being encouraged to continue the intervention themselves and buy the particularly expensive brand of insecticide (Vectocid) effective against both tsetse and ticks, but which was discernibly being used by SOS to exclusively target tsetse and trypanosomiasis, and not the tick-borne diseases which concerned farmers more.



Cattle queuing in the crush before receiving a trypanocidal injection and insecticidal spray treatment.

My role was to assist in the pilot trial of a mobile data collection application for collecting, monitoring, and analysing data from the treatment trial to inform the intervention's final design and create the evidence base for its investment case. At the exit of the crush, Robert's colleague Mohammed had been tasked with entering the number of treated cattle leaving the crush into the mobile app. Comparing the number of animals injected and sprayed in a given time, and the rate of attrition recorded between the point of entry and exit would allow programme managers to assess the most efficient method of conducting mass treatment in settings where turnout was high. Despite the best efforts of farmers and staff, many cattle – either bolting through the exit before being injected, or being small enough to squeeze through gaps in the crush – were evading treatment, and thus reducing coverage. But Mohammed continued to record each animal as treated. When I asked him why he decided not to record the animals that had gotten free into the 'not

treated' category provided in the electronic form, his response was unexpected.

"I know. I should record those ones as not treated, but the data is so important, as you know. If many cattle are getting away untreated then the method will look bad, or like we did not do our jobs well. The project might not get funded, we do not want to disappoint the donors. I do not want to disappoint [them]".

A representative from one of the DIBs partners who had travelled from London to co-direct the treatment trials had become a particularly conspicuous feature in the daily running of things. That morning, as a young and precariously employed group of vets climbed into their protective clothing and assembled their treatment kits, they declared that their presence and participation was to ensure that the programme was run like a well-oiled machine, frequently proclaiming the DIBs model would introduce the "rigour of the market" to public health projects, protecting them from the small "corruptions" that become cumulatively costly to large interventions. The focus on eradicating low-level corrupt practices, which allegedly marred previous phases of SOS, was evidently an issue of concern to investors. The concern was shared, and a collective focus on accountability was welcomed as a necessary and positive step toward building a strong investment case. However, some younger, local members of the team felt the accusatory tone of continual references to poor programme governance was not without demoralising side-effects.⁶ Mohammed's comment was sobering, and revealed how the tone of an intervention can affect the very real ways in which people practice data collection, and thus evidence production, particularly in high-pressure performance monitored settings. It was a rare

⁶ Some individuals communicated privately that the tone of communications from management demonstrated low levels of trust the programme held for local staff, often undermining the treatment teams' confidence and morale.

moment of clarity that rendered the socio-technical nature of these relationships starkly visible at the point of implementation, with profound implications for the evidence produced in these moments.

Re-examining SOS: reflections on an intervention

Performance measurement is assumed to change behaviour, and it is generally accepted that there will be some gaming in any system (Bevan & Hood, 2006). 'Gaming' holds negative connotations of deviancy, and while it may be a very deliberate choice, it may simply be a means for meeting the required targets in difficult circumstances (Lewis, 2017). Unsurprisingly then, performance measurement, as demonstrated by Mohammed's actions, can have unintended consequences that negatively influence performance. One study in India found that this kind of focus on numerical compliance and reaching targets may lead to Community Health Workers to developing 'gaming behaviours', whereby strategies included falsification of evidence in order to hit particular targets (Mishra, 2014. p.971). Health systems and staff working under the pressures of reporting positive results therefore can result in the production of poor quality data about what is happening in the field. The kind of systematic exclusion of experiential knowledge of patients and healthcare workers described in Mishra's study is a significant challenge to controlling NTDs like HAT, where funding is limited and staff like Mohammed and his colleagues face uncertain employment futures.

As things transpired, SOS was unsuccessful in its bid to secure funding under the Development Impact Bonds initiative. Compared with the smaller projects that attained funding under this model, some have speculated that the vast sum of money SOS had sought made the operationalisation of such a large and complex intervention seem logistically unfeasible. One former collaborator on the programme later offered some reflection in hindsight, on how the SOS strategy may have been less appropriate in a non-epidemic setting than the outbreak scenario it was initially designed for.

“SOS the way it was, in an unscaled format, cannot take away sleeping sickness [...] SOS was more or less a fire brigade approach, it isn’t one of the best approaches you would want if you had to systematically control the disease. Back then we were faced with an outbreak fuelled by livestock movement northwards [...] there was a need to do a fire brigade approach then, to stop the merger of the Gambiense and Rhodesiense”.

After it’s ‘brigades’ had momentarily ‘put the fire out’ as it were, the withdrawal of SOS had left the door open for tsetse to return. But the scaled up and sustained effort needed to maintain low prevalence would not be funded solely by their initial backers, DFID. After their application for the Development Impact Bond was unsuccessful, some local partners viewed its failure as a symptom of being a low political priority for Ugandan and foreign governments, and that a changing political landscape in the UK had scuppered the proposal’s chances.

“The country that you see is still on its knees in terms of development, and the national priorities, sleeping sickness doesn’t come very high. We had I think almost succeeded to get the outcome funders, but the main guarantor was DFID, and after the politics and voting [UK election in 2014] I think they said ‘I think our appetite to invest in Uganda is quite off for now’. So we made all this nice evidence, put a business case which was very attractive to the department in London. But every time it goes there of course the politicians don’t seem to be interested in Uganda for now, so we will hold our peace, maybe in future”

- Former SOS collaborator 1

At this time it is difficult to know precisely why the bid was unsuccessful, but one individual involved in the original collaboration later gave me their own take on the process and outcome of the SOS-DIB endeavour:

"It just died. I think looking back there were a few things about it that made it a bad proposal. SOS was looking to pour a huge amount of money into advanced technologies into a setting where, for example, people aren't accustomed to using smart phones etc. So it was already less sustainable than the other more modest interventions being proposed".

- Former SOS collaborator 2

Had it been successful, another reason SOS ver. 3.0 still might have struggled to sustain impact, was the lack of local capacity it had built in, and poor co-operation with in-country partners. On more than one occasion, members of staff from COCTU expressed disappointment at the way the new phase of SOS had been conducted, effectively cutting local partners out of the proposal altogether. One said of the failed DIB application that "I honestly could not tell you what went wrong, because they did not consult us in any way about it. We were never involved". Given that SOS had been lauded as the poster child of One Health, it is surprising that such a large intervention could be conceived or implemented without extensive consultation or involvement of Ugandan stakeholders. Michael and Madon (2017) critique the "now long established paradigm in conducting and delivering global health interventions", whereby decision making and power are leached away, or "hollowed out", from national governments to 'global epistemic communities' that frame problems, and generate the knowledge, solutions, and strategies to deal with them (2017: 2). While the One Health model may be built on a philosophy of intersectoral collaboration, questions over expertise, ownership, and power still hang over one health interventions while these epistemic communities continue to undercut local stakeholders and state actors.

The concerns expressed to the young vet Robert throughout the treatment trials in 2014 were by no means solely on the part of farmers alone. Nor were they simply in response to the nature of the SOS strategy, but part of a wider

constellation of economic and animal health priorities. The suitability and efficacy of RAP was a subject of particular contention among veterinary, entomological and farming communities.

“When SOS came in I was not supporting spraying the legs. For me I would prefer spraying the whole animal, it doesn’t cost much. If someone has brought his animals, if you say to the farmer ‘we are spraying legs only’, then the turn out will be low. There is no harm in spraying the whole animal because it gets rid of the ticks, it is like a one stop centre. I still advocate for spraying the whole animal as an entomologist, and as a commissioner in charge of tsetse control”.

- Government Entomologist, MAAIF

Although an advocate of RAP, the perception of efficacy to farmers was also a consideration Dr Muhanguzi later admitted as a potential short-coming of the SOS strategy:

“I tend to believe also that farmers are researchers in their own right, because they see things happening every day. Now it actually might not be very effective, because farmers don’t see tsetse flies. But they permanently see ticks, and the kind of arrangement we were using for tsetse control is [spraying] once every 28 days, and that is not necessarily very effective on ticks”.

Interested to know how these assumptions reflected livestock-keepers perceptions and priorities, I conducted a small sub-study to investigate how the small-hold subsistence farmers targeted by SOS perceived the need for such interventions amid a spectrum of local animal and human health priorities.

Farmer Focus Group Discussions

In April 2016 I conducted 9 Focus Group Discussions (FDGs) with small-hold subsistence farmers in Lira, Alebtong, and Kole, the most recently *T.b. rhodesiense* affected districts due to the unregulated northward trade of infected cattle (Selby et al., 2013; von Wissman et al., 2014). FDG sites were selected to sample a mixture of locations that had locally experienced confirmed cases of HAT and areas where no HAT cases had ever been reported. Focus group size ranged from of 6-9 individuals, comprising 53% male and 47% female participants on average (table 4). All identified themselves as being subsistence farmers, keeping a range of animals including pigs, sheep, goats, chickens, guinea fowl, and ducks. Every participant owned cattle, the median number of cattle owned was 2 (range 1–9). The vast majority kept local breeds (mostly zebu), citing their low sale price (to buy), draught power, and relative resistance to disease (including trypanosomiasis) compared to exotic foreign breeds.

Table 4: Focus group discussion participants

FDG Location	District	No. of participants	Male	Female
Ogur	Lira	9	3	6
Amach	Lira	9	4	5
Aroma	Lira	7	5	2
Barr	Lira	7	4	3
Alito	Lira	7	6	1
Apala	Alebtong	9	5	4
Aloi	Alebtong	8	4	4
Abongdero	Kole	8	3	5
Akeca	Kole	6	3	3
Total:		70	37 (53%)	33 (47%)

During focus groups, discussions explored the agency of farmers as part of the human-animal ecosystem of HAT, such as the prioritisation of diseases of concern farmers had for their animals, spraying and treatment practices of livestock, and how these are influenced by local knowledge and awareness of human and animal trypanosomiasis.

Local Health Priorities and Experiences of Healthcare Services

When asked the open-ended question of which local human health problems affected participants, of all those identified by participants, HAT was mentioned only once by one respondent. Other health priorities ranged from well-known and endemic diseases such as malaria, HIV, Hepatitis and TB, to worms and diarrhoea (see figure 18).

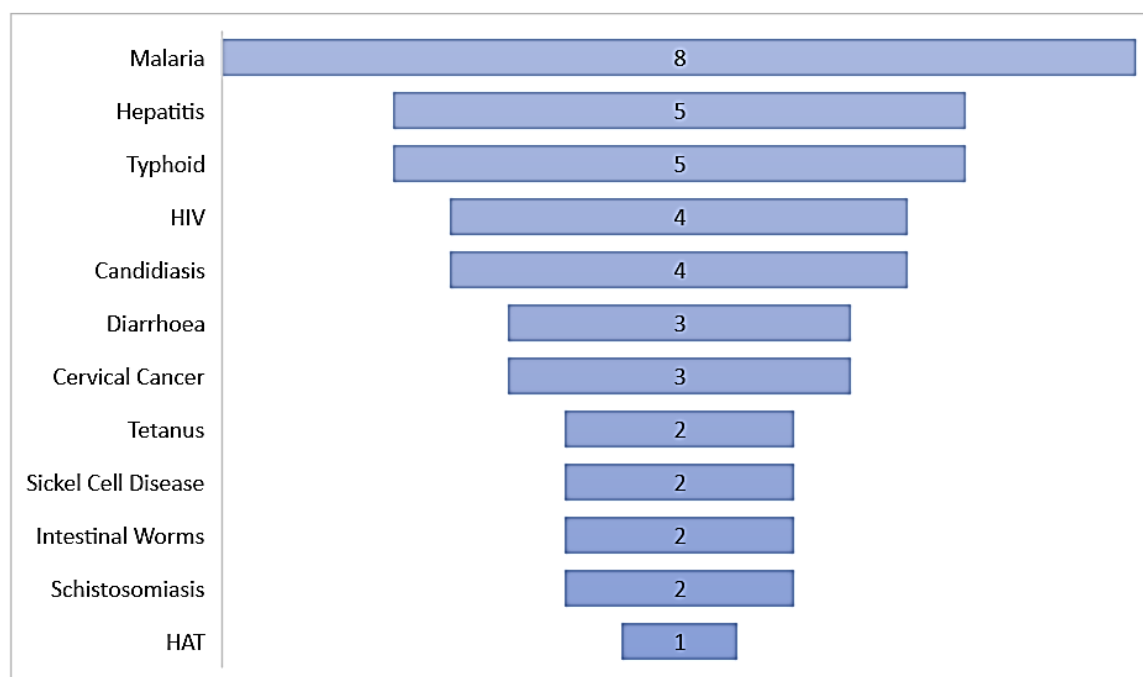


Figure 18: Local health problems identified by focus group participants

Satisfaction with local healthcare services were largely poor, with responses referring frequently to drug stock outs, poor relations with healthcare staff, and overstretched facilities.

“The clinical officer has written the forms, but there are no staff to record and give the drugs, that is because of the absence and late coming”

- Focus group participant, Amach, Lira district

“They will chase us away on Fridays, on weekends we go to health centres in town. When you come here there is no one to support you, you are supposed to wait until Monday. And disease does not wait for the weekend”.

- Focus group participant, Amach, Lira district

“Sometimes they come so late some arrive by 11am, like for instance my child and I came here at 6 in the morning. Unfortunately I had not got any person to attend to them. I brought my child here for help but the child passed away because those people refused to attend to him”

- Focus group participant, Apala, Alebtong district

“This health centre is providing services for five districts. That is Oyam, Pader, Gulu, Kole, and five Lira. All of them from here to access the services!”

- Focus group participant, Ogur, Lira district

While participants from 3 focus groups reported to be generally satisfied with their local healthcare services, all groups complained of regular drug stock outs and health worker absenteeism which contributed to a widespread preference for using private clinics.

“We go to the clinic because they offer services very fast compared to that of the health facility”.

- Focus group participant, Aloji, Alebtong district

“When we fall sick we go to the health centre, that is where we get the RDT diagnosis then we go to the clinic to buy the drugs”.

- Focus group participant, Aroma, Lira district

Knowledge and Awareness of HAT

HAT knowledge was generally low for all groups. While approximately half of the participants indicated an awareness of the disease, only a handful of respondents demonstrated an understanding of signs and symptoms in humans, or the zoonotic connection between AAT and HAT. Even among those aware of HAT where outbreaks had occurred in recent years, some cited the absence of screening as evidence that HAT was not a problem locally.

“Since the disease is not there, there is no testing. We have not thought about it” (Amach, Lira)

“Generally sleeping sickness at this place is not very common, I have witnessed them in Kaberamaido, however on this side I have not witnessed any yet”. (Aroma, Lira)

Awareness of HAT was most commonly linked to local cases that occurred in their own or neighbouring parishes (4 out of the 9 FDG locations had reported cases within the last 2 years).

“We know someone but not within this area, they are in a village called Luolango in Aiyra parish, in Barr sub-county” (Barr, Lira)

“I saw it from one person who was infected from it here and they passed away” (Aloi, Alebtong)

Tsetse flies were considered to be a problem locally for many respondents, mostly in relation to environmental features known to be natural habitats for tsetse.

“It’s a problem to us, when the animals always gather around the centre and the water catchment areas around there”. (Apala, Alebtong)

“Yes there are many, especially at the swamps where we get our drinking water from”. (Akeca, Kole)

“We get bitten, it brings about the swelling”. (Amach, Lira)

“Mostly when we go grazing it bites us”. (Barr, Lira)

One person mentioned the deployment of tsetse traps and their connection to HAT, while others claimed they had not been made aware of their purpose. Overall, few said they were aware of any tsetse control activities in their area.

“They have brought a lot of nets around here so it has reduced that illness around this place, but they are still present” (Apala, Alebtong)

“Yes they have brought some nets but we are not aware that’s what they were used for, they didn’t make people aware it was for that purpose” (Abongdero, Kole)

Animal Health Priorities and Awareness of AAT

On the topic of knowledge and awareness of Animal African Trypanosomiasis (AAT), responses suggested that farmers in areas previously affected by HAT outbreaks (Aloi, Abongdero, Amach, and Barr) were largely aware of AAT (commonly referred to as ‘nagana’), and attributed this knowledge to local cattle spraying interventions conducted by SOS and the 3V community spray network. However, nagana was only identified in three focus groups as a priority disease among their livestock, and were ranked lower in priority to other diseases such as Foot and Mouth Disease, Lumpy Skin Disease and East Coast Fever (theileriosis) and ‘tick’ diseases, which may include ECF (figure 19).

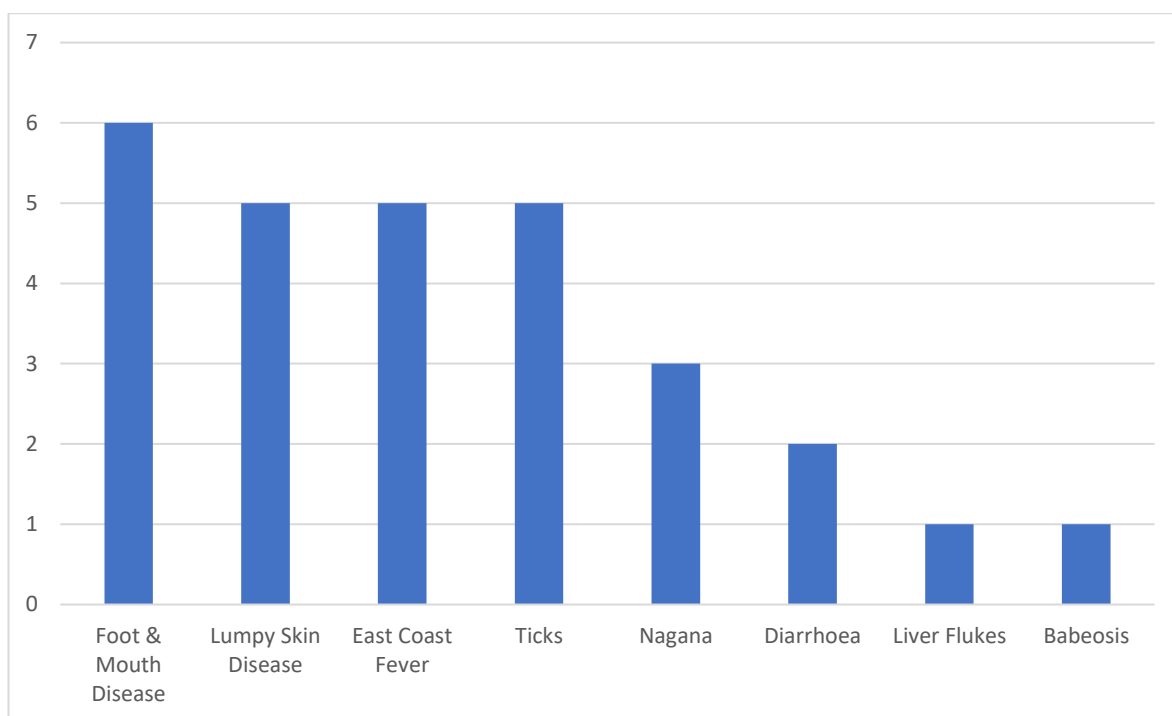


Figure 19: Local animal health concerns among small-hold farmers

“We also have a problem of ticks, you continuously treat the animals but when they have ticks they are continuously sick. I don’t know what the sickness is”. (Ogur, Lira)

“We call [nagana] the wasting disease which makes the animal thin” (Akeca, Kole)

Livestock Treatment and Spraying Practices

Only in those areas covered by 3V mobile community spray teams did participants claim to see an incentive in treating for trypanosomiasis and have their animals regularly or semi-regularly sprayed with pyrethroids effective against tsetse. In these cases however, it was only on the condition these would be effective also against ticks and preventing tick-borne diseases, which farmers were primarily concerned with. The vast majority of participants complained of a lack of access to professional veterinary services.

“We do not have any access to these services, and they are expensive. It’s very hard to access the vet personnel and they don’t easily turn up (FDG participant 1, Ogur, Lira)

“And they don’t even know us” (FDG participant 2, Ogur, Lira)

“Sometimes they could be available, however those who are professionally trained are not present so we usually use the [government volunteer] para-vets” (Abongdero, Kole)



Focus group facilitator Joel Ekol (left) records a lively discussion on local animal health priorities. Photo taken and published with participants’ consent.

As a result, most claimed to self-diagnose their animals and purchase drugs from informal vendors at livestock markets. Here they can purchase only as much as they can afford, taking advice from drug vendors as to dosage and administration, as few knew anything about the compounds used or how they should be administered. Those who demonstrated some knowledge of drug preparation, dosage, and administration reported to have learned this from 3V vets or their own spray workers who had treated their animals. No one

had their livestock treated prophylactically at the point of sale at livestock markets per the national policy.

“When the animal is ill we diagnose ourselves, get the medicine, then the person who knows how to inject will teach us how to inject the medication” (Amach, Lira)

“You go to the place where they sell the drugs, you describe the condition of the animal to the salesman, then he will tell you which drug to come and inject with” (Alito, Lira)

“If the government could look at the perspective that we are poor and do not have money, perhaps they should come in and help us to treat the animals” (Aloi, Alebtong)

At the start of the outbreak in this previously unaffected region, HAT cases were clustered around the local cattle market trading a high proportion of cattle from endemic *T. b. rhodesiense* areas (Selby et al. 2013). Cattle trading outside of markets is commonplace, and the activity of purchasing cattle from markets and other locations in high risk districts threatens to introduce greater numbers of cattle infected with *T. b. rhodesiense* into the northern districts where prevalence is currently low and HAT is absent (Miller, 2016). Government policy now requires that all cattle sold at official markets are to be treated with trypanocides at point of sale (Wendo, 2002), however, this has not been effective regarding unregulated trade outside the market system, thus unofficially traded animals are a greater risk factor for disease spread (Fèvre et al, 2006). Therefore, the treat-at-point of sale policy cannot be implemented into the complex cattle trade networks that operate outside of state control, thus failing to prevent the continuing spread of disease northward (von Wissmann et al, 2014).

The challenge of preventative innovations

Preventative innovations such as spraying cattle to prevent HAT have a particularly slow rate of adoption, as their advantage is not so readily

apparent at the time. The sought-after consequence is distant in time, and so the relative advantage of a preventative innovation is a delayed reward, compared to incremental innovations which provide a desired outcome in the near future (Rogers, 1995). Acaricides are a major private market in rural areas, and both pyrethroids (effective on both ticks and tsetse flies) and amidine-based products (effective on ticks but not tsetse) are sold widely. Preventing reinfection of cattle with *T. b. rhodesiense* after mass cattle treatments in Uganda requires the sustained monthly application of pyrethroid-based products, thus the availability of appropriate veterinary services, targeted education campaigns and access to acaricide at the village level is also necessary (Bardosh et al., 2013).

Treating an animal visibly affected by ticks with pyrethroids leads to the improvement of their condition and avoids the productive loss of their death. This occurs in a period of time short enough to associate the causal link between treatment and the rewards. Rewards of adopting preventive measures are not only delayed in time, but uncertain as to whether they actually will be needed. Furthermore, the unwanted event that is avoided by adopting a preventive innovation is difficult to perceive because it is essentially a 'non-event', the absence of something that otherwise might have happened (Rogers, 1995, p.217). It cannot be known at the time of paying for spraying, that not adopting this measure will have caused the undesired outcome (i.e. cattle becoming infected) (see figure 20).

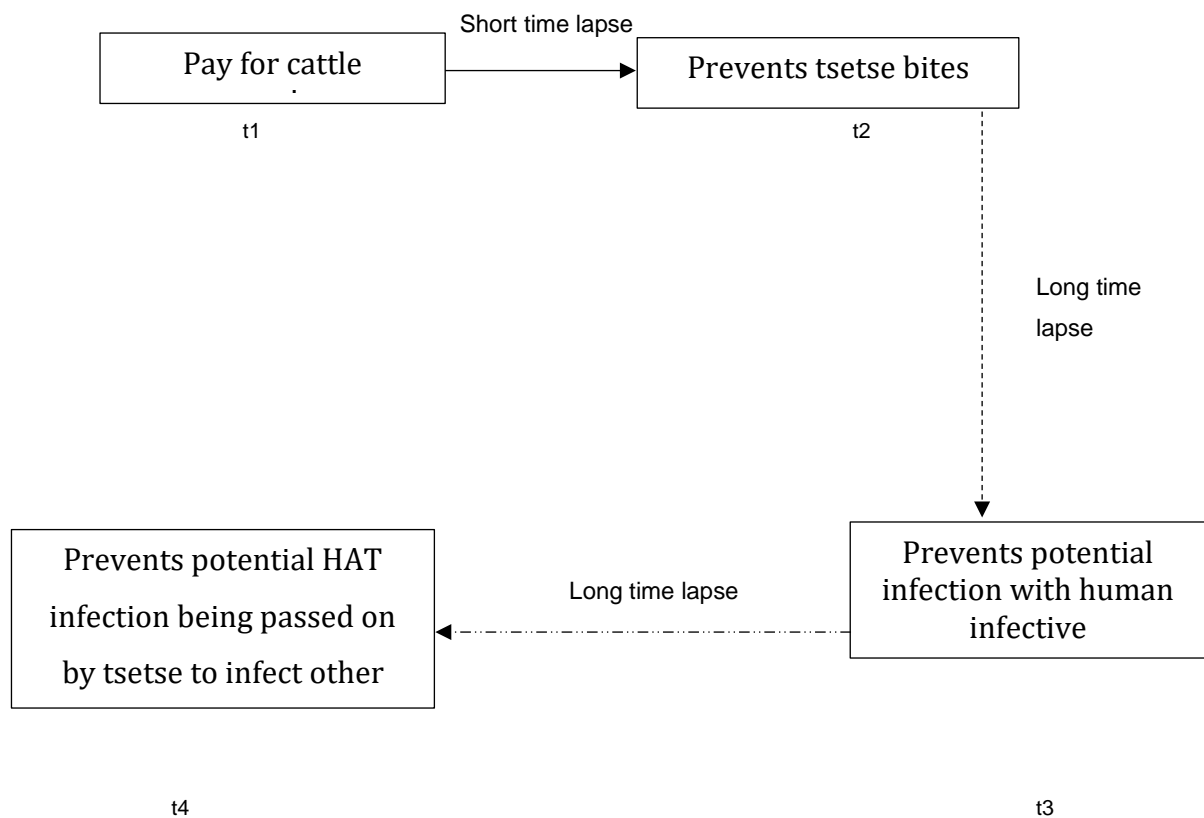


Figure 20: Preventative HAT control through trypanocidal cattle spraying.

(Adapted from Rogers ,1995).

Measurable indicators for evaluating behavioural change and impact is complex and difficult to define, and as such has been notably low on the agenda for research on Neglected Zoonoses. One dimension of the compatibility of an innovation is the degree to which it meets a felt need (Rogers, 1995: 228). This is largely the case for rhodesiense HAT, where farmers may not see the need to continually treat livestock for a disease that does not appear to affect their animals, or indeed themselves. “It is important that people make a link between the animal disease and the human disease, but it’s not an easy message” (Franck Boué, 2014. *ICONZ Magazine*, Issue 7: 4). Instead, the incremental benefits of spraying their cattle to prevent ticks for example, which transmit visible and devastating diseases such as East Coast Fever, have proven to be far more affective in promoting adoption. One study found that cooperation with National Malaria Service spray teams

in Guatemala might be improved if malaria workers would emphasize that “house spraying reduces the numbers of nuisance mosquitoes and other pest insects, rather than focusing solely on malaria prevention, which most informants believed was less important” (Klein et al., 1995). Likewise, framing cattle spraying as a method to prevent AAT, which causes sickness and production losses in livestock may also be more successful than framing it as preventing HAT. It is evident from these findings that the perceived need to invest in preventative treatment for HAT and nagana, both low priority diseases for farmers, is low and therefore difficult to sell.

Community spraying in Kaberamaido

Dr Odongo and I leave his shop at around 6am to meet one of his community sprayers, Julius, who had arranged to spray the cattle of several villages in his catchment in Kaberamaido. Julius has already begun work before we arrive, and I approach him spraying a young bull tethered to a small tree. The animal flinches and tugs its horns from their anchor as Julius pumps the insecticidal mist around it's ears. Eventually the sapling buckles and the bull brakes free. Julius puts in a half-hearted chase, but conserves his energies for the remaining herd. “*Ah! These young ones are stubborn*” he chuckles, sojourning over to greet us. By the end of the morning all the cattle that are sprayed are recorded on a data entry sheet, which Frederick collects at the end of each month from his sprayers. I ask him how many on average a district will spray in a month. “*It's not uncommon for 10,000 cattle to be sprayed across Kaberamaido in one month, but it varies throughout the year*”. Uptake is seasonal, and there are generally two peaks; one after harvest, as people have more money to invest in spraying their cattle then,

and one after rainy season, when there are more ticks and farmers are particularly motivated to spray their animals.

The Local Chairman tells me his community was glad of the spraying service 3V and the mobile sprayers were providing, but the only problem was affording the treatments since the cost had increased from 300 to 400 shillings that month. Despite this, many continued to turn out their cattle for regular spaying, citing the close relationship they had with their own local 'spray person'. "Julius is a member of our parish and community" [...] "we would trust him in all things." Others praised his professionalism and dedication to the role, saying "he is very good at what he does, and very punctual." While Julius' personal connections to his community made him a trustworthy provider of animal health services, his employment by Frederick also seemed to lend him professional legitimacy by association. "It is good that these activities are monitored by Dr Odongo, to ensure we are getting a good service," the LC confides quietly to me, "it is a good arrangement we have with them, they are not quacks".

The following morning Frederick and I ride to a location the other side of Lwala town, not far from the HAT treatment centre. We pull up to the side of the road, which is densely populated with *obelowinyo*⁷. Here we meet a man, dressed in a distinctive bright orange boiler suit, who beckons us to follow him into the thicket. I can make out a pair of large Ankole horns swaying in the bushes, and on approach come upon 4 cattle in a small clearing. One is tethered and being sprayed attentively by an elderly looking man. I turn to the orange suited gentleman and ask if he is the LC here – "Oh! No, I am the spray person" he replies. "I am Daniel". He tells me that the man spraying is actually a farmer, and that sometimes they show customers how to spray their own cattle when they prefer. The farmer is measured and meticulous in his technique. He has had the RAP taught to him by Daniel, and

⁷ The local Lango translation of 'Obelowinyo' is 'tick berry', the colloquial term for *lantana camara*, a bush habitat considered favourable for tsetse.

demonstrates the procedure in a textbook manner. He takes his time, making quiet and slow movements, ensuring that the animal is covered thoroughly on the belly, legs and behind the ears, before moving on to his other animals.



Community Animal Health Officer Daniel sprays a local zebu cow in his parish

Returning from Omot livestock market one morning, Frederick and his 3V colleague Ronald talk at length about the economic benefits of the initiative for community sprayers, but complain that many people decide to invest this by opening shops or other lines of business and give up spraying. Ronald remarks that there is a saying locally about money being where you eat it (referring to a hand-to-mouth existence), saying “these spray people we recruit can be short sighted, or not willing to do the fieldwork”.

Daniel used to be a soldier, and like many here grew up nearby through a tumultuous period during the LRA’s insurgency. He has been spraying for some 14 years since then, and working with Frederick for the last 7 since he recruited him 6 months after he arrived in Dokolo. Frederick tells me he is

one of his longest serving sprayers, and that it is uncommon for sprayers to work with him for so long, but that Daniel has built up a large network of his own. Under the 3V vet initiative, sprayers recruit and build their own network of farmers who they then train to spray, operating as independent ‘micro-entrepreneurs’ with support and training provided by their local 3V vet (Welburn and Coleman in Zinsstag et al., 2015). Farmers pay them for the acaricides which they can provide from Frederick and his colleagues’ stores in the town centres. Mobile sprayers have come to be known locally as ‘animal doctors’ to their communities in some areas, and are generally held in high regard. Their position is respected, and they are generally considered to be knowledgeable persons whom people seek all manner of advice from, from where in town is best to purchase certain goods, drugs, or equipment, to “where would be a good school to send their daughter”.

“The SOS is where you find that the science is put to use in a simple and easily acceptably way to the community. The technologies are the ones that the community really wanted, and it was solving other problems like tick borne disease, so you find that the farmers were very receptive to the technology being used. Compared to others, SOS was being a bit higher in the level of acceptability of other approaches because it trains the local persons, the Community Animal Health Workers, the farmers. The effect of the interventions can still be felt after some time, once the farmer learns to use the technologies they keep using them and it doesn’t need expert knowledge to keep doing it”

- 3V Veterinarian



Dr Ronald Were in his 3V Vet Drug Store in Kaberamaido District

While Frederick remains, as a veterinarian, the expert authority on animal health that locals may seek advice from regarding their animals' health and treatment, the community sprayers can also administer vaccines and other treatments. Frederick often advises his sprayers on the correct course of treatment to give an animal for them to communicate to their owners, so as to enhance their trust in the sprayers expertise and thus ensure their continued custom. In some cases, farmers may often trust the expertise of their own local 'animal doctor' over Frederick's – even where the advice they offer comes directly from Frederick. One young farmer shared with me he would not believe what Dr Odongo told him about the medicines he should buy for his animals, or trust the prices he quoted, but when "our own" Daniel advised him and quoted the same prices he would take him on his word, saying "I am more happy to phone home and request the money be transferred there and then when Daniel tells me". Above all else it seems, the

success or failure of these social interactions, and thus interventions, hinges on relationships of trust and respect.

As a point of contact between remote rural communities and the larger trading centres and towns, people like Daniel become central nodes in their communities' social networks, and the role comes with certain levels of prestige and responsibility. A sprayer becomes established as a respectable and trusted local group member, providing goods and services to his peers. This makes individuals like Daniel and Julius important nodes in a socially complex socio-economic system. Where customers, like many of those in my focus groups, cannot afford to follow 'proper' treatment recommendations, most farmers may care more for price over quality (Bardosh, 2016). Here, drug vendors, or in this instance, community sprayers/'animal doctors', invest in building reputations and relationships of trust with local customers (Kingsley, 2015) to build livelihoods.

After several months travelling with Frederick's 3V colleagues and mobile sprayers, I returned to where this journey began, to observe another relatively innocuous technology take on a life of its own through a socio-ecological network of tributaries, talk, and tsetse in Uganda's West Nile.

Targeting Tsetse



Emmanuel takes a log of our position on the GPS unit of the location of the target we have placed. This 'geo-tag' waypoint data will be used to update the programme map to show where we have placed the target. "It is good for monitoring, it means they can see when one of us is not laying enough traps, or putting them in the wrong places. We get feedback and that keeps us motivated to do the job well, or else you might get sent back to do it again!" One of several 'entomological assistants' recruited to the programme, Emmanuel is responsible for deploying targets across a relatively large area of west Arua district. The work is demanding, with each deployment taking many hours of travel and physical work along hundreds of the Nile's vast network of tributaries. His jovial disposition conceals an otherwise serious enthusiasm for his work, his investment in the project's success is quite personal. "My uncle died from sleeping sickness when I was quite young. It was terrible, many people were dying then. MSF came and they took over, it helped a lot. But this place has always suffered from tsetse, we must fight it at its root".

During the project's early days in Arua, local staff were incorporated into a dialogue early on.

“When they come in the region, they reactivated this coordination, they hosted us in Moyo and Arua as they were rolling, they are leaving a good legacy” - District Entomologist, Yumbe

However, despite investing in community sensitisation for the pilot study, initial deployments of the tiny targets did not go as smoothly as planned.

“Within 3 months we realised there were quite high losses and damages to targets, so basically they'd still be in the field, but the central metal pole would be gone. So then we obviously realised that the value is in the metal itself so it turned out about seven of the individual metal poles can be sold on the scrap metal market for the cost of about loaf of bread or bag of maize meal, but it was also useful for making arrows and fish hooks and all sorts of things. So this was all Vanja, the social scientist looked into all of this. So then we turned to a wooden design, replacing all the metal parts with wooden sticks”.

(Field manager, Dr Johan Esterhuizen)



Various iterations of the tiny target design as it evolved through field testing and pilot studies hang in the office of the LSTM field station in Arua.

For example, during deployment they found that community members perceived baits very differently. Villagers who had never seen traps before expressed fear, anxiety and panic when they first encountered them. This was related to associations with witchcraft and “ghosts from the river” which are traditionally linked with physical or mental illness, death and misfortune (Kovacic et al, 2013).

“Initially we were just walking along rivers to see what the habitat looks like and if we could actually deploy these things right next to water, and quite often would come out of a water bed or out of a river valley and people would just scream and panic, especially women working in the field, they would just throw down their tools and run screaming back to the village. One guy just completely took off his gumboots and started running, you know, just so he could run faster! Eventually Vanja found out, because I was there maybe, big bearded guy with a hat and panga,

and the ghosts come out of rivers, the water spirits you know, and you see this guy! [himself]"

- Dr Johan Esterhuizen, Field site manager

A study on sustainable vector control and management of Chagas disease in Argentina found that sustained community participation grew out of establishing a trusted relationship with the affected communities and the local schools, particularly through close cooperation with locally nominated leaders (Gürtler et al., 2007).

Elsewhere, an study on mosquito control in Guatemala noted the participation of women in malaria control, emphasising a need to understand “how women influence their environment, particularly the family habits, hygiene, and the interaction as a family unit with local health and education systems” (Klein et al., 1995: 111). To this end, making the Tiny Targets as socially proximate as possible by engaging naturally organised groups of women – who are predominantly responsible for water management at the household level in many countries in Africa (Sorenson et al, 2011; Stevenson et al, 2012; Baguma et al, 2013) and thus are more exposed to HAT – likely enhanced the acceptability and sustainability of the programme overall (Gunn et al., 2017).

Technology as advocacy: awareness of HAT from tiny targets deployment among RDT-positive HAT suspects

During my interviews with rapid diagnostic test (RDT) positive HAT suspects in the West Nile, awareness of HAT was very high. Some cited active screening in the past and public health awareness activities as the source of this knowledge, however a prevailing source of information appeared to be local tsetse control activities, with frequent references to the tiny targets deployments. Some claimed programme staff members had informed them

of their purpose, however most appear to have discussed the tiny targets with other members of the public, and learned about their purpose through these informal interactions. The knowledge they received this way heightened awareness of HAT locally.

“I saw them [targets]. There is something in the valley there I am told that thing when it bites you, you get this sleeping sickness. And so these targets I’m seeing in the valley, I heard it from public. I keep asking “why are these things hung here”, they say “these things are to prevent tsetse flies”. (RDT+ suspect 17, Kerwa, Yumbe)

“I have seen it. I heard they are placed there to prevent tsetse fly from increasing. I asked people whom I know why that thing is hung there, and they tell me it is there to catch tsetse flies” (RDT + suspect 16, Drajini, Yumbe)

“We are told that it is hung there to prevent sleeping sickness. It works because in Kochi there were so many tsetse flies when you go to wash clothes by the river, you would be bitten by many of them. But since last year when these blue targets have been hung there, when you go and wash clothes you don’t experience tsetse fly bites, so it has controlled the number of tsetse flies in the area”. (RDT+ suspect 14, Kochi, Yumbe)

“I knew about sleeping sickness the first time when the government started deploying some things at the riverside that it is for preventing tsetse flies. That is where I heard about HAT”. (RDT+ suspect 19, Koboko)

“I have fear in my hut, I have seen tsetse fly nets being hung up. The person who deploys these things tells us we should not remove them because it prevents the tsetse flies in that area. They work, this time the tsetse flies are not so many” (RDT+ suspect 19, Ayipi, Maracha)

These anecdotes show that targets have stimulated HAT awareness among communities through these unsolicited conversations. In doing so they reveal how information travels through informal social networks, and how socially proximate technologies can be used effectively as tools of advocacy for tsetse and HAT control. A study on Indoor Residual Spraying teams for malaria control found that, although malaria knowledge was poor, knowing the benefit of indoor residual spraying was associated with a reduction of mosquitoes and other pests such as rats and cockroaches in their

homesteads made IRS more acceptable and compelling (Klein et al., 1995). In the West Nile, I found that the Tiny Targets became a compelling technology, particularly among women who spent much of their time close to the river banks and were frequently bitten and bothered by tsetse. This tangible benefit opened a space for conversations about tsetse's relationship with HAT which acted to heighten awareness about HAT and improve knowledge about its transmission.

The dissection

As Emmanuel and I pull into the courtyard of the field station we meet Edward, one of the project's two lab technicians, who has also just arrived back from his fly collection in Maracha district. Having visited several monitoring traps, he has brought back around a dozen flies. Not many these days, compared to the veritable harvest they would have been collecting a few years ago at the beginning of the project. "Ah, you are back early! You are just in time" he says, gesturing toward the lab. "I am about to begin the fly dissections".

There are few trained technicians that can dissect tsetse as skilfully as Edward and his colleague Victor. The lead entomologist and field site manager, Dr Johan Esterhuizen, trained them both himself in the early days of the project. Previously they had worked in local hospital labs where they had been more familiar using microscopes to search for helminths or malaria, not so much for dissecting tsetse. Soon they were processing hundreds of flies a week, all the time creating ginormous archives of data on trypanosome prevalence in local tsetse populations. The piles of record books stacked on the lab workbench were satisfying to me in their tactility. Having become accustomed to scrolling through reams of digitised spreadsheet data made the voluminous tomes of handwritten records markedly more enthralling, like

antique artefacts of entomological history. I cannot say that this sentimental appreciation is likely shared by any of the Ugandan entomologists who have to compile and search these records on a day-to-day basis. Each book is filled row on row with data. Species, sex, age, blood meal status, presence and location of trypanosomes, and each row book-ended with the corresponding fly itself, adhered to the page with a square of Sellotape. I'm surprised to learn from Johan that this wealth of information is not fed back into programme's operational strategy, given the number of District Entomologists and District Veterinary Officers I had interviewed who lamented not having detailed data on infection rate among local tsetse populations.

Edward loads his first fly under the microscope and makes himself comfortable, signalling me to pull up the chair next to him. He raises his hand abruptly and hushes me to attention. "Watch. I am going to first remove the head" he whispers, adjusting his fine tweezers delicately like a seamstress. His steady hand makes the smallest of movements carefully and deliberately. "Come look now, I have already removed the mouth part". He rolls his chair back and invites me to peer down the scope. Indeed, the head is quite separate from the abdomen, and yet looks otherwise untouched, as though it were carefully picked apart at the seam and unstitched. He resumes the delicate procedure, explaining at each stage of dismemberment and inspection that seeing trypanosomes in different parts of the body indicates the stage of infection in the fly, as the parasite moves throughout the body in its various forms.



Dissected tsetse fly and its constituent parts assembled on separate slides for inspection by microscopy.

In tsetse, the parasite permeates and inhabits different spaces in the fly's body, something that entomologists can observe to deduce the trypanosome's strain and infection status (Bouyer et al.). During dissections, I observed how Edward and his colleague carefully dismembered flies under the microscope, using fine tipped tweezers to pluck the heads from the thorax, before gently teasing apart the key components of the tsetse anatomy; the mouth part, the salivary glands, the midgut and ovaries. Only once each part of the body was systematically disassembled in a sequential process and separately neatly on one slide would the parasite be rendered visible to the investigator and located spatially. The trypanosome's position, whether in the salivary glands or the midgut, point to a 'diagnosis' in the fly, which is then translated into a number and entered into a data sheet, recording the sub-species of tsetse, the sex, age (determined by examination of the ovaries), and the presence and position of trypanosomes found.



Left: Lab technician Edward performs dissections on tsetse flies in the Tiny Target's field station laboratory, Arua. Right: Opening the abdomen of the tsetse fly (Photo: W. Yoni & C. Bila, in Bouyer et al.)

We do not find any parasites in the fly, nor any of the others in today's catch. Edward tells me that there are very few infected tsetse collected these days, and as it turned out it would be two weeks before they found another.

Contesting control: discordant narratives on the role of evidence for elimination

Was the dramatic reduction of tsetse that Edward and many of my serological suspects observed a direct result of the tiny targets? The data emerging from the lab in Arua seemed to support the association between

the deployment of impregnated targets in North West Uganda and the significant reduction in the tsetse population by over 90%. With fewer flies the probability of infected vectors circulating also reduces dramatically, and it has been calculated that a drop of 72% in the tsetse population is sufficient to break transmission (Tirados et al, 2015). It is understandable then, that many of the local entomologists I interviewed expressed deep concern at the prospect of losing the rare and highly specialist skills of people like Edward, and the capacity to conduct laboratory analyses on tsetse once LSTM completes its handover to COCTU and withdraws.

“I’m not so sure if LSTM will leave the lab for us, if they do we will be able to analyse the flies, otherwise the district doesn’t have a lab. It is important, those analyses will help us to eliminate the existence of the parasite in the environment in the tsetse flies, that one can only be done in the laboratory. So if we realise one incidence of trypanosomes in a specific location or village, we can shift our efforts and put more activity there, targets in that place to wipe out the existence of the trypanosomes [...] We could do that with the lab, so we can keep on monitoring trypanosome presence in tsetse flies. If we register zero, zero, zero, then it would be good prevalence”.

- District Entomologist, Arua

“When LSTM leave the problem in our department is one of the equipment, we don’t have the equipment to use for dissecting. I think also the personnel, in most of the districts - if not all - entomology is a one-man section. Even if we came to some arrangement before LSTM left that we could continue using their lab, we would not have the staff”.

- District Entomologist, Moyo

The concerns raised by local government entomological staff that poor lab capacity prevented them from establishing where tsetse populations were infected seems pertinent to a situation where numbers are high. However in

settings where tsetse numbers are very low, the practical utility of this information becomes limited. The issue then becomes one of discordant conceptions of what kind of intervention is being conducted, and to what ends. Tiny Targets managerial staff dampened the importance of such information beyond the purpose of research, and appealed to a pragmatic framing of the intervention.

“It’s probably not really necessary, and in fact we get quite a low infection rate and most of that is in the animal tryps, so that is really, really low. So we just do it because we’re a research institution and have the facilities and the capability of these guys to do it [...] But it’s not essential for the control” (Dr Johan Esterhuizen, Field Manager)

“Entomologists always catch flies and dissect them, and why are we doing that? We do it for research purposes. But we do not need to do it for this. We did it for the last project because we wanted to look at impact, you expect numbers to go down, so it’s a research exercise. We’ve got infection rates of about 1 in 10,000, so when they say ‘we want to measure infection rates’, and you’re catching less than a fly per day... So they have asked us that, and we are happy to train them to do that, but do we think it should be part of monitoring? It should not”. (Prof Steve Torr, Programme Director)

As one programme staff member remarked, a mismatch in how Tiny Targets is perceived within the broader landscape of interventions and how its objectives are framed need to be made clear.

“It’s sort of managing the expectations, this is not a research project, we’re moving towards a routine intervention. And lots of the things that entomologists like to do are not relevant, and expensive! So we have to be frank [...] Does entomology need to have an entomology lab? I would

say they do not need that capacity, and that would divert them from the things they do need to be investing in". (Programme staff member).

Indeed, results elsewhere appear to demonstrate that target deployment could be sufficient in achieving a significant impact on HAT cases. In the focus of Boffa in Guinea, a pilot elimination programme combining medical screening and tiny targets was launched in 2012. During the Ebola outbreak, HAT active screening activities were suspended, and passive surveillance was also significantly diminished. However, tsetse control using the insecticide impregnated targets could be maintained. The disruption of screening activities over a two year period led to a dramatic increase of HAT prevalence where vector control was not implemented, whereas control levels were maintained in areas covered with impregnated targets, with no cases found in 2016 (0/799) (Kagabadouno et al, 2018). Ebola in Boffa revealed the fragility of the screen and treat strategy, as rapid outbreaks of HAT occurred once operations were disrupted. It also added to evidence that augmenting medical activities with vector control using impregnated targets can reduce human-tsetse contacts, and even implemented alone, provide an effective level of protection against infection (Mahamat et al., 2017).

It was clear there were differences in how the tiny targets were conceptualised between groups. To local entomologists, the programme could, and ought to be part of an integrated control effort that incorporates data on infection rates in flies to help target medical screening in human populations. However, managerial staff were keen to stress that Tiny Targets is exclusively a vector control intervention, "we are in fact intentionally trying not to say that our intervention is a human health intervention, that's all its about, the targets, that's all that they do" (programme director, Prof Steve Torr). While this framing makes a pragmatic argument for limiting the scope of what evidence from the programme could be mobilised for, it fails to address the loss of empowerment local entomologists fear when LSTM pull out of the West Nile.

Trypanosomiasis and tsetse control in Uganda has often been portrayed as a success story of One Health (Bardosh, 2016), but the Tiny Targets' singular approach does not chime well with the holistic paradigm. "I don't think anyone thinks of it as a one health intervention that we are doing [...] In the previous project we knew we were never going to be able to monitor impact on human trypanosomes" (programme staff member). In contrast, it was noted by interviewees that the SOS intervention, despite clearly targeting the vector, had been 'dead against any entomological monitoring' of its impact on local tsetse numbers. In the same way Tiny Targets being framed as a vector control intervention centred tsetse numbers as their outcome variable, the framing of SOS as a public health intervention prioritised tracking the prevalence of *T. brucei* s.l. and human infective *T. b. rhodesiense* in the livestock reservoir. This could be viewed as a political decision, given funding apparatuses may favour explicitly human health interventions. As one interviewee pointed out, "[another] element is about a quite contentious area, it's about ownership [...] I would think quite a lot of it, there's a lot of compelling intellectual rhetoric which attracts a lot of funding, there are big grants".

Discussion

Sustaining interventions through social proximity and enterprise

The issue of health program sustainability has received attention over recent decades as a central topic in both academic and policy literature. The concept of sustainability broadly refers to the acceptance and continued use of program components and activities beyond the initial intervention or funding period, usually toward the achievement of desirable or intended health outcomes (Shediac-Rizkallah and Bone, 1998; Scheirer and Dearing, 2011). However, the issue of what is to be sustained precisely has been a

recurrent and contentious theme (Madon et al, 2018). Within a medical or health systems framework, emphasis is placed on tracking the long-term impacts on health, and their 'institutionalisation' within the pre-existing structures and processes (Pluye et al., 2004; Shigayeva and Coker, 2015 in Madon et al, 2018).

Tracking the effects of 'One Health' interventions are inherently tricky however, given that the trajectory of outcomes being measured depart from multiple species, under the remit of separate disciplines and programmes, creating evidence toward diverging interests and ends. The political landscapes that forge these divisions, through networks of neoliberal funding structures and pedagogical siloes, ultimately splinter the HAT control assemblage in ways that prevent the One Health philosophy from being realised in practice. They also tend to re-inscribe and reproduce the steep power gradients embedded in these structures (Sariola et al., 2017), inhibiting intersectional collaboration between stakeholders in the Global North and South. Ideological shifts from one techno-fix solution to another over the past century have been facilitated by framing HAT as a disease of singular origin; of tsetse flies that must be eradicated through scorched earth policies; of cattle that must be treated en masse in militarised campaigns; or of poor people, who must present themselves at government health centres and navigate convoluted diagnostic pathways at their own cost.

This chapter has shown how relatively modest interventions differ in their approach to conventional interventions by promoting long-term, stable growth and impact through local partnerships and capacity building. Conventional public interventions (particularly where the overall objective is elimination) tend to prioritise creating high visibility success stories with demonstrable 'bang for your buck' for donors. Yet tiny insecticide treated flags and mobile sprayers, while arguably less glamorous, have achieved results that are far-reaching and sustainable over much longer periods of time.

“Something like what the 3V vets are doing is the only way. It might not get as high a return immediately, but over a longer period of time the small gains you get are long-term and sustainable, and you can build on that. If you think for example, you are at ‘A’ and you want to get to ‘B’, using something like the SOS you might get there quickly and see results, but it won’t last very long and the impact will drop off. But with something smaller and more measured like [3V], you can move a small way towards B, but with less risk and more chance of sustaining, and it gives time for things like government, local government, staff and communities etc. to adjust and adopt it properly, so then you can build on that. It’s slower, but in the long term achieves more. There was very little sustainability built into the SOS DIB from that perspective, nothing at the local level”.

- Former SOS partner

Reviews of past control programmes identified the inability to transfer responsibility for AAT control to cattle-owners once interventions had ceased as a key failing (Meyer et al. 2016). While the establishment of a network of community based spray teams provides a model of preventing parasite reinfection, ensuring reliable and affordable access to drugs is key to maintaining a commercially sustainable market (Zinsstag et al, 2015). Shifting the costs of maintaining mass treatment and spraying interventions onto poor populations in a post-war subsistence economy is ethically and practically problematic (Bardosh, 2016a). This ‘social entrepreneurship’ approach forms part of a broader move toward putting HAT control in the hands of ‘market forces’ to encourage sustainability from the ‘bottom up’. But in a socio-political landscape where disease control is felt to be the remit of government responsibility, placing the ‘public good’ of HAT control onto the shoulders of extremely poor individuals has had an understandably underwhelming reception among rural communities in central Uganda.

My research in the West Nile found that community knowledge about HAT, and the link between tsetse and the disease is very high. This is in part due

to the organised sensitisation activities the Tiny Targets programme initiated before and during the initial months of deployment. However, another interesting discovery was that much of this knowledge circulating was communicated between members of the public via social networks, particularly between women who spent more time working in the vicinity of targets along river banks. It is interesting to note that, while the tiny targets, framed exclusively as a vector control intervention, achieved more sensitisation for local HAT awareness and vigilance among local populations, than the scaled introduction of HAT rapid diagnostic tests in primary healthcare facilities described in the first empirical chapter. The visibility of targets along rivers are almost certainly a significant element of this outcome, visually prompting conversations among local social networks about tsetse and the purpose of local control activities for HAT prevention. The RDT on the other hand was a largely invisible intervention, that achieved very little in the way of promoting HAT awareness among local populations.

Across both tsetse control interventions, compared with large scale, vertical interventions of the past (such as aerial spraying, sterile insect technology, and SOS), more modest but socially embedded technologies such as Tiny Targets and 3V Village Spray Teams are more sustainable owing to their social proximity and community buy-in. A study on Inside Residual Spraying (IRS) in a rural area so Mozambique found that acquaintance with the sprayers was a significant factor associated with adherence, being “members of the communities, resulting in an unclear line between the intervention providers and the receiving communities, and this has acted in favour of rapport building between the two parties” (Munguambe et al., 2011: 11). Meanwhile, disagreement over procedures were a key driver of non-adherence (*ibid*). Similarly, in my study disagreement over the efficacy of RAP in being able to target both ticks and tsetse was a point of contention between farmers and the professional veterinary community (and also contested within the veterinary community), while a key driver of pyrethroids

spraying adherence among farmers in my study was also familiarity with their local sprayers, or 'animal doctors' whom they trusted.

Contesting tsetse control through the One Health lens

Additionally, my findings corroborate those of previous chapters, and show that despite successful national and international commitments to One Health partnerships, collaboration between veterinary, entomological, and public health staff at the district level is limited. The devolution of governance and service delivery in the 1990s had far reaching consequences across all sectors, and many officials argued that decentralisation has degraded rural veterinary and tsetse control capacity (Smith, Taylor, and Kingsley, 2014). District officers complained frequently that decentralised and under-resourced district offices often struggle to maintain operational cohesion, as a precarious assemblage of entomologists, veterinarians, and community animal health workers endeavour to align vertical programmes with fragile and fragmented control networks. Training, since it is presumed to convey information and skills that will 'empower' people to achieve goals for themselves and continue programmes after vertical management structures withdraw, is seen as central to the tenet of sustainability (Swidler and Watkins, 2009). Indeed, local entomologists and community sprayers I spoke with felt empowered by vertical projects and the resources and training they provided. However, these members of the community often went overlooked as key stakeholders or important sources of knowledge by national control programmes, as demonstrated by the Tiny Targets' controversial withdrawal of lab capacity. It was evident from my encounters and conversations with community sprayers and farmers they served that these are key nodes in local HAT control networks whose knowledge and position in social networks ought to be utilised and valued by local government and the 3V intervention. Based on these findings, and in line with an eco-social approach to developing 'culturally acceptable' and 'culturally compelling' health interventions (Panter-Brick et al., 2006), I suggest that the definition of

'community' participation should expand to engaging implementation staff, whose agency is often overlooked as gatekeepers of local knowledge and trust.

Conclusion

Vulnerability and risk to HAT is dynamic and complex, and the people who disproportionately suffer the impacts of the disease are rarely involved in the design of control programmes (Holt et al. 2016). Many human and animal health interventions have assumed to be implemented onto passive populations and static networks. This is typified by an array of elegant mathematical modelling studies conducted to evaluate the impact and cost effectiveness of various interventions (Steinmann et al., 2017; Rock et al., 2018). But as this chapter has shown, people are active participants in transforming their social landscapes (Perdue, 1994). Preventative innovations that target the tsetse vector must pay greater attention to the interactions of people (including social and cultural factors), patches (changing habitats and ecologies), and parasites (including spatial patterns of disease transmission) (Scoones et al., 2017: 643). Populations in these 'patches' affected by HAT (*ibid*), have been subject to numerous displacements and inward migration, doubling the parasite's ecological range in some areas (Selby 2013; Bardosh, 2016), from decades of military conflict in the northern and eastern regions, to the recent influx of refugees fleeing conflict in Gambiense HAT endemic South Sudan threatening elimination efforts in the West Nile (Picado and Ndung'u, 2017).

By taking into consideration how people construct livelihoods in these landscapes and interact with tsetse and trypanosomiasis, adaptive and locally specific interventions that capture these complex socio-ecological dynamics can be devised (Booth and Clements, 2018; Michael and Madon, 2017). A truly integrative One Health approach relies on this interdisciplinarity

being replicated on the ground however, requiring intersectoral efforts to dismantle the structural barriers preventing this implementation at the district level. Responses to HAT must therefore take these entangled socio-ecologies into account, and address the social and political drivers of disease as well as the ecological.

This chapter illustrates some of the key tenets of this thesis; that technologies do not exist and operate in a vacuum, nor do they work on a passive static ecosystem. They are part of a dynamic HAT assemblage, and rely on the interaction and agency of the population they are intervening on to adopt and continue to use them. They can be used as tools for advocacy, as highly visible and socially embedded interventions promote awareness and understandings of HAT among local populations. Conversely, relatively high tech but aloof interventions which shift responsibility of referral, treatment, or of preventative spraying, onto poor communities in post-conflict subsistence societies is evidently problematic. Introducing technologies and expecting vulnerable communities to continue their implementation long after with their own resources does little to promote trust or incentive, and is potentially damaging to communities and health systems. Thus, while modest and incremental, locally adapted interventions which are more socially proximate and integrated with 'local ecologies' achieve greater sustainability than some of their more elaborate predecessors, as they take on, and persist through, social lives of their own.

CHAPTER EIGHT

Conclusion

*“When we try to pick out anything by itself,
we find it hitched to everything else in the Universe.”*

- John Muir, 1910

Boarding the last ferry across Lake Kyoga and nearing the end of my time in Uganda, I met a young man named Richard, a lab technician in a level three facility in Lira district. We passed an otherwise uncomfortable journey chugging across the water with conversation, in which he corroborated many of the problems he and his counterparts in other districts faced. He expressed interest in my study of HAT control, making regular references to the ‘disastrous’ culture of point of care testing and its effects on diagnosing other febrile illnesses. I shared my own observations from my research, and reflected on what I had learned throughout my fieldwork about sleeping sickness, the disease. Some from in-depth, probing interviews with programme managers and government ministers, or eloquent presentations by eminent researchers at meetings or conferences. But so much I had come to know of sleeping sickness was not just as discrete pathological events and the epidemiological patterns they form, but as a construct; systems borne out of decades-long demographic upheaval, conflict, and decentralisation, embedded through socio-technical performances and relationships between donors, governments, health systems and people. These entanglements had been revealed, in glimpses, by patients and health workers, or community

sprayers and farmers, often in snatched conversations in fleeting encounters with people like Richard.

“For a long time, sleeping sickness had been a many number of things in my mind,” I wrote in my field diary during my final days in Arua. “A parasite, a fly, a symptom, a test, a number on a sheet”. These narratives had conjured a new version of HAT altogether, one outside conventional definitions of ‘health infrastructures’, and generally undetected by conventional epidemiological method, uncovering a hidden ‘ontological choreography’ of biomedical intervention (Cussins, 1998). As much a flagellate on a blood smear, or burning ‘fire in the blood’, HAT is a memory or a fear, a calculation of risks. It is known of, and yet a constellation of ‘fundamental unknowns’ (Checchi et al, 2008).

It had been my hope that by the end of my time in Uganda I might have begun to untangle these multiple realities of HAT, and how these come to shape and are shaped by that most unquantifiable of parameters in epidemiological enquiry; of human behaviour. It wouldn’t be until much later that I reached the crux of this realisation, that the Trypanosomiasis I sought to trace cannot be situated in fixed terms or specific ‘moments’ or ‘hotspots’, thus cannot be extricated from their environments or life histories, nor those of their hosts and victims. The version of HAT often problematized in board rooms and scientific conferences far away is a distilled caricature of properties demonstrated through risk maps and eloquent mathematical models. These may be good enough in their approximations of an epidemiological picture, that in an emergency outbreak setting may allow resources to be allocated and directed in effective strategies. In an elimination setting however, the importance of these models and the underlying data that underpins their accuracy becomes crucial, and much more sensitive to the effects of unquantifiable or less predictable parameters, otherwise too complex to capture or predict in reductive terms. The ‘wrong but useful’ axiom may help to negotiate uncertainties in disease modelling,

but the utility of models in the face of uncertainty is a function of ‘interpretive flexibility’ (Christley et al., 2013: 12).

Contextual explanations of technology offer a great deal to the study of their impact on society (Perdue, 1994). The case studies presented here provide contextual analysis of contemporary innovations being implemented for HAT in the landscape of elimination. I have constructed this thesis as a biographical narrative, using technologies as departure points from which to explore the socio-technical ecology of sleeping sickness, tracing its permutations throughout the One Health assemblages of surveillance, management, and prevention. In doing so I have been able to draw out recurrent themes that trouble the techno-centric narratives that define contemporary global health interventions (Smith, 2011; Montgomery et al., 2017). Much of this thesis explores some of the professional and humanitarian pressures placed on health workers at the most crucial point of surveillance, how these tensions play out during point of care interactions, and ultimately how these further shape the likelihood of patients completing diagnostic and treatment referral. By seeking out the ‘voices of the field’ (Okwaro et al., 2015) of health workers’ experiences across both *T.b. gambiense* and *T.b. rhodesiense* affected sites, I have presented some examples of the “endless tinkering of real people in specific circumstances” to establish a system that works within their own context (Cartwright and Hardy, 2012 in Biehl and Petryna, 2013: 9).

The fourth and sixth chapters take a patient-centred approach and show how events leading up to the point where the infected body is identified, translated, and rendered legible to biomedical intervention ultimately govern the likelihood of diagnosis and referral success. Tracing Trypanosomiasis to these points of origin ‘at the end of the track’ reveal the myriad pathways that meander, stall, circumnavigate, and (sometimes) lead to diagnosis. The scale of such journeys that fail to reach this destination remains a troubling ‘fundamental unknown’ (Checchi, 2008), with under-detection posing one of

the greatest challenges to HAT control and elimination. In heeding those who undertake these journeys, the pathways people navigate to access these technologies of promise, and where they fail to intersect with control programme infrastructures can be exposed.

Here we also met some of those tasked with making this new enhanced passive surveillance strategy work, as district supervisors devise innovative compromises to retain suspects in referral. What the testimonies of practitioners and patients reveal is how the elimination programme's imagined treatment landscape looks compared to that encountered by actual treatment seeking patients. Here, symptomatic individuals rarely seek diagnosis from government health facilities where RDTs are placed, or even seek diagnosis at all, instead opting for more socially proximate informal health providers such as private drug clinics where interactions are founded on acquaintance, trust, and the availability of drugs that can be accessed easily. Conversely, government health workers are perceived as aloof or dismissive, driven by negative experiences from social interactions at the point of care. The follow-up testing described in my vignettes 'the bleeding' and 'circumventing microscopy' typifies how these brief encounters, where little information is communicated between health workers and patients, can lead to a lack of understanding of how HAT referral works, and ultimately pose harmful effects on the wider health system by undermining important aspects of trust.

In chapter five we re-located to the central Teso and Lango sub-regions of Uganda, where the zoonotic strain of rhodesiense HAT is less a subject of surveillance toward elimination, than an ongoing struggle to merely establish the extent of its scale. Here, case detection is framed as a problem of patients' undesirable and 'poor treatment seeking behaviours', or inadequate laboratory infrastructures (often defined as a lack of diagnostic equipment like microscopes or PCR machines). However, as a survey of the material capacity of frontline health facilities to diagnose HAT revealed, the social

infrastructures of diagnosis are also important determinants of case detection at this level. We also met Serena Akello, who is a key node in a focal network in HAT case management, and whose personal ambition to leave Dokolo Health Centre to further her career is curtailed by the local HAT assemblage's reliance on her experience and expertise in dealing with HAT cases. The fragility of this ecosystem is revealed by accounts of health workers who have never learned how to identify HAT in either syndromic or parasitological terms.

In frontline laboratories, a shift toward rapid point of care testing has created a diagnostic culture whereby staff are no longer routinely performing microscopies, or investigating causes of febrile illness beyond what can be determined by rapid tests. Here, a lack of equipment (most health centres had microscopes but no staff that were skilled or comfortable in using them) was far from being the primary driver of under-detection. Instead, misdiagnosis is the consequence of a lack of confidence, or time to conduct more detailed diagnostic investigations, compounded by low awareness or appreciation of the local scale of HAT. Furthermore, few health workers understood what the procedure in terms of case referral and case reporting would be in the event they suspected a patient had HAT. This draws attention to many of the immaterial and unseen relational aspects of infrastructures that hold the surveillance infrastructure together. Health workers described problems implementing the mobile data reporting system mTrac, designed to replace slow and cumbersome paper-based reports. While this streamlines reporting for easily testable and high priority diseases like Malaria and HIV, this digital surveillance infrastructure excluded less common diseases with more complex diagnostic algorithms like HAT. This raises important questions regarding how infrastructures elevate and promote the collection of some evidence over others, entrenching the 'neglected' status of diseases like HAT which have distinct reporting mechanisms at the national and international level.

The sixth chapter re-centres the patient as a key agent and active participant in the HAT socio-technical ecosystem. While it too explores treatment seeking, and how passive surveillance struggles to detect cases in a pluralistic diagnostic landscape, focus shifts to the next stage in the lifecycle of HAT, to treatment and thereafter. Here, rhodesiense HAT survivors recall experiences of treatment and hospital admission, where many struggled to pull together money and social care to support them through their admission. Serena reflects on her work managing HAT cases, and her regret for not having the time or resources to adequately follow up patients once they leave her care - one example of how policies derived from medical guidelines at the global level struggle to be implemented in practice.

Despite the hardship endured throughout diagnostic staging, treatment and hospital admission, the prospect of a new oral drug candidate into this experience poses some thought provoking considerations. Most patients and health workers agreed a course of oral tablets, that could be taken without the need for painful lumbar punctures or invasive blood drawing was preferable. However a significant proportion (nearly half) felt uncomfortable taking this treatment outside the hospital setting where they could not be monitored closely by medical staff. This concern was echoed by health workers who raised concerns over treatment adherence, where patients might fail to correctly take or store medications at home, or stockpile tablets (Cohen et al., 2015; Fitzpatrick and McClaren, 2017). This raises some points of consideration for the introduction of Fexinidazole. While Fexi will undoubtedly transform the HAT management ecosystem, the expectations formed by patients from treatment experiences can become embedded in the collective memories of communities (Kovacic et al, 2015). Introducing a different method of treating HAT outside of the traditional treatment centre space can cause unintended disruptive effects on the socio-technical ecosystem of HAT treatment and case management. This implementation ought to be accompanied by thorough social scientific analysis to gauge the

acceptance and integration of a new drug into socially embedded therapeutic landscapes (Gesler, 1992; Winchester, 2017).

The seventh and final empirical chapter moves away from the medicalised configurations of HAT largely 'owned' by the public health sector, and turns to the various preventative strategies employed in intervening on the tsetse vector. Early on I describe a day in the life of a large and resdrugource intensive mass cattle treatment campaign. This militarised vertical operation, co-ordinated through public private partnerships operating parallel to Uganda's control programme, becomes a site of contention for expertise and authority, where the RAP method and expensive sprays used to spray cattle cause disagreement between farmers, vets, and programme partners. While initially successful in interrupting transmission and reducing HAT cases, two phases of the intervention fail to sustain these gains and ultimately a third phase of the campaign is abandoned. This raised the importance of sustainability and led to the establishment of a network of privately funded veterinary drug shops and 'micro entrepreneurs' to provide mobile spraying services to communities (Bardosh, 2016). In accompanying these vets and their community sprayers, and interviewing key members of staff involved in previous SOS interventions, key issues of sustainability are identified that point toward the social proximity of the services provided by local community sprayers, and key aspects of trust and long-term co-operation that could not be fulfilled by as large and ambitious project as SOS.

Finally in this chapter, we return to where this journey began, in the West Nile where efforts to eliminate gambiense HAT are being spearheaded by a new RDT and a novel technology for tsetse control. Here I draw on interviews and ethnographic observations of those implementing the Tiny Targets programme at a critical moment as it is handed over to the government control programme. Here, the previously donor funded vertical research project has been scaled up across the West Nile, and proven successful in dramatically reducing tsetse numbers in the region. However,

mismatched expectations of the remit and the future of the project between programme managers and local entomologists reveal how the framing of an intervention is as much about ownership as it is about the politics of knowledge and peoples' jobs. Drawing on interviews conducted with RDT positive suspects earlier in the year, I also present the unexpected finding that the majority of respondents who had a high awareness and knowledge of HAT had learned about it, directly or indirectly through their social networks, from the Tiny Targets intervention. This can be partially traced back to the programme's early attempts to integrate a local women-led initiative to improve acceptance and maintenance of targets. However much of the circulating knowledge about the relationship between tsetse and HAT, and HAT as a local problem, was reported to have come from informal conversations with other members of the public about the visual presence or appearance of targets along riverbeds where people congregate, long after this initiative had ended. The proximity of targets, physically, visually, and socially had not only improved the retention and sustainability of tsetse control, but had the unintended effect of enhancing local awareness and vigilance about HAT. This, alongside feedback from farmers about the importance of being acquainted and trusting of spraying services in central Uganda, highlight the importance of social proximity to the sustainability of technologies for HAT control. It also raised the importance of acknowledging the role of implementers themselves as gatekeepers of local knowledge and central nodes in social networks. While the resources and expertise provided by these programmes was empowering for local sprayers, target attendants, and laboratory staff, their views and feedback were rarely acknowledged or fed back into programmes. This may require a re-imagining of whom precisely comprise the 'communities' targeted by interventions advertising 'community participation' as their *modus operandi*.

In telling this story of course, I too have engaged in the kinds of knowledge politics that reproduce some of the power imbalances that govern global health (Montgomery et al., 2017). This is evident in the technologies I have

chosen, the partnerships I have been able to develop and foster, thus the perspectives and voices I have been able to glean and raise up in my analyses. In situating my analysis at the point of implementation, I have made a conscious effort to seek out perspectives less explored in the literature on One Health collaborations and the role of technology for global health and development. The narrative outlined above is not intended to be presented as an objective account of the state of HAT control and elimination today, but a catalogue of snapshots from selective vantage points across a vast and complex landscape. These ethnographic data points help to build a more comprehensive and grounded picture of how global health technologies become subjects of ongoing social experimentation (Bardosh, 2016). To describe everything is impossible, and with any case study there must be a focus and boundaries drawn. The outcome is more like a painting of a landscape than photograph; an interpretation rather than a mirror image (de Vaus, 2006: 225). This collage of vignettes presents a disjointed but rich contextual aid for an otherwise intangible and messy phenomena; the global assemblage at work. By 'zooming in' on these local enactments of the broad and ambitious promises made by technologies for HAT elimination, several key themes and contributions to the literature can be argued.

Infrastructures are relational

As much of Global Health and STS literature point out, it takes work for technology to function (Sariola et al., 2017), involving factors and elements that go beyond typical definitions of 'health systems' or 'infrastructures'. Diagnostics for example are often regarded as replacing infrastructure (Street, 2018). However, rather than circumventing infrastructural deficits, in many cases we find they require more infrastructure (resources, supply chains, community health workers, the information required to make them work). To perform, RDTs effectively need precisely the infrastructure they were designed to substitute: the medical expertise, organisational

mechanisms, and access to diagnostic and treatment options from well-funded and functioning health systems (Beisel et al, 2016). Making technology function involves several layers of work; the work that patients have to do to reach health centres to access diagnostic tests and adhere to their drugs; the work of suppliers and distributors to ensure tests and drugs are in stock; the work of researchers, industry, and donors involved in developing these devices, drugs, and vector control methods (Sariola et al., 2017: 3). Assumptions that Global Health technological interventions exist independently of this wider assemblage of labour fails to capture the complexity of this dynamic socio-ecology (Michael and Madon, 2017).

Another emergent issue from this line of inquiry is how infrastructures map onto subjective socio-ecological landscapes. In contrast to the mobile team-led system which preceded the RDT, the diagnostic algorithm for HAT is now divided across different levels of the health system and geographic spaces, requiring patients to travel between institutions by their own means. Tracing patients' experiences navigating these disjointed referral pathways raises the important question of who exactly is doing the unseen work behind the scenes to make this infrastructure ostensibly function. Tools will always be used in different ways than originally intended to suit changing intervention contexts (Palmer, 2018). For example, RDTs have largely not been used in the ways envisioned by Uganda's elimination programme, or by humanitarian agencies responding to the unfolding humanitarian crisis spurred by ongoing conflict in South Sudan (Palmer et al., 2018). RDTs are more likely to be found in health facilities than on the backs of motorcycles, and rarely used in refugee populations at all (Palmer, 2018). Instead, the Ugandan control programme has reconfigured the referral system to integrate HAT screening into government health centres' everyday work. However as accounts from health workers have shown, this everyday work is already performed in a challenging environment amid competing local health priorities and high patient demand.

This pressure has been reinforced by the global health community's fixation on point of care testing, with unforeseen destabilising effects on laboratories' capacity to investigate and diagnose non-RDT testable febrile cases. This phenomena can be viewed in two ways; as strengthening the case for developing an RDT for rhodesiense HAT (though this may likely be subject to the same issues encountered for the gambiense RDT-based referral system explored in the first chapter). The other perspective is that the global health community, including diagnostics developers, donor funders, NGOs and governments, must re-imagine the role of the central laboratory and re-invest in core lab capacity, including increasing health worker training and staff numbers to support the implementation of sophisticated devices. To argue that to keep up with the RDT revolution, HAT (as an assemblage of state and non-state actors) must innovate more point of care tests to keep up with this rapid cultural evolution, is symptomatic of a prevailing tendency to insert short-cut, single-disease solutions to shore up broader structural paucity and neglect.

While accessibility is at the forefront of their design and specifically called for by the global health community, the introduction of the gambiense RDT into the HAT diagnostic landscape has paradoxically resulted in making the point of care test more socially remote, and in the case of refugee populations in northern Uganda, troublingly unavailable to populations most at risk of disease (Palmer, 2018). The irony is that this re-imagination of the HAT referral algorithm and the laboratory's role in it was only made possible with the development of the RDT which now spearheads the enhanced passive screening approach to elimination. The hope that the sleeping sickness RDT would integrate seamlessly into an existing malaria diagnostic ecosystem was premised on a presumed similarity between the two RDTs that in fact did not extend beyond the physical features of the device itself (Lee and Palmer, 2018). Diagnosis is a spatially and temporally distributed process that comprises a dynamic assemblage of infrastructures, including health information systems, supply chains, clinical expertise and, crucially, patient

decision-making (Lee, 2018). Overall, this study has revealed how socio-technical ecosystems of surveillance are fragile as they are dynamic and complex, and that “the effectiveness of diagnostic technologies is inextricably linked to the social infrastructures surrounding them which make disease detection work” (Palmer, 2018). As I have argued in my second chapter on the role of the centralised laboratory in HAT surveillance, the gaps in these infrastructures of surveillance are not merely physical but relational, and inextricably political. We therefore cannot expect low resource countries, already subjected to the legacies of colonialism, structural re-adjustment programmes, and whimsical fashions of global health policy, to simply innovate their way around structural paucity and out of poverty (Babe, 2016).

‘Communities’ are multiple and emergent publics

Another cross-cutting theme has been that of ‘community participation’, the definition of who comprise these ‘communities’, and to what extent or end ‘participation’ translates across programmes. ‘The community’ in question is rarely defined, generally taken to be the people existing in a given area, with whom researchers or programmes engage, mobilise or sensitise to facilitate co-operation (or retention in the context of referral systems). Communities are assumed to pre-exist programmes, to be timeless, homogenous wholes. In relation to public health interventions, it is more common to speak of ‘the community’ as a singular, static entity, than of ‘publics’, which are multiple and emergent. A conceptual shift from ‘community’ to ‘publics’ recognises these populations as dynamic and transient (Kelly, MacGregor and Montgomery, 2017), “situated at the intersection of various forms of inclusion and exclusion, both locally and globally” (Montgomery and Pool, 2016: 50). Findings from my studies highlight the need to form long-term models of engagement and participation which transcend the quantitative goals and individual timelines of specific interventions.

It is evident from the case studies presented throughout this thesis that the communities targeted by interventions are often conceptualised as homogenous, static, and predictable. Symptomatic individuals are expected to present themselves to public health centres upon falling ill, to be instantly recognisable as HAT suspects to health workers, and to follow the disjointed referral pathways set before them after testing positive with a HAT RDT. Farmers are expected to see the incentive of regularly spraying their cattle with relatively expensive pyrethroids from a limited network of outlets to prevent human infective strains of trypanosomiasis from circulating local animal reservoirs, and to comply with policies to treat at the point of sale. Meanwhile, the spectrum of concerns, collective memories from past interventions, negative experiences at the point of care, perceived risks, cultural beliefs, dissatisfaction with local healthcare delivery, and conflicting priorities all shape an alternative landscape in which communities conduct their daily lives. While they are potential HAT suspects, patients, and survivors, people are also subjects inscribed in domestic space (Brives, 2016).

Furthermore, programmes have often been too limited in their definition of 'communities', restricted to those who are thought to passively receive and adopt, or 'accept' new technologies. Rarely do interventions expand their object of participation to those who implementing them, much to their detriment. Front line data collectors, health workers, community sprayers, vets and entomological assistants are key gatekeepers of local knowledge that can shape the social proximity and adaptability of technologies. However, the expertise and insights offered by these individuals working at the interface between programmes and people are largely overlooked or overridden.

The framing of who falls outside and inside of the community is highlighted in Parker and Allen's piece (2018) on the response to Ebola in the village of Mathiane in Sierra Leone, which describes the affected population as "those

on the receiving end of byelaws enacted by these customary authorities” (Parker and Allen, 2018). Boland and McKay (2018) argue that this creates a false dichotomy, categorising villagers as ‘insiders’ at odds with those ‘outside’ their community, thus implying that the Ebola response workers are ‘outsiders’. They argue no such delimitation should be drawn, given that the vast majority of response workers were Sierra Leoneans, who worked in their ‘own communities’ to stop the outbreak (ibid). In many cases this was true, though Parker and Allen in their response defended their original claim, arguing that while many of those responding to Mathiane may have been fellow Sierra Leoneans, they were not ‘local’ in terms of priorities and their relationship with the population, which was often “distant or fraught” while being “primarily focused on supporting the enforcement of quarantine for known cases. Their personal loyalties were elsewhere”. (Parker and Allen, in Boland and McKay, 2018). Furthermore, far from being passive recipients of public health intervention during the outbreak, Parker and Allen go on to describe how they actively resist them too; “*Although people in Mathiane heard about the public health regulations on the radio, they did not accept them, or even believe that they could possibly relate to them [...] Instead, they developed their own strategies to contain infection*”.

The above example speaks to my own observations, and considerations for what constitutes ‘local’ and comprises ‘communities’. It is evident that locality is more than a matter of drawing geographical, ethnic, and cultural boundaries, but factors in complicated relationships of trust between government and state actors or professionals with recipients of services and care. Just as farmers in Dokolo trusted their ‘local’ man Daniel over Dr Odongo, interventions are delivered through carefully cultivated social relationships that hinge on trust and respect (Kingsley, 2015).

Social proximity is a tool for sustainability and advocacy

It has become widely recognised in the literature that to be sustainable, interventions should build on existing local practices, target health messages at the most receptive community members, align with local priorities, recognise limits on human agency, such as time, economic, cognitive and social constraints, and feature community mobilisation (Panter-Brick et al., 2006). The empirical examples presented in this thesis suggest that the extent to which interventions integrate and become socially embedded into the daily lives and practices of target populations is associated with their relationality, or social proximity, to people within the wider socio-technical ecosystem of HAT control.

A growing body of literature in global health and development views community participation as an essential driving force for health program sustainability, based on the assumption that engaging with communities makes interventions more relevant to local priorities (Rifkin, 1986, 2014; WHO, 2002; Draper et al., 2010). However, the mechanisms by which community participation leads to sustainable health outcomes exactly, and to what end, are unclear (Hossain et al., 2004). My study suggests one mechanism by which the way technologies are introduced and integrated into local socio-technical ecosystems determines how socially embedded they become in daily practice. As my study on the introduction of the gambiense RDT found, devices situated in government health facilities would likely only be used where patients' own treatment seeking from informal health providers had failed, and on eventually presenting to a health centre tested negative for malaria. Even in these interactions at the point of testing, it is unlikely that patients are made aware of what they are being tested for necessarily, much less which diagnostic device is being used. The fact that so few people were aware of a rapid test for HAT being available in their local primary facilities also highlighted its low visibility as an intervention. This is in sharp contrast to the Tiny Targets project, made highly visible and widely advertised through sensitisation activities. This suggests there is a

great deal of unseen work that technologies can do, and that they can be used, where deployed strategically and sensitively, as important tools of advocacy.

As my final chapter on tsetse control demonstrated, the relationships of trust and reputation cultivated over time by community mobile sprayers increased access of spraying services to rural and remote farmers in high risk HAT areas. Their affiliation with the 3V vets franchise lent them the professional legitimacy to practice as mobile 'animal doctors', while their close ties to local social networks afforded them a level of trust and acceptance not extended to Dr Odongo and his fellow 3V colleagues. The establishment and growth of subnetworks from this organisation has allowed the mobile spraying initiative to grow organically, and become socially embedded as a routine part of preventative livestock treatment for tsetse and tick-borne diseases. As one informant described, such an approach may be a longer and more iterative journey to attaining intervention objectives, but the gains are more permanent and sustainable than the large and aloof approaches of traditional interventions. Being socially distant proved partly the undoing of SOS, as convincing farmers to take up the responsibility of spraying their own animals for a low priority disease was poorly argued and received. The social proximity of spraying services offered by the 3V network however allowed for important relationships of trust, political commitment from local government, and endorsement from local community leaders to develop naturally.

Devolving One Health is constrained by structural barriers

In her history of disease eradication programmes, Nancy Leys Stepan argues that, despite their scale and the vast resources they deployed, eradication campaigns can be historically singled out as being among the weaker determinants in health outcomes (2011). Although often initially resulting in sharp declines in the incidence of disease, campaigns like SOS

are often set up as autonomous operations, relying on specific, technical interventions organised independently of the country's health system. This 'crowding out' of the state from regional planning contexts and perspectives limits local knowledge and the consideration of different preferences for public goods. This can impact acceptance of interventions and potentially give rise to conflicts regarding potential benefits at multiple scales and between different actors (Michael and Madon, 2017). These are not always flexible enough to adapt to unexpected variations in the socio-technical ecosystems they encounter. This makes it difficult to sustain the political will or financial resources needed to maintain them, particularly where districts have many other competing health priorities. However, trying to measure the independent impact of elimination programmes on health is, perhaps, to miss the point; "it is the dynamic interaction *between* social, political, economic and public health activities and interventions that brings about population health" (Stepan, 2011: 31). The case studies presented here describe some of these dynamic interactions, hopefully providing a more grounded perspective of One Health as it is enacted through interventions at the district level.

Much like the target of elimination, One Health is a handy conceptual tool for mobilising resources and galvanising political will and commitments across sectors and disciplines. However, its rise in popularity has been compounded by either a lack of understanding, or mismatched expectations of what these 'collaborations' entail, which has limited its utility and application to practice (Lee and Brumme, 2013; Parker and Kingori, 2016). While this 'conceptual fungability' has made the model influential in capturing and coordinating complexity, this flexibility is limited, prioritising global contagions over regionally endemic diseases, emergency interventions above elimination contexts, and scale over locally adapted iterations (Smith, Taylor and Kingsley, 2015). For many African governments forced to restructure and align health activities with the priorities of the World Bank, a 'public' health system has only ever been a theoretical concept, or one greatly

compromised by multiple social, material and political constraints (Kelly, MacGregor and Montgomery, 2017). Overlaying the One Health concept onto this fragmented and decentralised landscape has highlighted, and in places reproduced, some of these constraints by insisting district offices plan and manage their own HAT control in isolation from each other. As this study has shown, the translation of global notions of One Health down to national and district levels becomes problematic for a number of reasons: the failure of international, external actors to engage with the Ugandan state; interventions and activities being set up and operating parallel to those of the state; weak state capacity to coordinate Uganda's own integrated response to HAT; and limited collaboration between core Ugandan sectors and offices in planning activities amidst a weak, increasingly decentralised district health system (Smith, Taylor and Kingsley, 2015). Chapter seven on tsetse control in particular highlighted some of the difficulties in implementing a One Health model of HAT control in practice, as a precarious and fragile network of district offices struggled to align programme objectives with local priorities.

Promoting behavioural change for health outcomes requires a deep understanding of the various cultural and social contexts to which a programme is being implemented. As my seventh chapter shows for example, it is important to consider when appealing to the motivations of farmers who may not perceive the benefit of delayed preventive innovation of spraying their cattle to deter tsetse and thus free of HAT, particularly where local health priorities for their animals diverge from that of a specific, single-disease intervention such as SOS or 3V. Where monitoring and evaluation protocols are designed with very specific targets in mind, the risk of selectively excluding important behavioural indicators and local knowledge is substantial, particularly where those setting the research agenda and enforcing intervention compliance prioritise maximum returns with minimal risk. This limits the room for creative flexibility and adaptability of intervention strategies on the ground, as health workers find themselves responding to

individual situations while confronting pressures of reporting particular data (Mishra, 2014).

The micro-adaptations that District Supervisors in the West Nile had to make to follow-up 'defaulting' suspects and meet the elimination programme's objectives are illustrative of these creative adaptations, and testament to the resilience of staff struggling to manage expectations and environments of uncertainty. However, I urge caution against fetishizing the 'tinkering' undertaken by implementers, as the conditions under which such measures are contrived by necessity is neither ideal nor acceptable. Glamourizing the resourcefulness of actors in resource poor settings overlooks the structural neglect of primary healthcare, and shifts incentive from making technologies locally relevant and acceptable, to forcing local actors to 'make them fit'.

As discussed in chapter 2, the environment in which programmes supposedly integrate global health technologies are fragile and immensely overstretched. A common theme throughout the thesis raised in this chapter was how the decentralisation of the health system has removed HAT as an item of national importance, thus making it a low priority for districts, meaning little training or resources for HAT control are mobilised to these areas. Staff regularly have to manage the expectations of health service and disease control programmes amidst budget and resource constraints. The introduction of digital surveillance infrastructures enables comparative accountability between districts, but also creates often unseen work for time and resource constrained health workers. Elsewhere, the high turnover of frontline health facility staff and intermittent training has left a significant gap in the structural capacity for HAT cases to be detected. The low index of suspicion among health workers feeds, and is fed by, a point of care testing culture that overlooks potential causes of febrile illness that cannot be determined by a limited selection of rapid diagnostic tests. It is also important to note that behavioural change extends beyond the target communities in question, but to the health workers and practitioners responsible for

suspecting and testing for disease in the field and clinical settings. Health promotion and education should not only target lay communities, but the network of professionals, some of which may not have received adequate training to recognise symptoms of HAT or suspect cases in their region.

Attention must also be paid to the ways in which evidence is produced at these intersections between interventions and their intended publics, including those who are active participants in its creation. Data collectors play a vital role in producing scientific knowledge, and as my observations of Dr Mohammed's dilemma in the SOS treatment trials underscored, they are also an important component in understanding the practice of public health interventions. Yet little attention has been given to their daily experiences or the context in which they are expected to perform these tasks (Kingori, 2013). Incorporating these 'voices of the field' (Okwaro et al., 2015) are crucial to understanding how global assemblages of One Health and HAT are rendered locally through socio-technical enactments.

The Socio-ecology of Sleeping Sickness is fragile as it is complex

What can be learned from this study about the socio-ecology of sleeping sickness, and the relationship between policy and practice for HAT control and elimination? I would draw similar conclusions to David Mosse on implementing aid policy for development, that imposing policy prescriptions without taking local contexts into account is potentially irresponsible, and that policy change "ruptures informal systems supporting projects" (Mosse, 2004: 230). The case studies presented here reveal some of the informal systems at work that support and stabilise the HAT assemblage as delicate and dynamic, held together by the daily struggles and tinkering of individual programme staff, state health workers, patients and farmers to make surveillance and control infrastructures function. My findings contribute to a growing body of literature that emphasise how the enactment of social

processes during the implementation phase of interventions have profound implications for programme sustainability (Pluye et al., 2004; Madon et al., 2018). I have shown through this selection of case studies that 'communities' are often narrowly defined (Kelly et al., 2017; Montgomery and Pool, 2017) and assumed to be passive recipients of technological interventions designed to change their behaviour and integrate tools into everyday socio-technical practices. However, the socio-ecological assemblages of sleeping sickness are as fragile as they are complex. They are sensitive and adaptive, lending agency to innovations as they integrate and take on social lives of their own in unpredictable ways. Others are poorly fitted and ultimately fail, being too large and monolithic, or socially distant.

Technologies do not exist and operate in a vacuum, nor do they work on a passive static network. They are part of a dynamic HAT assemblage, and rely on the interaction and agency of the population they are intervening on to adopt and continue to use them. They can be used as tools for advocacy, as highly visible and socially embedded interventions promote awareness and understandings of HAT among local populations. Conversely, relatively sophisticated but aloof interventions which shift responsibility of referral, or treatment, or of preventative spraying, onto poor communities in post-conflict subsistence societies is evidently problematic (Bardosh, 2016). Introducing technologies and expecting vulnerable communities to continue their implementation long after with their own resources does little to promote trust or incentive, and is potentially damaging to communities and health systems. Thus, while modest and incremental, locally adapted interventions which are more socially proximate and integrated with 'local ecologies' achieve greater sustainability than some of their more elaborate predecessors, as they take on, and persist through, social lives of their own.

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