

**WOMEN-LED TSETSE CONTROL:
A PILOT STUDY IN NORTHWEST UGANDA**

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy by Vanja Kovačič.

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DEDICATION

This piece of work is dedicated to two people, who greatly influenced me with their values of integrity and profound understanding of freedom. I was lucky enough to be born into your company.

To Jožica and Stane Kovačič

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'Ba alu pamvu siri (a) ru.

"The footprint (track) of only one person is narrow¹".

(Lugbara proverb, Uganda)

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¹ "EXPLANATION: Unlike a single track, many travellers create a wide path. This Lugbara proverb refers to the fact that someone working on his own does not achieve as much as those who work together to achieve success." (In: Steward D. (2005) *Wisdom from Africa*, A collection of proverbs. Struik Publishers, South Africa)

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ABSTRACT

Women-led tsetse control: a pilot study in North West Uganda

Vanja Kovačič

INTRODUCTION

Human African Trypanosomiasis (HAT) is a disease caused by infection with trypanosomes and transmitted by tsetse flies, which continues to threaten thousands of people in Africa. Tiny targets –small pieces of cloth impregnated with insecticide– are a new, cheap, and effective entomological tool to prevent transmission. The most sustainable and effective way to implement these targets remains uncertain, but their simplicity makes them an excellent candidate for community led schemes. The aim of this research was to design, implement, and evaluate a women-led tsetse control intervention using tiny targets in an area endemic to HAT.

METHODS

The research was conducted in North West Uganda and organized in three distinct phases: 1) The *baseline phase* used in-depth interviews, GPS human tracking, seasonal calendars and participatory mapping to explore the factors influencing community participation; 2) The *intervention and evaluation phase* piloted a women-led tsetse control operation in three villages and evaluated its impact using action research; 3) The *stakeholders' reflections phase* explored the community and decision-makers' perceptions of community involvement in future HAT control interventions, through community role play and in-depth interviews with decision-makers.

RESULTS

During the baseline phase, the community did not express negative perceptions towards HAT control programmes, although they recalled past experiences with different programmes imposed upon them. Both men and women perceived women to be at greater risk of tsetse bites than men because of their daily activities in close proximity to rivers, and this was an important facilitator for their involvement. However, the GPS human tracking study suggested that the actual risk was similar among men and women.

During the six month pilot intervention, women were highly motivated, and their ownership of the programme and sense of empowerment increased. Participants perceived the intervention as feasible. The evaluation demonstrated that more tiny targets were functional at six months post deployment in the pilot villages than in an expert-led programme in an adjacent area, due to community maintenance of the targets. The pilot community-led intervention was also more cost-effective.

Through role-play in the stakeholders' reflection phase, women demonstrated with confidence their ability to define priorities, good negotiation skills, and critical insights into decision-making. During in-depth interviews, decision-makers acknowledged that the community has an important role in HAT elimination, but that they lacked knowledge and skills in community based approaches. Women are not well represented in HAT control policy and planning, and the perception of tsetse control as a male domain was an additional barrier to women-participation approaches.

CONCLUSIONS

This study demonstrated that a community-based tsetse control programme organized and led by women was feasible and cost-effective. The high-level of engagement and motivation of these women and their effective management of the tiny targets provide evidence that community-based approaches may be a sustainable option for tsetse control. However, this will need widespread engagement of policy and programme staff and recognition that communities are equal partners in HAT elimination.

ACRONYMS

| | |
|--------|--|
| AIDS | Acquired Immune Deficiency Syndrome |
| AR | Action Research |
| AU | African Union |
| CAR | Central African Republic |
| COCTU | Coordinating Office for Control of Trypanosomiasis in Uganda |
| DALY | Disability-adjusted Life Year |
| DFID | Department for International Development |
| DRC | Democratic Republic of Congo |
| EU | European Union |
| FAO | Food and Agriculture Organization |
| FGD | Focus Group Discussion |
| GLM | General Linear Model |
| GPS | Global Positioning System |
| HAT | Human African trypanosomiasis |
| HIV | Human immunodeficiency virus |
| IAEA | International Atomic Energy Authority |
| ICIPE | International Centre on Insect Physiology and Ecology |
| IMC | International Medical Corps |
| LSTM | Liverpool School of Tropical Medicine |
| MOH | Ministry of Health |
| MSF | Médecins sans Frontières |
| NGO | Non-Governmental Organization |
| NTD | Neglected Tropical Disease |
| PAR | Participatory action research |
| UGX | Uganda Shilling |
| UN | United Nations |
| UNICEF | United Nations International Children's Emergency Fund |
| UNCST | Uganda National Council of Science and Technology |
| USD | United States dollar |
| VHT | Village Health Team |
| WHO | World Health Organization |

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Chapter 1: INTRODUCTION

1.1 Sleeping sickness burden in Africa

Sleeping sickness or human African trypanosomiasis (HAT) is a neglected tropical disease which affects remote rural populations of Africa [1]. HAT is endemic in 24 countries [1] and approximately 57 million people are still considered at risk [2, 3]. The largest number of cases are reported in Democratic Republic of Congo (DRC) (about 80% of cases [4]) followed by Central African Republic (CAR), South Sudan, Chad, and Angola. Despite a decrease in the number of new cases globally, in 2013, over 6,200 new HAT cases were still reported [5] and Uganda, with 459² cases of HAT reported between 2008 and 2012, is an important country on the global HAT prevalence map [1].

There are two types of sleeping sickness and they differ by geographical distribution and epidemiology. The first type, caused by *T. b. gambiense*, is endemic in central and western Africa and is characterized by slow progression of symptoms. The second or the acute type, caused by *T. b. rhodesiense*, occurs in east and southern Africa and is characterized by rapidly progressive symptoms [6]. *Rhodesiense* cases represent less than 5% of the total current HAT cases; thus, the more common *gambiense* type of HAT is the major focus of HAT control and elimination plans [1]. Uganda is the only country where both forms of disease occur, but both do not occur together in the same geographical area [6]. The geographic area where this research study was conducted is only endemic to *gambiense* HAT, and the study therefore focuses only on this form of the disease.

HAT is caused by sub-species of *Trypanosoma brucei*, a flagellate parasite transmitted by tsetse (*Glossina*) [6]. Other less common transmission routes include congenital transmission from mother to baby, transmission via infected blood during blood transfusion and accidental laboratory transmission [6, 7]. However, these routes are relatively rare, and sleeping sickness is primarily transmitted by the tsetse vector.

Tsetse flies are exclusive blood feeders and HAT infection occurs when an infected fly transmits the parasite to humans as it takes a blood meal. The disease progresses over two stages: the first stage is characterized by the onset of fever and other nonspecific malaria-like symptoms [6]; in phase two, when

² This refers to cases of *gambiense* HAT.

the parasite migrates from the blood stream into the central nervous system, more serious symptoms occur. The most commonly reported symptoms include headache, sleeping disorders, enlargement of lymph nodes, a severe itching sensation on the skin, enlarged spleen, and several mental health symptoms such as abnormal behaviours, hallucinations, delirium and speech disorders (ibid.). Except for some very rare cases, where patients have been infected for decades but without serious symptoms [8], it is still generally accepted that in the absence of treatment sleeping sickness is fatal. Both stages of disease on average develop over the period of two years [6].

In addition to physical and neurologic symptoms, sleeping sickness leads to negative socio-economic problems for patients, their families, and the communities in which they live. Community based research in DRC, suggests that reduced productivity as a result of sleeping sickness amounts to economic loss equivalent to five months of the household income [9]. Another community study in DRC reported a range of social consequences for HAT patients ranging from family conflict, divorce, and suspicion of sorcery [10]. Study from Cameroon [11] also showed that treatment of HAT in children, particularly with the toxic drug melarsoprol, caused them to have slower growth, delayed puberty and poorer academic performance compared to controls without a history of HAT.

Because of its many negative health impacts, HAT is ranked high in terms of burden of disease, expressed as disability-adjusted life years (DALYs) [12]. In Uganda, *gambiense* HAT, with its high mortality rate contributes to high DALYs. In the most affected district (Moyo) in northern Uganda, the impact of *gambiense* HAT reached 2,144 DALYs/100 000 persons/ year, which is comparable to the national average burden for malaria, tuberculosis and HIV/AIDS [13].

Sleeping sickness is a disease endemic only to Africa. It is thought that this fact may have contributed to the long neglect of the disease, in terms of international health interventions and lack of development of diagnostic tools and treatment [14]. As Bradol noted [15], it is shocking that only two new drugs were developed in the past fifty years and the toxic, arsenic-based drug melarsoprol is still used for treatment of the patients. Further, he argues that the scientific and political community has not sufficiently responded to past HAT epidemics and thousands of lives have been lost as a result. These earlier epidemics were brought under control largely by non-governmental organizations (NGOs) such as MSF (Médecins Sans Frontières), Maltesa, Caritas, International Medical Corps (IMC), Merlin, and Care International [16] who were also advocating for HAT to be placed on the international health agenda [15]. Today, there is a new wave of optimism amongst the international community with respect to HAT, as reflected in current plans and inter-governmental commitments to HAT elimination.

1.2 Current trends in sleeping sickness control

In 2012, in the London Declaration on Neglected Tropical Diseases (NTDs), the World Health Organization (WHO) brought together all the main health actors including governments, non-governmental organizations, donors and the pharmaceutical industry, to establish the largest public-private partnership ever in the history of NTDs. In the declaration there is a commitment by all parties to eliminate the most important NTDs, including Gambian sleeping sickness, by 2020 [17].

Towards this end, there is renewed vigour in the development of new diagnostic and treatment technologies for HAT, which have been inadequate for the sustainable management and control of the disease [18]. Several rapid serodiagnostic tests have been developed, which do not require laboratory conditions and these have increased case detection rates considerably [19]. Current treatment options require identification of the clinical stages of HAT (i.e. whether the parasites have entered the central nervous system) but this may also become redundant, since new oral drugs effective against the both stages of the disease, look promising. A new treatment option, Fexinidazole, has entered the third stage of clinical trials and if proven to be safe and effective, can expect to be available for use within the next couple of years [20].

Despite all these recent medical advances, delivery of these clinical interventions across remote foci of HAT will pose a major challenge and may prevent the elimination of HAT by 2020. A new and innovative approaches, entailing inter-disciplinary methods to improve delivery of interventions, has therefore been proposed to eliminate and to prevent new outbreaks of HAT [18, 21].

1.3 Why medical interventions are not sufficient

Past sleeping sickness treatment campaigns were mostly organized by humanitarian organizations in collaboration with national control programmes, in response to HAT outbreaks. While these responses were effective in detecting and treating patients through active screening approaches, those campaigns were often short-lived. When the outbreaks were considered to be under control, and the number of cases dropped, most NGOs closed their programmes. In 2012, for instance, only two registered NGOs provided HAT treatment programmes [22].

More recently, humanitarian agencies have been handing over their HAT interventions to national health programmes. While there are benefits to this approach, weak health systems in HAT endemic countries

are often unable to absorb the cost and meet logistical requirements for active screening activities, which results in sub-optimal passive case-detection approaches [23]. Many HAT-affected countries are also those affected by long-standing civil conflicts. Therefore, as NGOs reduced their involvement, their already over-burdened health systems, were unable to maintain effective case detection and treatment processes. Scaling-down surveillance and treatment activities in countries where the disease is seemingly under control poses a risk of HAT re-emerging. Countries affected by HAT are prone to this cyclical pattern as recently observed in the case of South Sudan [24]. Furthermore, in some foci, such as Mandoul in southern Chad, despite repeated active screening and treatment campaigns over several years in 2011 over 200 HAT cases were still reported [25, 26]. Hence, medical campaigns so far delivered either by NGOs or national control programmes in affected countries have not yet achieved sustainable and effective HAT control.

In the absence of active screening additional challenges, such as long delays in treatment and undetected HAT cases often occur. Long delays in diagnosis and treatment have been recorded in multiple-foci. In DRC for instance, it was observed that on average patients received a correct HAT diagnosis only upon the fourth visit to a health facility and up to seven months after symptoms first occurred [27]. I observed a similar trend in north-western part of Uganda in 2008, where in the absence of active screening, most patients (98% between 2005 and 2008) reached the Omugo treatment centre when they were already in the second stage of disease and on an average of nine months after they first experienced symptoms [28]. This resulted in more complicated medical case management, more severe consequences to the patients and reduced likelihood of complete recovery. In the same study, I noted that patients paid considerable amounts of money for (inappropriate) drugs at drug shops or for traditional treatment before they finally sought hospitalized treatment for HAT.

Under-reporting of HAT cases due to poor health-seeking behaviour of patients or weak diagnostic capacity in health facilities [28] poses a risk for further infections. Studies from DRC suggested that two thirds of cases were undetected and untreated [29]. In addition, asymptomatic carriers of HAT, which are not confirmed as HAT cases by parasitological diagnostic methods, remain untreated [30]. These undetected patients serve as a hidden reservoir of disease, with the slowly progressing *gambian* HAT remaining a source of infection for many months, if not years [21].

In addition to the many medical challenges associated with HAT diagnosis and treatment, such as invasive diagnostic procedures, drug resistance and drug toxicity [31], there are a number of operational difficulties. Active screening campaigns are expensive and logistically demanding, especially in areas with

compromised human security [32], and complete population coverage during active screening is seldom achieved. For instance, participation rates at some of the active screening campaigns in DRC were as low as 50% [10]. A number of barriers to community response were identified, including: fear of drug toxicity and lumbar puncture, transport-related financial barriers, lack of confidentiality, perceived restrictions during HAT treatment, social stigma associated with positive diagnosis, and lack of communication among mobile teams and local communities [10, 33]. Additional barriers were related to a lack of updated health information and beliefs about prohibitions after treatment, which originally aimed to minimize adverse side effects of treatment with melarsoprol [34].

Thus, the combination of technical and operational difficulties for both active and passive approaches to HAT management create a demand for different methods. A combination of medical efforts and vector control has been recognized as essential for elimination plans [18, 21]. Tsetse control, in the absence of prophylactic treatment or available vaccine and poor prospects for developing one in the near future, is the only means to protect people against infections. Vector control also impacts on reducing transmission rates since its use contributes directly to a reduction in the number of human cases [21]. In the past it has been argued that vector control is too expensive and logistically too demanding to be used at scale and in a sustainable manner. This argument, however, has recently changed with development of new cheaper and simpler methods of vector control [35-37].

1.4 Tiny targets: new tsetse control tools, new opportunities

A number of tsetse control methods have been used in the past, many of which posed implementation challenges. Aerial spraying of insecticide, for instance, usually requires five cycles of spraying to kill adult flies in intervals. This technique is delivered by the use of planes, which makes it logistically demanding and costly [38]. Similarly, the sterile insect technique (SIT), used for elimination of small (remaining) populations of tsetse, is technically challenging and expensive since it requires fly rearing and aerial release of sterile males. SIT is currently not recommended as a single method for continuous tsetse control [39]. These technical and logistical implications resulted in relatively expensive tsetse control interventions in the past, which were not financially viable for local governments in HAT-affected areas of Africa.

Some methods of tsetse do control, such as the use of artificial baits and insecticide application on cattle do appear more suitable for HAT control. For instance, the restricted application of insecticide to cattle is cost-effective [40] and has been successfully used in the control of *rhodesiense* HAT foci [41]. This

method, however, is limited to areas where cattle densities are high (>10 cattle/km²), which is not the case in most *gambiense* HAT foci [21].

In 2010, a new tool for tsetse control, so-called 'tiny targets', were developed offering the prospect of a more cost-effective and simple intervention suitable for controlling Gambian HAT. Tiny targets overcome several difficulties associated with other control techniques. In particular, in areas where insecticide application on cattle is inappropriate, such as in north western Uganda, tiny targets offer the only alternative cost-effective tsetse control method [21]. Tiny targets are made from blue cloth with a flanking panel of black netting. Previous research demonstrated that tsetse are attracted to blue objects [42-45]. Tsetse collide with the netting panel which is impregnated with deltamethrin, and hence pick up a lethal dose of insecticide. These targets, deployed in tsetse habitats, rapidly reduce tsetse population. A modelling study [46] suggested that deployment of tiny targets control will reduce the density of tsetse by 90% within three months. Such a reduction is predicted to reduce the incidence of HAT. Field studies confirmed these theoretical predictions. In northwest Uganda, deployment of tiny targets reduced tsetse numbers by more than 90% [47]. Similar effects have also been observed in control operations conducted in Guinea where tiny targets were deployed in a mangrove swamp [48].

Tiny targets are the smallest artificial bait for tsetse control developed to date and they measure only 0.125 m² [47]. As a consequence of their small size, they provide a more cost-effective means of control by killing more tsetse per surface area of cloth, compared to larger targets and biconical traps [37]. In short, tiny targets kill more tsetse per dollar. The small size has many logistic advantages. Larger targets for instance require lorries and large vehicles to carry the targets and their deployment teams and they are relatively difficult to erect [38]. By contrast, one person can carry 30 tiny targets in a backpack, which greatly improves deployment costs [49]. The targets themselves are much more affordable and costing only USD 1 each; they are an eighth of the size and cost of the old larger targets, which drastically reduces the delivery cost and makes them easy to transport and deploy (ibid.). These advantages in many ways revolutionized tsetse control and made it applicable for the large scale control interventions. The use of tiny targets is therefore emerging as an essential part of HAT elimination strategies [50].

After their efficacy was piloted on a small scale on a Kenyan island on Lake Victoria [37], a large-scale trial, funded by Gates' foundation, was conducted in 2011-2014, to assess the efficacy of tiny targets over 500 square kilometres in the West Nile region of Uganda [47, 51]. This trial, which later in this thesis is referred

to as an “externally led intervention”³ was led by expatriate entomologists who trained and organized local technicians to carry out the work. Local technicians deployed and maintained targets over a period of three years. In this intervention, targets were deployed along river systems (Figure 1.1) at about 6 per km² in two southern districts (Arua, Maracha). The northern district (Koboko) served as non-intervention (experimental control) area (Figure 3.3). Traps were deployed over the entire trial and control to assess the relative density of tsetse. The main objectives of the trial were concerned with entomological and parasitological outcomes.

This trial, as the vast majority of other tsetse control operations to date [52], was organized and implemented by external experts and their technical staff. The role of local communities in the intervention area was limited to passive participation; they were informed, via series of sensitization meetings, about benefits of the targets and requested to keep them intact and in working condition [49]. This type of implementation, also considered as a ‘top-down’ approach [53], positions beneficiary communities outside decision-making and implementation roles, in contrast to ‘bottom-up’ approaches, where communities plan, organize and implement intervention. The core of my research was developed by using a bottom-up approach, where communities were supported to place tsetse control interventions within their own priorities and play an active role in decision-making and execution of tsetse control intervention.

³ “Externally-led intervention” was used to compare pilot community-based intervention with the ‘standard’ delivery model, implemented by the expert field teams.



Figure 1.1: Picture of tiny target deployed in in operational area in Uganda

1.5 Rationale and research questions

The development of tiny targets presents a new effective, cheap and easy-to-use tsetse control tool. All these elements make tiny targets excellent candidates for use by local communities. Organization of such community-based control intervention using tiny targets has, until this study, not been rigorously evaluated. Furthermore involvement of women specifically in tsetse control operations remains largely unexplored, but it was shown to have beneficial impact on outcomes of other disease control programmes [54] (see section 2.5 for more details). The aim of this research was to design, implement and evaluate tsetse control intervention led by women in a HAT endemic area of Northwest Uganda as a novel and alternative approach to current top-down control strategies. The overall goal of the project is to inform future operation, and contribute to HAT elimination efforts.

This rationale was shaped into the two following research questions:

- i) **Could involvement of local communities, and particularly women, improve sustainability of tsetse control using tiny targets?**
- ii) **How could community-based approaches become part of the HAT control policy and implementation?**

Objectives

Specific objectives were addressed over three research phases:

BASELINE

Objective 1.1: To explore the potential influence of the past HAT control interventions on community attitudes towards their involvement in HAT control

Objective 1.2: To explore the perceived risk of exposure to tsetse and the risk of HAT

Objective 1.3: To measure the risk of exposure to tsetse bites

INTERVENTION AND EVALUATION

Objective 2.1: To implement a pilot, women-led tsetse control intervention

Objective 2.2: To evaluate the process of participation and the operational impact of the women-led tsetse control intervention

REFLECTIONS OF STAKEHOLDERS ON CONTROL STRATEGIES

Objective 3.1: To examine community perceptions of decision-making processes

Objective 3.2: To examine programme planners' and policy makers' views on community participation as a component of HAT control strategies

1.6 Organization of the thesis

The thesis comprises seven chapters: three introductory chapters (Chapters 1-3), followed by descriptions of findings related to each of the three research phases (Chapters 4-6), and the final chapter drawing together findings, analysis and conclusions. Figure 1.2 illustrates how the thesis is organized into three research phases (baseline, intervention/evaluation and stakeholders' reflection) and the specific objectives addressed by each phase and related chapters.

In Chapter 2, I critically examine published literature addressing key issues and debates related to HAT and its control. In Chapter 3, I outline the main theoretical approaches which influenced my methodology and described all the methods. In Chapter 4, I discuss community experiences from previous HAT interventions and the perceived and actual risk of tsetse bites and HAT. Chapter 5 presents the findings related to the women-led tsetse control intervention, implemented and evaluated using action research methods. In Chapter 6, I describe stakeholders' perceptions of HAT control. Chapter 7 summarises the

main findings, discusses the relevance of this research for policy and practice and contains conclusions and final remarks.

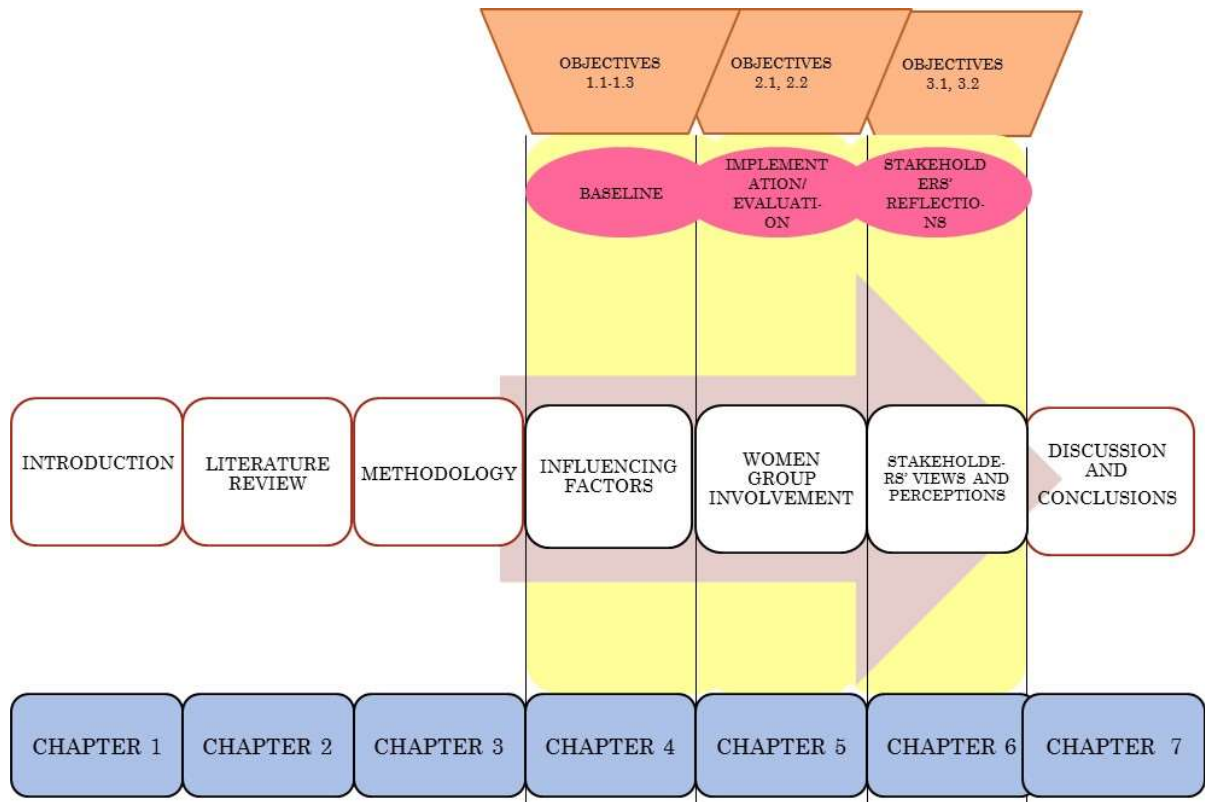


Figure 1.2: The thesis structure

Chapter 2: LITERATURE REVIEW

2.1 Chapter overview

In this chapter I examine published literature in three different areas related to the three phases of my research, namely: (i) the factors influencing community participation, in particular human exposure to tsetse and HAT, as well as the historical context of HAT control interventions in Uganda; (ii) previous attempts at using community participation in tsetse control, with a focus on sustainability and involvement of women; and (iii) literature related to stakeholders in HAT and trypanosomiasis control and processes of policy development. The chapter concludes by summarizing what is known in each research area highlighting the knowledge gaps that this research study attempts to address⁴.

2.2 Past sleeping sickness control interventions in Uganda

History of HAT epidemics and early control programmes in Uganda

Uganda played an important role in the history of sleeping sickness control. Soon after the discovery of the cause of the disease, there was a huge outbreak of *rhodesiense* HAT in 1904 near Lake Victoria. About 200,000 people, which was estimated as one third of entire population in the region, lost their lives in the Ugandan Protectorate during this epidemic [55, 56]. The shores and islands of Lake Victoria were heavily affected and in some villages the disease killed entire population [57]. This epidemic was followed by another epidemic during the period of British colonial rule between 1930 and 1940 [58, 59].

The colonial government responded immediately, acknowledging that the disease presented a threat to the Europeans as much as to the native population. The first Sleeping Sickness Commission, led by Castellani and Bruce was sent to Uganda [57] on a scientific mission; this is when the first protective measures were implemented. Infected individuals were segregated into camps, healthy people were re-settled in tsetse free zones, and affected areas were cleared of vegetation by forced labour. These were the first vector control operations aimed at controlling the spread of the disease.

⁴ This literature review does not include literature related to application of insecticide on cattle, which is mostly used to control animal trypanosomiasis and *rhodesiense* HAT.

Restrictive measures were applied around all the sleeping sickness foci in Lake Victoria region, along the river Nile and Lake Albert. The territory was strictly administered [60] through inspection check posts and penalties for those who failed to respect the rules on restrictive movements. The situation was described in the *Lancet* in 1906 as follows:

“Every negro whose cervical glands are enlarged without obvious cause must be considered to be a cause of trypanosomiasis until the contrary is proved. From the nature of things it follows that the rational form of prophylaxis would be the prevention of entry of infected persons into a district where Glossina palpalis is known to exist and where the disease does not occur. For this purpose Dr. Todd suggests the establishment of medical posts of inspection along the trade routes leading from infected to uninfected districts and the removal of infected persons from the posts in uninfected districts to places already infected. Neglect to carry out preventive measures must inevitably result in a loss of life among the great native populations” (p. 102 [60]).

Resettling people was considered customarily to ‘natives’, by the colonial officers who described African local communities as culturally pre-disposed to mobility. Local communities, who were refused access to the natural resources for fishing and pastoral grounds in de-populated areas, rebelled against the rules despite the potential penalties. The colonial administration blamed them for the spread of disease as well as victimized them--which justified reinforcement of control measures. People who failed to follow the re-settlement rules and preferred to stay in the bush areas were considered ‘primitive’ and ‘non-compliant with their civic duties’ (ibid.).

Areas surrounding settlements were cleared of vegetation, mainly by local men who were separated from their families and forced to engage in these land clearings. Many did not report for work or deserted these clearing activities. Such behaviours were attributed to the ‘native lack of efficacy and misunderstanding of the task’, by British officers [61]. However, the local people were traditionally leaving their lands empty and uncultivated due to the abundance of tsetse flies. Hoppe [61] argues that coercive anti-sleeping sickness campaigns were used to exercise colonial authority and power. These Western ideas of institution and power strongly interfered with traditional social rules in the cultivation rights and practices of local populations. Furthermore, he points out that colonial authority in British Uganda used resettlements as means to ‘civilize’ local populations and train them into ‘modern pastorals and farmers’.

As documented in colonial texts, chiefs were responsible for encouraging the population of an area to present themselves for medical examination when summoned by the District Officer. Chiefs were also in

charge of reporting every sleeping sickness case in their area [60]. Patients with enlarged neck glands were sent to the segregation camps built by forced labour and patients themselves. Hoppe [61] reports that some of the elders, who lived near Bussu camp in Uganda still recall people hiding their sick relatives in the bush to prevent them from being sent to the camps. Colonial camps were considered the last resort and the last destination for the patients who were often abandoned by their relatives and which gave the establishment complete control over them. Furthermore, the literature at that time reports on medical experiments conducted on patients in colonial camps. Injections of highly toxic substances, such as arsenic-based atoxyl, combined with strychnine and mercury or atoxyl or mercury alone were routinely tested on patients [62]. Patients who became violent were handcuffed and sent to a 'special lunatic annex'. A vast majority of the patients never left the camps which led to a widespread belief that they simply died and that no one who entered the camp would leave it alive.

Gambiense HAT epidemics and control in West Nile

Present day DRC was described as the original entry point of HAT into West Nile [63]. Unlike other parts of Uganda, where the sleeping sickness situation was well-documented since 1910 [64, 65], the HAT situation in the north-western part of the country, administered by Belgian Congo until 1919 and later by Sudan, is not well documented [63]. After the Sudanese border was defined in 1914, West Nile fell under the British rule and the first British administrator was posted in Arua, Uganda, in the same year [64]. In 1920, the Medical Department investigated the area and documented a number of HAT cases on both sides of the Nile stretching from Albert Nile to Sudan. Control measures, similar to those deployed in the rest of the country were applied. The highly affected southern and eastern parts of the region were evacuated and pronounced to be 'prohibited' areas and people were moved to the less affected north. These people, like those in the rest of the country rebelled against forced re-settlement and the evacuees later moved back to their homes [63].

The first well-documented epidemic occurred in West Nile between 1927 and 1934. This epidemic was attributed to increased population movements due to severe famine--people in search of food moved into the forested areas along the rivers for hunting and fishing purposes. In 1929, at the peak of the epidemic, the medical department treated more than 1,800 cases in West Nile. This triggered intensified control measures: rivers and road crossings were cleared of vegetation, 'sleeping sickness villages' were established for segregation of patients and restriction of movements in the area was imposed through a system of permits and passes. Morris [63] suggests that these coercive measures and the responses they promoted from the local communities, served to reinforce, rather than prevent the spread of HAT:

“It is possible that imposition of these compulsory restrictions on a primitive and as yet loosely administrated native people, at first hastened rather than checked, the spread of the epidemic. The cleared and policed roads and paths were rapidly forsaken for uncleared bush tracks where everyone could pass freely. The result was greatly increased contact with G. palpalis and wider and more rapid dispersal of infection” (p.322 [63]).

A decline in the number of cases was recorded until 1936, when the second epidemic erupted across the entire region of West Nile. This was attributed to the failure of some tsetse control measures or rather, community behaviour which was not compliant with these measures. People moved away from cleared water points and washing places and in their search for privacy started using parts of the river which were left out of the vegetation clearance efforts. In 1936, over 1,800 cases were reported again. Control measures were intensified, active screening was carried out every three months and additional vegetation clearing was conducted along rivers. The number of cases declined and by the 1940s the epidemic was considered under control. In the 1950s and 1960s, some isolated outbreaks were observed but as elsewhere in Africa in the 1960s HAT epidemics were considered largely controlled and almost no deaths were reported due to HAT [66].

Sleeping sickness was considered to be under control until the 1980s, when HAT re-emerged in West Nile. This re-occurrence was associated with the regional civil unrest that resulted from clashes between the Lord's Resistance Army and the Ugandan People's Democratic Army and the people of northern Uganda [67]. The war created an influx and re-settlement of refugees from infected areas of South Sudan back into Uganda in the 1990s; this caused one of the major epidemics in the history of Uganda [65, 68, 69]. Decline of health systems during the war and poor access to health services were argued to be key factors in development of this epidemic. The non-governmental organization- Médecins Sans Frontières (MSF)-France, responded to the outbreak in 1987. It introduced active screening and treatment campaigns and established the treatment centre in Omugo which is, to date, one of the main facilities in the region for diagnosis and treatment of HAT. Due to MSF's efforts, it was estimated that at least 8,000 lives were saved [70]. According to Checchi's dynamic transmission model [71], the maximum likelihood of the true incidence rate of HAT in West Nile at the time was 0.5 to 1 per 1000 person-days and it was argued that HAT, in absence of treatment, would be, by far, the main cause of death in the affected human population. Hence, in this era the local communities of West Nile suffered a double burden: re-settlement of refugees back into the war-affected West Nile followed by the impact of the HAT epidemic.

The second MSF-Spain mission opened in West Nile in 2010 when an active screening and treatment campaign was carried out in the two following years [72]. Similar to the first MSF mission in West Nile, this campaign delivered active screening and treatment of HAT to target villages. Both MSF interventions, however, were strongly focused on epidemiological outcomes [72, 73] and no attention was given to the community's perceptions of the MSF programmes.

In summary, communities in Uganda have witnessed a number of HAT epidemics and control programmes, yet very little is written about community perspectives. By examining elders' memories in this research I aimed to explore what memories have been preserved in relation to colonial HAT control measures and more recent MSF interventions as the first attempt to document collective memory of HAT affected communities in Uganda. Oral tradition is strongly present across the African continent and historical narratives are passed from generation to generation across decades [74-76]. Any potential negative collective memory of experiences with previous HAT control programmes could have an impact on the community's attitudes towards participation in tsetse control, which is what this thesis examines.

2.3 Human exposure to tsetse, HAT-risk and gender

It has been shown that gender roles and relationships shape vulnerability to disease [77]. For instance, women are predominantly responsible for water management at the household level in many countries in Africa [78-80], hence water-related diseases, including exposure to HAT could potentially threaten women more than men. Based on this hypothesis, I examined what is published in relation to human exposure to tsetse and HAT to understand available literature that documents gender differences in vulnerability to disease.

Tsetse behaviour and factors influencing this

Tsetse behaviour has been studied extensively in relation to the development of different control strategies. A large volume of literature exists on tsetse host-seeking behaviour, on improving trap and target designs [40, 81-84] and on effectiveness of insecticide treated cattle [40, 85]. All this research has contributed towards understanding of behaviour of the savanna group of tsetse, such as *G. pallidipes*, *G. morsitans* subsp., *G. austeni*, *G. longipennis* and control of animal tripanosomiasis. However, the savanna group of tsetse is not attracted to humans and is not an important vector for *gambiense* HAT [86]. Therefore the focus of this literature review is on the examination of host-seeking behaviour related to riverine species of tsetse which play an important role in transmission of *gambiense* form of sleeping sickness.

The behaviour of riverine species, such as *G. fuscipes* and *G. palpalis* subssp. has been studied less intensively compared to savanna species, but with similar objectives to develop more effective control strategies [37]. As riverine species respond only to visual stimuli, studies tend to examine their response to different shades of colour, shape and size of targets [37, 44, 81]. This knowledge contributed greatly to improved tsetse control methods [21, 47, 49] and therefore to prevention of sleeping sickness. Even so, understanding of tsetse behaviour towards artificial baits cannot directly explain their behaviour towards human hosts. The relationship between vector and human host has been extensively studied in relation to other insect vectors such as mosquitoes [87-90], sand flies [91-93], and blackflies [94]. However, little has been published on riverine tsetse and their behaviour towards the human host [36, 81, 95].

Some researchers have analysed tsetse blood meals to determine if there is a relationship between feeding preferences of tsetse and prevalence of HAT [96-100]. In these studies, large numbers of tsetse from HAT endemic foci were dissected and the proportion of blood from human and animal hosts was established using laboratory techniques. Results from these studies indicate that the nutritional preference of tsetse largely depend on various factors, namely the tsetse species, availability of different hosts, and the season. It was also argued that the zoophylic/anthropophylic index calculated as proportion of human and animal blood in the tsetse blood meal is insufficient for use as an indicator of the degree of prevalence of HAT [96].

In addition, tsetse biting preference, when multiple hosts are available, which was also studied with analysis of blood meals, is not fully understood. It is generally concluded that tsetse prefer feeding on animals compared to humans [98, 99], although some studies did not concur with this argument. The co-presence of pigs in proximity of humans, for instance, was sometimes suggested to be a protective factor for humans [101]. Other studies suggested a preference for humans over pigs [102]. Given the varying results, the studies of tsetse blood meals are not sufficient to determine the risk of HAT but are suggestive of humans entering frequently to tsetse habitats.

Another attempt to quantify exposure of humans to tsetse was through analysis of human immune response to tsetse salivary antigens [103]. A study conducted in West Africa showed that higher antigen responses in humans occur in areas with higher density of tsetse. There was no correlation, however, between high immune response to tsetse saliva and parasitological or serological positive HAT status of participants. Furthermore, individual host-related factors, which influence anti-saliva response, complicate standardization of this method as exact measurement of exposure to tsetse bites. Therefore, this study showed that analysis of human immune response does not represent a reliable biomarker of

the disease risk (ibid.). Hence, up to date no specific method is developed to determine human risk to tsetse bites or HAT.

It is known that habitats of riverine tsetse stretch as a linear belt along rivers [86]. These species of tsetse are relatively less mobile compared to savanna tsetse, due to their restriction to riverine vegetation [104]. Due to their poor mobility, tsetse largely depend on hosts entering into their habitats. Human activities along the river banks in HAT endemic foci are hence an important driver of HAT transmission.

HAT foci, risk activities and gender differences

Across all endemic countries, there are currently 303 foci recognized as active HAT transmission foci [1]. HAT foci are largely found in rural areas [22], but the semi-urban areas of Kinshasa are an exception to this [105]. The patchy geographical distribution of HAT, which is extremely localized, is not fully understood. In Uganda, for instance, high transmission parishes occur within endemic districts [13]. The striking phenomena of persistence of localized focal distribution of HAT is also demonstrated by reports of such areas in West Nile, in the 1920s [106] as well as in recent HAT medical registers ([72]; personal communication: Wamboga, C., MoH, Uganda, June 2014), The dynamic relationships between tsetse-humans-trypanosomiasis, necessary to maintain active transmission in these localized foci and the absence of these relationships in nearby non-HAT areas, have thus far not been identified.

Similarly, there is a gap in knowledge related to HAT risk groups and risk activities. Epidemiological research, focussed on screening and treatment outcomes, rarely documents risk groups and related risk activities. *Gambiense* HAT transmission is generally described as being associated with human activities around rivers or lakes and associated with the use of natural water resources. The risk activities proposed are everyday activities, that bring people into tsetse habitats, such as collecting firewood, fetching water, washing clothes, hunting, fishing, farming and mining along rivers; and the groups executing these activities were said to be the most vulnerable [6, 107-113]. Some authors note that HAT is mostly acquired within a radius of three kilometres from patients' houses [114] and the pattern of multiple patients originating from the same households is observed, suggesting that daily activities in similar living environment increase the risk [105, 114, 115]. However, the primary purpose of many of these studies is to evaluate the effect of medical interventions and not exposure to tsetse, therefore few details are provided in relation to tsetse-human exposure.

One study that provides more evidence on the risk for exposure to tsetse and HAT was carried out in Guinea and confirmed the frequent entrance of patients into riverine habitats [110]. The study compared

the daily movements of 19 sleeping sickness cases and similar controls. Using GPS techniques and following the daily movements of participants, the authors concluded that HAT cases were more mobile compared to their control counterparts. Patients also used more occupational activity sites, such as rice cultivation or pirogue jetty sites. This paper makes an important contribution to understanding of human movements in tsetse habitats. But these movements are very location specific, and no studies from other regions exist to corroborate on this evidence.

Research on differences in risks on acquiring HAT between men and women is also scarce. A few papers discuss aspects of gender-based activities, such as Gouteux et al. [116] who suggested that in Central African Republic, men working on coffee plantations, women processing cassava at the rivers and children bathing in the rivers were at greater risk of HAT. The study found that infants and young children were becoming infected as they accompanied their mothers to their activities, generally carried out in tsetse risk zones. Similarly, Morris [63], described some gender-related risk activities in West Nile in 1962. Women were reported to increase their risk by washing clothes and pots, bathing, collecting water and socializing at the river banks. Men were considered at risk for extensive traveling for social purposes, hunting, working in the fields and gathering timber. This description is now outdated given economic development of the region in the past decades, which could have influenced community behaviour. Hence, there is a need for reassessment of gender related risks.

Similarly, no epidemiological analysis related to gender exists on patients' cohorts to date. Very limited information is provided in epidemiological papers focused on active screening and treatment—and is limited to general information on patients' profiles, including gender distribution among HAT cases [105, 109, 111, 117, 118]. According to these databases, gender disaggregation of the disease is relatively balanced and the median age of patients is 20-30 years. However, no studies have considered specific health-seeking behaviour especially in relation to gender-related differences in disease. Many studies have documented that women have higher attendance at HAT screening compared to men [10, 117, 119]. Furthermore, there was a significant difference in severity of disease among men and women at the time of the first diagnosis, as observed in DRC, suggesting that women seek health care more promptly [117]. In addition, some other socio-demographic changes may influence gender distribution among HAT patients: a selective migration of men out of the foci was argued to contribute towards higher proportion of female patients in Nioki hospital in DRC [117]. These examples suggest that medical records may not serve as accurate indicators of gender differences, and therefore cannot be used to estimate differential of HAT risk between men and women.

2.4 Past attempts at community-based tsetse control with focus on sustainability

From the end of the 1980s to the end of 1990s, and along with the efforts to strengthen national health systems, commitment to involve local communities in tsetse control was strong. Post-independence, national governments in Africa struggled to finance vector control activities and community involvement was viewed as a cost-cutting solution to the problem [52]. There was also international interest in community participation, which by then was regarded as essential part of an integrated vector control strategy. WHO wrote about transferring responsibilities of vector control to the community by transforming skills and responsibilities to local communities—here is an excerpt from a WHO report written over thirty years ago:

“At present, vector control was usually carried out by specialists within an organized system and mostly in vertical control programs. The time had come for a gradual transfer of responsibility for vector control activities to the communities themselves in order to improve the long-term effectiveness of programs for the control of vector-borne diseases and to achieve economies. In the past, the role of community benefiting from control operation had been primarily that of spectators. Transformation of these people into actors has to be done gradually until control techniques were fully mastered by members of the community and undertaken by them to the fullest extent possible” (p. 8 [120]).

WHO expert groups acknowledged the need for involvement of social scientists to engage with the beneficiary communities in order to assess their priorities, the social acceptability of the new methods, appropriateness of different levels of participation and community attitudes to the vector control programmes (ibid.).

The first attempts at community engagement started soon after. In 1985 [121], Gouteux and Malonga conducted a socio-entomological survey of the Yamba focus in Congo (Brazzaville) and reported the community’s interest to be involved in tsetse trapping. One of the pioneering attempts of active community participation was conducted two years later in Niari focus across five villages in Congo [122]. Villagers were given traps and instructed where to place them and how to maintain them. Within a couple of months villagers successfully controlled tsetse, achieving more than a 95% reduction in the tsetse population. Particularly high motivation among villagers to use traps was observed in three of the villages where tsetse were more abundant. Researchers, encouraged by this success, recommended community participation in tsetse control as the only cost-effective option in Congo (ibid.).

The next step was an assessment to examine if scaling up of these small-scale community participation operations was feasible. A large scale trial was conducted in Niari River HAT focus in Congo between 1985 and 1987 [123-125], involving 55 villages, 25, 000 inhabitants and the deployment of 1, 263 traps. As a result of this large community-based campaign, tsetse were eliminated in 9 villages, and reduced by more than 90% in 38 of the villages. During the course of the programme, seroprevalance of HAT also decreased from 2.69% to 0.4%.

Similarly encouraging achievements were observed by Laveissiere et al. [126] in a three-year long intervention, which started in 1987 involving farmers in Vavoua focus in Ivory Coast. Over 3,000 farmers received ~3800 targets with instructions to deploy them on their land. High levels of participation, reinforced by disappearance of biting nuisance, continued in the second and third year of the programme with about 80% of farmers collecting insecticide for re-impregnation. Farmers carried out operations as instructed and achieved remarkable results: 90% of reduction in tsetse numbers occurred within 1 month followed by over 99% reduction after 3 months of intervention and no case of HAT was reported during the intervention period, even with implementation of active screening. The researchers concluded that farmers commitment to intervention and their knowledge of specific characteristics of their land, were responsible for this success and so they promoted this approach as time- and cost-efficient (ibid.).

However, successful large-scale operations involving communities have faced some challenges and often have not achieved complete participation. Authors attributed this to a number of socio-cultural factors, such as diversity of ethnic groups and their inter-relations, all of which were poorly understood by programme planners [126]. Supernatural beliefs, such as trapping being associated with witchcraft have been suggested as barriers to community participation [123]. Both the above-described trials recommended community participation in large-scale tsetse control operations, but the authors also concluded that communities cannot independently carry out such operations. They recommended the international and multidisciplinary teams to coordinate and supervise activities. Due to the nature of the challenges, that is the lack of understanding of socio-cultural contexts, they prioritized involvement of social scientists who were largely absent in the professional teams launching these trials (ibid.).

Other community involvement interventions using artificial baits followed until the end of 1990s. Barrett and Okali [127] reviewed several community-based projects and identified debates around factors that influence participation. They evaluated projects implemented in Kenya, Uganda, Zambia, Zimbabwe, Ivory Coast and Ethiopia, ranging in scale from 4 to 930 square kilometres. The types of community involvement in these interventions included: i) raising awareness to prevent vandalism and theft, ii) free supply of

targets from local governments or other agencies with communities being responsible for their deployment and maintenance without payment, iii) free targets, but paid labour provided by the communities, iv) free targets and labour, but individual community members contracted and paid to maintain them, v) provision of external technical assistance, but with community financing, constructing and maintaining targets.

Three major criticisms emerged from the evaluation of community involvement projects. First, the authors recognized that the majority of these projects were 'top-down', where project planners were interested in community participation as a means to achieve their own objectives as suggested by White [53]. The majority of the projects covered in Barrett and Okali's review [127] were supported by local provision of unpaid labour for target and trap deployment and maintenance, and communities were not involved in decision-making. Dransfield and Brightwell pointed out the lack of 'true' community participation:

"Farmers and communities have not controlled tsetse because, with few exceptions, they were not given the opportunity. Continent-wide, tsetse control has remained as top-down as before" (p.544, [128]).

The second criticism was about unclear objectives and expectations. Catley et al. [129] noted that these projects lacked clarity with regard to key objectives of interventions and were ambiguous about the extent to which the community was responsible for maintaining targets. They also did not incorporate local organization capacities into the project design. The third criticism was that despite community participation being generally promoted, there was a lack of commitment on part of the project planners and donors, towards community involvement. Barrett and Okali [127] commented that the number of community involvement projects was relatively small, considering the large area infested by tsetse. Similarly, Williams et al. [130] criticized a large World Bank funded-project aiming to eradicate tsetse over thousands of square kilometres in Western Uganda, for not proposing community participation methods.

However, in the number of top-down projects, there are three published exceptions, designed as bottom-up interventions, and which seemed to address some of these criticisms. The bottom-up approaches are defined by the interest being placed in participation itself and by participants being given decision-making powers [53]. The earliest project was established in 1987 with the Maasai community in Kenya [130]. Two British scientists acted as advisors and community members carried out their own tsetse control. The Maasai community constructed, deployed and maintained traps and sustained suppression of tsetse

density to below 10% in the first three years of the project. The project, managed by Maasai, was extended for an additional three year period, during which time the area of control was expanded to nearly 1,000 square kilometres and additional beneficial changes occurred in the community. Success of the project attracted the interest of different stakeholders and the region gained new development opportunities through ecotourism, women's education and local trade.

The second exception, published in 1991 [131] involved local farmers in Southern Uganda. Local communities were encouraged to provide trap materials and were trained in making and using traps. Traps were deployed on sites previously mapped by the members of community. This intervention also involved collection of the monetary contributions from cattle owners and well users in tsetse control area. Sixty-six traps were made in three months and each trap owner kept tsetse monitoring sheet. Authors do not report on the duration of this intervention or its impact on prevalence of HAT or density of tsetse, but they recommend community participation as feasible.

The third example was a project conducted in Tambura County, South Sudan, in 2002 in the context of HAT control [132]. In this project, extensive training programmes were established at national, county and village levels, which were organized as 'training of trainers' interventions. Villagers were involved in creating village maps, making decisions about trap sites, and constructing, deploying and maintaining traps. Between 1997 and 2001, over 3,000 traps were produced by local tailors and women's groups and deployed in the sites frequented by villagers. These activities, carried out by 350 volunteers, particularly female traditional birth attendants, resulted in a reduction in the apparent abundance of tsetse from 25 flies per trap per week before the intervention to less than 3 flies per trap per week four years later. The prevalence of HAT also dropped from almost 9% to less than 2%. In this operation, the community was involved in decision making and took complete responsibility for tsetse control.

After 2000, an interest in community-based interventions seemed to decline and very few papers were published on community participation in tsetse control. Most of these studies did not focus on core community participation methods and activities; instead, they were about examining factors which influence community participation, particularly community willingness to contribute money and/or labour towards tsetse control [133-137] or their perceptions of the tsetse control tools [138]. Only three studies in the past 15 years were concerned with active participation of the local communities (Table 2.1). In the Guinean study, members of the community were informed about the project objectives and expected to support the intervention by creating access routes and burning vegetation to clear sites for control baits [139]. Similarly, in Ethiopia [140] communities were provided with training and traps and

required to participate in their deployment, maintenance and collection of the tsetse catches. From a community-participation standpoint, both projects were designed as top-down interventions, as they excluded community members from any decision-making roles. Thus, the only bottom-up intervention, where communities were given an opportunity to fully participate in decision-making and actively organize and implement tsetse control was that implemented in South Sudan (as already described) [132].

Table 2.1: The summary of active community involvement projects published after year 2000

| Author | Country | Extend of community involvement | Key findings | Main approach |
|-------------------------------------|-------------|--|---|---------------|
| Kagbadouno et al. 2011 [139] | Guinea | Community sensitized, requested to support externally managed control programme. | Successful tsetse control operation; no tsetse caught in monitoring traps after intervention; support of local communities crucial for this success. | Top-down |
| Sciarretta et al. 2005 [140] | Ethiopia | Community involved in trap deployment and monitoring. | Community involvement contributed to more effective use of the tsetse control tools. | Top-down |
| Joja and Okoli, 2001 [132] | South Sudan | Active community involvement in making, setting and maintaining traps. | Four years of community-based programme resulted in over 3000 traps being manufactured and maintained achieving effective tsetse control. Participation contributed to better community awareness and participation in medical interventions which had an impact on drop of HAT prevalence in the region. | Bottom-up |

Community provision of programme support was only one aspect of debates on cost and technical difficulties of different tsetse control interventions and the impact of these elements on sustainability. Towards this end, some economic studies comparing different techniques have been conducted [39, 141-143]. Economic analyses have been used to improve cost-effectiveness and to provide comparative tools for advocacy [144]. Despite community-based approaches being used to improve cost-effectiveness of interventions, very few community-based studies using artificial baits included cost analysis and all of them are outdated [125, 126]. Further, all these studies treated community labour as a voluntary component, therefore community contributions were not accounted for in these analyses. To date, only one publication on tsetse control attempts to cost farmers' time in terms of opportunity cost of bringing cattle for insecticide application to control tsetse [145]. In summary, no community based intervention, using artificial baits as the main tsetse control method and including the full cost of both, expert and community components, has been published thus far.

2.5 Involving women in tsetse control and other health prevention programmes

Gender differences in preventive health behaviours are well-documented across the globe for a range of communicable and non-communicable diseases [146-150]. In this body of literature, women are generally described as being more concerned with health [146], more constructive in their health-seeking and health-protective behaviours [10, 117, 119, 147, 150, 151] more knowledgeable [10, 146], having more contact with health facilities [10, 146, 149], adhering better to health interventions [151] and are less concerned with stigma [149]. Elsewhere, the participation of women's groups has had beneficial impacts on intervention coverage [152], sustainability [152] and quality improvement of the health facilities [153].

A considerable amount of research has been generated on women's group interventions, particularly in the area of reproductive, child and maternal health [150, 154-158]. These interventions have been implemented through participatory action and learning cycles and were organized through establishment of formal women groups having common health interests and concerns. Debates in this literature are focused on the evidence of the clinical outcomes. Meta-analyses of studies from Bangladesh, Malawi, India and Nepal using women group interventions to improve maternal and new-born health [54] showed encouraging results. If at least one-third of pregnant women participated in interventions, this resulted in significant reduction in maternal and neonatal mortality. Furthermore women-based interventions, which were organized as long-term (~3 years) and large scale (~30 village clusters) programmes, were cost-effective according to WHO standards. In addition to these positive examples from maternal and child health, women's group interventions showed positive outcomes in other disease prevention programmes such as malaria [159], HIV/AIDS [155, 160, 161], and access to clean water [156] among others.

While there are numerous instances of women-based interventions having a positive impact on the effectiveness and sustainability of disease control, only two exist from tsetse and HAT control. The first study involved traditional birth attendants in tsetse control operation in South Sudan [132]. Although the success of this operation in terms of coverage, and reduction of tsetse and HAT was attributed to involvement of women, this paper provides no details on exactly how women contributed to the intervention.

The second study evaluated involvement of the women's groups in the dissemination of health messages related to trypanosomiasis in western Kenya [162]. Researchers examined the structure of community-based organizations and concluded that almost one-third of these organizations were women-based and that representation of women in other, formally established groups was also high. The study concluded that messages could be effectively disseminated via already existing groups and estimated that on

average, between 400 to 600 people a day could be reached through this approach. The results also highlighted adequate knowledge amongst participants on tsetse control techniques. However, no analysis of gender differences in this knowledge was carried out. Despite this limitation, the authors recommended involvement of women as an effective means for tsetse and trypanosomiasis sensitization campaigns. No further studies were conducted to evaluate the actual impact of this women's involvement approach.

In conclusion, despite the involvement of women in other disease control programmes, and the evidence to document the success of this approach, it remains largely unexplored in tsetse and HAT control.

2.6 Stakeholders in NTDs and current HAT control policies

A large volume of literature exists on translation of the research findings into policy and practice and factors that influence this process. For instance, this process can be fostered if the research evidence is presented so that it provides a convincing and feasible argument for policy makers [163] and this also requires time. Bowen and Zwi [164] call this period "adaptation", which is a period when decision makers are involved in the process of understanding and implementing the change. It has been suggested that "adaptation" is influenced by multiple factors, such as beliefs, knowledge, leadership, and professional networks. Personal traits such as attitude towards change, risk-taking capacity, and curiosity for innovation, were suggested in addition (ibid). Analysis, through systematic review, of how policy-makers use research evidence [165] further suggests that personal contact between researchers and policy makers, timely delivery of evidence and provision of policy recommendations to accompany research results, promotes uptake. Conversely, low interpersonal contact, lack of trust, irrelevant evidence delivered at unfavourable times along with unrealistic budgets and complex power dynamics can create barriers (ibid.). Recognizing who is the target policy audience, taking advantages of windows of opportunities, considering threats and being persistent are some additional factors suggested as catalysers of the policy change [166].

To explore the context in which HAT control policies are developed, I reviewed publications that examined collaboration between different stakeholders and their interactions. In the broader area of NTD control, specific attention is given to discourses on multi-sectoral and multi-actor collaboration (e.g., [167-170]). This literature promotes the need for long-term commitment, close partnership, definition of stakeholders' roles and coordinated action for success of sustainable control programmes. Certain frameworks (Okello et al. [171], zoonotic NTDs, for instance) examine the understanding of the actors'

networks, discourses, politics and interests as these are considered to be essential starting points for the development of recommendations for disease control.

In HAT control, few publications exist with a specific focus on collaboration between stakeholders. One publication is a WHO report on the first meeting of stakeholders working towards elimination of *gambiense* HAT [5]. This report lists participants from national HAT control programmes, expert groups developing new tools, national and international NGOs, pharmaceutical companies, such as Sanofi and Bayer healthcare, Belgian Development cooperation, Bill and Melinda Gates foundation and the Wellcome trust. Other actors working in HAT control mentioned in the literature include United Kingdom's Department for International Development (DFID), The International Centre on Insect Physiology and Ecology (ICIPE), the International Atomic Energy Authority (IAEA), the Food and Agriculture Organization (FAO), World Health Organization (WHO) and European Union (EU) [172].

Another example of an expert joint collaboration is development of global HAT elimination strategies [172]. Based on key informant interviews with multiple stakeholders, strategies for the possible elimination of disease were developed using new tools. Examples of new drugs for HAT, new diagnostic tools, the use of tiny targets and delivery of these tools using motorbikes are captured in this strategic plan. These indicate that multi-sectoral approaches were used for development of these recommendations.

Despite instances of collaborative efforts, little is published on networks and relationships between different stakeholders in HAT control arena. One example is Morton's discussion paper [173] on how the research knowledge is disseminated in the context of public-private efforts to control *rhodesiense* HAT in southern Uganda. Morton noted that Ugandan researchers were playing a major role in communication between British researchers working in Uganda and Ugandan policy-makers. He further proposes that research knowledge is mostly disseminated through informal interaction, rather than through scientific articles, briefing papers and executive summaries.

The WHO report touches upon the issue of partnership and attributes great achievements in reduction of HAT cases to 'strong collaboration and coordination' and 'opened dialogue' among all stakeholders [5]. Some publications however, demonstrate that not everything is smooth in the relationships of actors in this field. There are particular arguments and tensions around promotion of sterile insect technique and on goals to eradicate versus control tsetse in HAT elimination strategies [39, 172, 174, 175]. A critical article published by Scoones [172] also discussed frictions among different stakeholders and how each

stakeholder promoted their own preferred method of vector control. He argued that up-take of control strategies were affected by several factors, including personal ambition, corruption, the political economy of aid and development, and post-colonial attitudes.

2.7 Summary

Uganda and particularly the West Nile region has a long history of HAT interventions and control. A body of literature exists on colonial approaches to control HAT. This literature describes the rebellion of local communities against coercive control measures. It indicates that communities were forced to comply with the programmes and as a consequence potential collective negative memories may have been generated during this historical period. In addition, reports from the recent MSF campaigns are focused on epidemiological outcomes, rather than community views of their medical campaigns. Thus, so far, little attention has been accorded to the attitudes and perceptions of the local communities who for decades participated in different HAT control programmes. There is therefore a need to explore the collective memories of communities on previous HAT control interventions and to move away from only epidemiological outcomes to more community-based understandings of HAT control interventions and strategies. This thesis explored elders' views on HAT control interventions because of the potential insight this could provide on likelihood of acceptance of new interventions.

A vast literature on tsetse host seeking behaviour exists, but very little is published in relation to the human hosts. Furthermore, there is a gap in our understanding of whether exposure to tsetse and HAT is gender-related. To help better understand gender differences in exposure to tsetse and therefore HAT, this thesis examined daily activities of men and women, to what extent these activities brought them to tsetse infested areas, and any differences in exposure between men and women. Furthermore I explored if exposure to tsetse was related to perception of risk and these insights were used when introducing women-led tsetse control intervention.

Although community-based approaches to vector control were popular at the 1980s and 1990s, attention to community engagement has dwindled in the past three decades. Only one example of active community intervention exists from South Sudan and the same operation is the only attempt to actively involve women in tsetse control. There is however a collection of research studies examining the role of women in promotion of health and uptake of health-related services. The intervention developed and evaluated in this thesis is based on the premise that involving women has the potential to achieve better sustainability of tsetse control using tiny targets. Because intervention was implemented and evaluated

through action research, this provided an opportunity to better understand feasibility as well as the cost-effectiveness of such intervention, using finances from both, expert and community contributions.

Lastly, some evidence of collaborative efforts of different stakeholders such as various donors, WHO, governments and academic institutions exists, but little is known about relationships between these stakeholders, and how these relationships influence the decision-making process in global HAT control strategies. Further, the perceptions of decision-makers on the roles of local communities in HAT elimination plans is not really considered in the literature. To understand these perceptions is important because of the potential value of active community participation as opposed to passive acceptance of the programmes, particularly in the context of interventions aiming to eliminate HAT. I explored these perceptions in the last phase of my research study through interviews with different stakeholders in HAT control arena.

Chapter 3: METHODOLOGY

3.1 Chapter overview

The chapter begins with a conceptual framework illustrating theoretical models that influenced the research methodology. The broader background of social science theories and justification for the methodology and methods is provided in appendix (Appendix B). The study area and the study population are presented. This is followed by an overview of three research phases: i) factors influencing community participation, ii) intervention / evaluation of women-led tsetse control operation, and iii) stakeholders' reflection on control strategies. A detailed description of data collection and analysis methods is provided. The chapter concludes with a description of the processes used to ensure the maintenance of ethical standards in the implementation of this research.

3.2 Theoretical approaches influencing this research

In order to develop a research methodology, I drew upon elements from different theoretical approaches and models. A conceptual framework (Figure 3.1) illustrates these theoretical frameworks and links them to the specific areas of research that they influenced. All phases of this research were influenced by the theoretical framework of 'force field analysis', established by Lewin [176] and adapted to manage organizational change [177]. This framework examines the forces which work for and against change. The aspects of the 'health belief model' and the 'social ecology model' informed the baseline phase of the research, which emphasised the importance of exploring factors that influence community involvement in tsetse control operation. Principles of community participation framework, action research theoretical approaches and 'social ecology model' were the premises on which women groups' involvement was based in the intervention and evaluation phase. A description of each theoretical approach and how they influenced the choice of research design is provided below.

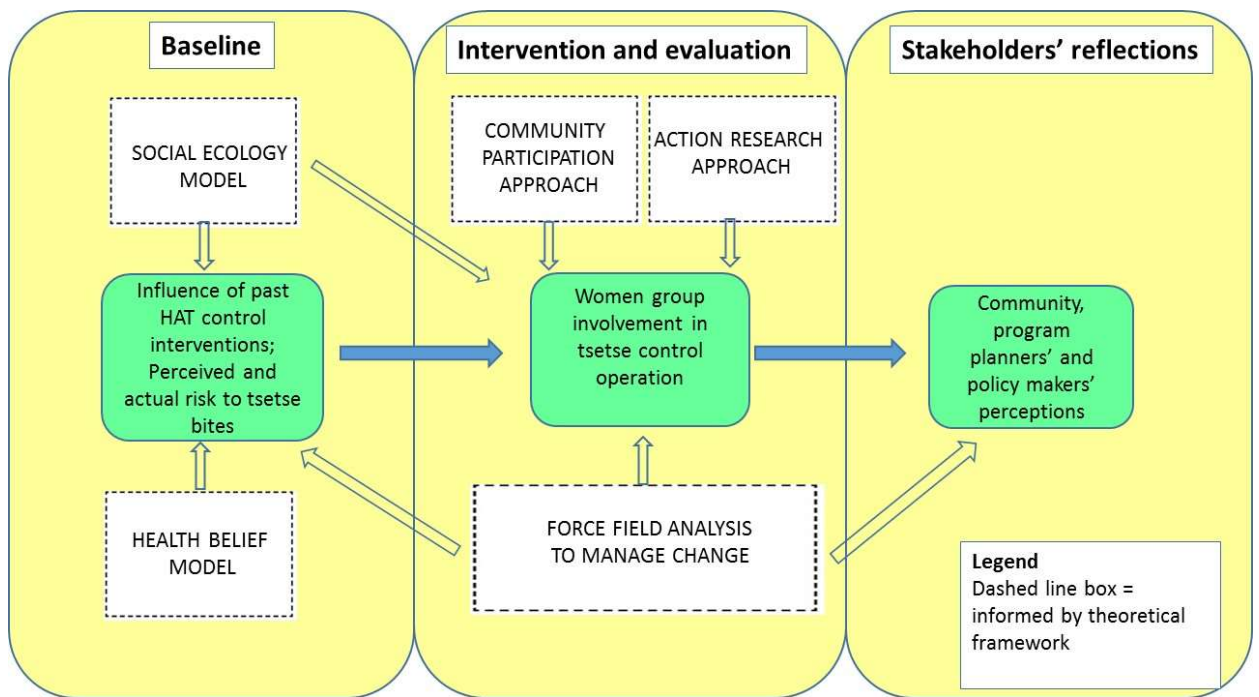


Figure 3.1: Conceptual framework

The 'force field analysis' framework

The overall framework, one that connects all the phases of my research is 'the force field analysis' which I borrowed from business management literature [177]. This framework, looks at change as a process that emerges between 'present status quo' (current situation) and 'new status quo' (desired situation). This process is influenced by 'driving forces' and 'resisting forces', which co-exist within the environment into which the change is introduced and which explore how the change may be expected to occur (ibid.).

Introducing active community participation into the current, predominantly top-down HAT control policies, required a certain level of conceptual and process transformation. In my study, the environment and its receptiveness for change (e.g. from no active community participation to active community participation) is associated with various factors: the participating community, policy makers and programme planners involved in HAT control interventions, and operational elements characterizing the intervention, as illustrated in Figure 3.2. Driving and restrictive forces, such as intra-personal, socio-cultural and political contexts, which exist at each of these levels are related to perceptions of all stakeholders and their social environment. Operational elements, such as cost, feasibility and sustainability of intervention also play a crucial role and (in Figure 3.2) are positioned between community and decision-making levels. To gain insights into transformative processes that require the change to

occur, I explored both interaction between driving and resisting forces within each level, as well as processes that occur in bottom-top-bottom interactions. I return to this theoretical framework in Discussion/Conclusion chapter to reflect on findings from all research phases.

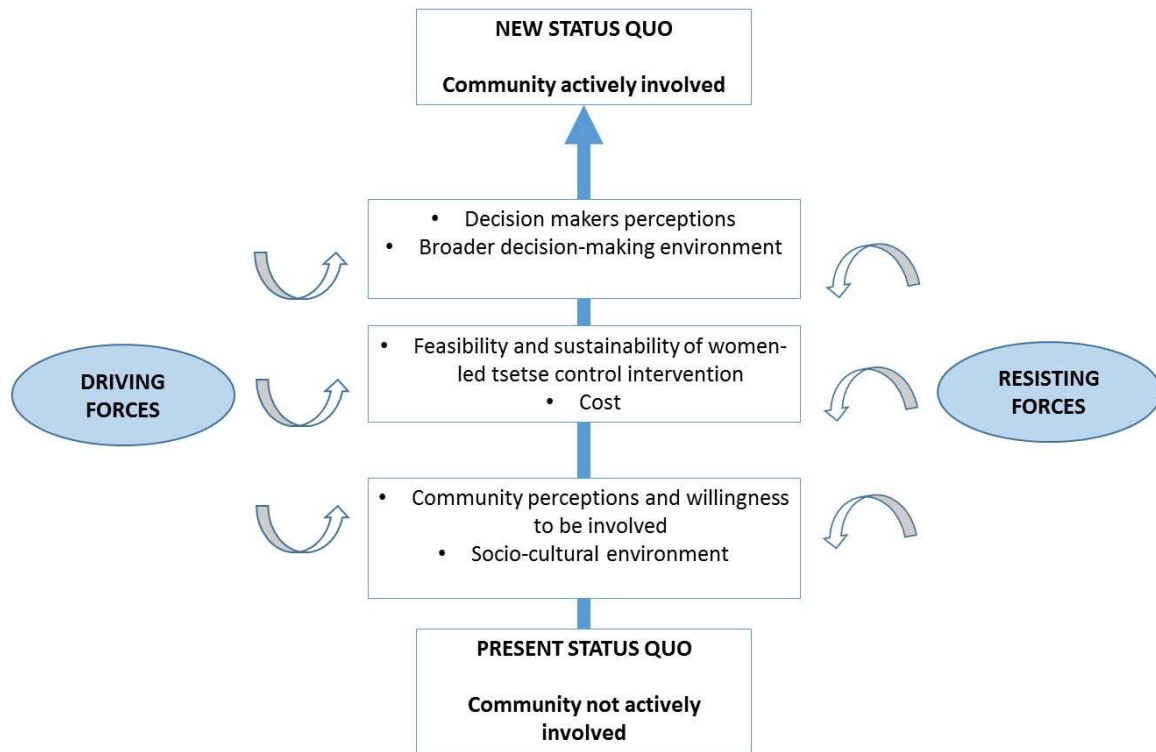


Figure 3.2: Driving and resisting forces in the process of introduced community participation

Health belief model

Various behavioural theories are used for understanding of health-related behaviours. Despite the existence of many health behaviour theories, such as ‘theory of planned behaviour’, ‘theory of reasoned action’, health belief model’, ‘trans-theoretical model’, and ‘social cognitive theory’ (all cited in [178]), there is a search for a single, stronger and more widely acceptable health behavioural theory, a process still underway. Criticism of all stated theories have centred around the similar nature of different variables cutting across different models, and the lack of a single empirically-tested and integrated model (ibid.). Janz’s health belief model [179], which influenced my research, has its origins in psychology and is guided by social cognitive theory [180].

The health belief model [179] was developed to explain and predict individual health-related behaviours. This model suggests that individuals who perceive themselves to be highly susceptible to diseases with severe outcomes are likely to adopt positive health-related actions, especially if barriers to these actions

are perceived to be low and benefits are perceived to be high [181]. This framework helped to make decisions on aspects to explore in baseline phase, namely to: i) examine which group in my study location perceive themselves to be under the high risk of exposure to tsetse and HAT and ii) to assess how this perception influenced community willingness to be involved in HAT control interventions. Being aware of the expanded versions of the original Janz's model [182, 183], I was guided by the most commonly used variables in health belief model studies, which remain the original four [181]:

- 'Perceived susceptibility' e.g. perceived risk of contracting HAT
- 'Perceived severity': e.g. seriousness of contracting HAT in relation to medical and social consequences
- 'Perceived benefits': e.g. advantages of involvement in tsetse control its feasibility and perceived efficacy
- 'Perceived barriers': e.g. disadvantages of involvement in tsetse control, such as time lost, cost barriers and inconvenience, and potential social disadvantages.

Social ecology model

Individual health beliefs are influenced by social, cultural and institutional context. The social ecology model [184] focuses on the broader environment, into which health related interventions are embedded. I used this model in my thesis to overcome some of the limitations related to more individualized factors proposed by health belief model (Ibid). Social ecology model, for instance, suggests that socially driven factors, such as knowledge of disease, interpretation of symptoms, and community attitudes towards control intervention result from internal group interactions and interactions of groups with their social and physical environment [184].

Panther-Brick et al. [184] used this model to analyse malaria control intervention. Authors provided an example of mosquito net sewing as a low-cost and socially acceptable solution, which was found to be successful promoting the desirable behavioural change. They criticise the expectations of disease control programmes as being unrealistic and propose that expected behavioural change must not only be culturally appropriate, but also culturally appealing and culturally effective. Thus, for an intervention to be successful, the authors emphasise inclusion of both facilitating mechanisms and barriers within accepted norms of the groups and their social environment (ibid.).

I applied the social-ecology framework to: i) evaluate the appeal and appropriateness of tsetse control interventions in the context of community experiences with previous HAT control interventions and; ii) develop women-led tsetse control interventions and examine if the processes involved in this are realistic

from programmatic and participants' viewpoints. In using this framework, I considered the local capacities, economics, time and social barriers that could potentially influence the process.

Another aspect, explored broadly by the social ecology model is the dynamics of the individuals in the groups and its influence on individual willingness to collaborate. Ostrom [185] for instance discussed evolutionary and social aspects of collaboration and the notion that individuals are driven by self-interest to the extent that they cannot participate in collective action, even if this has a mutual benefits. He describes two types of group participants: 'potential collaborators' and 'potential free riders' (or 'rational egoists'), who would not contribute, but would benefit from group efforts.

Experimental studies, using a set of different decision-making rounds and 'types of players' (both: 'potential collaborators' and rational egoists') showed that multiple factors play a role in collective action. A larger number of decision making rounds, higher degree of free riding and less information on decisions from other players, for instance gradually reduce collaborative action within the group. Ostrom, however comments that human social groups developed face-to-face communication and other mechanisms to monitor each other's behaviour. He concludes that from evolutionary perspective, potential collaborators had advantages by receiving more benefits compared to 'rational egoists', who got gradually mistrusted and sanctioned by the group. This hypothesis was used to explain a wide spread group collaborations in different settings (ibid.).

Community participation theoretical principles

Participatory research is concerned with handing over control and ownership of research activities, outputs and outcomes to beneficiaries and it perceives beneficiaries as drivers of the process rather than the process being imposed on them [186]. Community participation encompasses a range of different approaches, in various areas, such as health delivery, health promotion, community development, social, economic and political justice [187]. My research specifically focuses on the health delivery framework.

Different levels of community participation have been suggested depending on the level of engagement between 'outsiders' and 'local people' ([188]:96). This engagement varies from:

- i) 'co-option': local people are given a token, but have no input;
- ii) 'compliance': outsiders decide on agenda, direct the processes, and allocate tasks to local people;
- iii) 'consultation': local people are consulted, but all the action is decided by outsiders;

- iv) 'co-operation': local people contribute towards developing priorities, but outsiders decide on action;
- v) 'co-learning': local people and outsiders work together towards a mutual understanding and collaborate in developing action plan, which is facilitated by outsiders; and
- vi) 'collective action': local people set their own priorities, action plans and carry them out in absence of outsider (ibid.).

My intervention and evaluation research phase was guided by the 'co-learning' level of participation where the community took a lead in planning and managing interventions with external support i.e. that of myself and my research team.

Furthermore, my methodology was strongly influenced by current discourses which seek to establish links between participation and health outcomes. Rifkin [189] for instance reviewed a number of community participation interventions from communicable and non-communicable diseases and concluded that many participatory interventions have an impact on improved health outcomes. The role of community participation and its direct links with these outcomes, however, remain poorly understood and undefined. She suggests that this is due to several problems: i) there is no standard definition for the terms 'community' and 'participation'; ii) community participation is merely defined as an 'intervention' and evaluated only through health related outcomes, rather than through all the changes that occur in participation process; and iii) there is no practical and conceptual framework to measure the full impact of community participation. Hence, most community participation interventions are also hard to compare, since there is a lack of qualitative components for evaluating their replicability and generalizability (ibid.).

To overcome some of these issues my research was guided by definition of community participation as a 'process that supports interventions' as suggested by Rifkin [189]. This approach values the transformative and dynamic process of participation as being as important as other health-related outcomes [53, 189, 190]. Thus, the mutual learning process in this approach is defined as one of the main research objectives. This strongly influenced the development of the evaluation phase in my study. Women-led tsetse control was thus evaluated as a dual process: first, by its impact on the community and second, by its impact on control operation. Decisions on what aspect to evaluate were informed by Rifkin's framework [190] for measuring community participation which recognized the need to specifically examine the 'process' of participation. Specifically I adopted and measured Rifkin's suggested domains,

such as leadership, empowerment, ownership, capacity building, resources mobilization, management, cost-effectiveness, feasibility and sustainability [189].

My research approaches were also driven by critical debates that explore issues of participation in the context of power and control. Cook and Kothari suggested that the division of power is exercised on a different levels: among participants themselves, between facilitators and participants or between donors and beneficiaries [191]. Authors call this unequal distribution of power 'tyranny' and distinguish three areas where it is implemented:

- i) 'the tyranny of decision-making and control', where imposed by facilitators and their unequal power relation with participants is suggested;
- ii) 'the tyranny of the group', where power relation dynamics within group prevent less powerful members to be involved in decision making processes;
- iii) 'the tyranny of method', where authors question if participatory methods have not replaced other complementary methods, more suitable for the purpose (ibid.).

Furthermore, Mosse [192] argues that term 'participation' can be used by 'experts' to manipulate local communities and extract 'local knowledge', which they then use to serve their own interests. He argues that the knowledge is created by the dominant views and less dominant opinions, particularly if they are not in accord with the project objectives, are commonly excluded. Similarly, an influential medical anthropologist Farmer [193] writes extensively about 'whose knowledge counts' and how the authority of the external expert agencies involved in public health become institutionalized. He claims that organizations in the name of 'legitimized knowledge' exercise control over individuals and argues that inequalities in global health are driven by such disparities.

Participatory Action Research (PAR) approach

Participatory action research (PAR; or shortened 'action research' (AR)), which is also referred to as 'participatory learning and action cycles' [194] presents the core of my research methodology and is strongly focused on equal distribution of power. PAR was developed when social science researchers demanded more participatory approaches which feed directly back into the environment where research is carried out [195]. Action research approaches are based on the principles of conducting research 'with' people rather than 'on' people [196]. PAR is mostly, but not exclusively used in the context of empowerment of marginalized communities and is concerned with power and equity [197]. According to Chambers [195], three main predominant ideas are used across different types of action research: i)

powerless people are capable of analysing their own situation and planning for change; ii) an outsiders' role is concerned with facilitation of change; iii) powerless people can and should be empowered. Furthermore, in contrast to traditional research where roles of researchers and participants are mutually exclusive, in action research, the boundaries between them are blurred [196].

Action research is a dynamic process, oscillating between ownership and participation [198]. PAR is not a pre-designed process; its unpredictability reflects the unpredictability of human nature. The main characteristic of this process is therefore its flexibility and adjustable nature. In short, as other authors have phrased it: "perfect action research cannot exist" (p.547:[198]). The focus is shifted from participants being an object of research to actively contributing towards producing and owning research knowledge, which occurs as dynamic interactive process [199].

The Implementation and evaluation phases of my research were conducted through action research. Throughout these research phases the main principles of PAR, such as not having a hierarchical relationship between researchers and participants, a flexible learning process for both parties and decision-making processes dominated by participants [186, 200, 201] was followed. I used an adjusted version of the PAR cycle [202] with three main phases: i) planning, which included prioritizing the problem and planning tsetse control operation; ii) action, which comprised of deployment and maintenance of tsetse control tools; and iii) reflection on all the processes carried out. PAR consists of different techniques [199] and I used participatory and other qualitative methods along with some quantitative assessments which are further described below.

Theoretical approaches of research impact on policy and practice

Debates promoting bottom-up approaches are commonly opposed in the literature by authors who emphasise that apart from the community, involvement of government sectors is required for change in practices to sustainably occur. Reforms in political, health, educational, media, and agricultural sectors were, for instance, proposed in efforts to achieve the "health for all" initiative [187]. This process inevitably includes communication of the researchers with decision-makers from different disciplines and sectors.

This course of action, however, is not always straightforward and involvement of decision-makers in dissemination of research knowledge is widely debated in the literature focusing on translation of the research into practice. Nutley et al. [203] emphasise the need to use research knowledge in decision-making contexts. This process, they argue, depends on the nature of evidence, facilitating mechanisms to

translate it into practice and the context in which the change is yet to occur (ibid.). Morton [173], similarly argues that interpersonal relationships are more important as drivers in the process of dissemination of research results compared to scientific publications.

3.3 Study area and participants

Geographical position and research context

Studies were conducted in the north-western part of Uganda in Arua (N02°32'26.78"-N03°21'07.66"; E030°46'10.63"-E031°32'19.18"), Maracha (N03°07'10.68"-N03°22'08.59"; E030°48'09.17"-E031°04'30.42") and Koboko Districts (N03°19'24.76"-N03°44'34.68"; E030°51'44.35"-E031°06'05.69"). Figure 3.3 shows the river systems in this area and locations of the villages selected for each particular research phase.

This research was embedded in a larger programme funded by the Bill and Melinda Gates Foundation [47] (as discussed in section 1.4). In this programme, tiny targets were deployed over 500 square kilometres around river system of Maracha and Arua districts (see Figure 3.3, externally-led tsetse control). Tsetse were monitored in Koboko to provide an experimental control in which targets were not deployed. This Gates' funded or 'externally-led tsetse control intervention' was used to evaluate women-led tsetse control operation which is described in section 3.5 below.

My research sites were partly within the Gates' trial area and partly in the experimental control (i.e., non-intervention). In West Nile there are a few localized areas recognized as HAT foci [72]. Seven villages, selected for all the research phases were located in these HAT foci to ensure that results are actually relevant to HAT control strategies (Table 3.1, villages Ve to Vk). In the baseline 1, it was important to evaluate if community memories related to HAT interventions defer between both areas, therefore four of the villages for this study were selected in HAT foci and four in a non-HAT foci (Table 3.1, Va-Vd).

Gate's intervention was conducted in HAT foci as well (southern two districts: Arua and Maracha) and overlapped with some of the villages selected for my research. However, I ensured that this intervention did not impact on data collection. In the baseline 1, for instance, where it was important to keep communities unexposed to the tsetse control baits, data collection process was completed before any sensitization activities or target deployment was carried out in Gates' intervention.

Three villages (Table 3.1: Vi, Vj, Vk) in Koboko HAT focus were selected for ‘intervention and evaluation’ phases and the first part of ‘stakeholders’ reflection’ phase (the role play). This area was selected because communities had no previous contact with my research team nor with an intervention related to Gates’ project. This was absolutely essential so that the process of action research started on completely neutral grounds and unbiased by previous contact of the community with tsetse control tools or ideas related to delivery of this intervention.

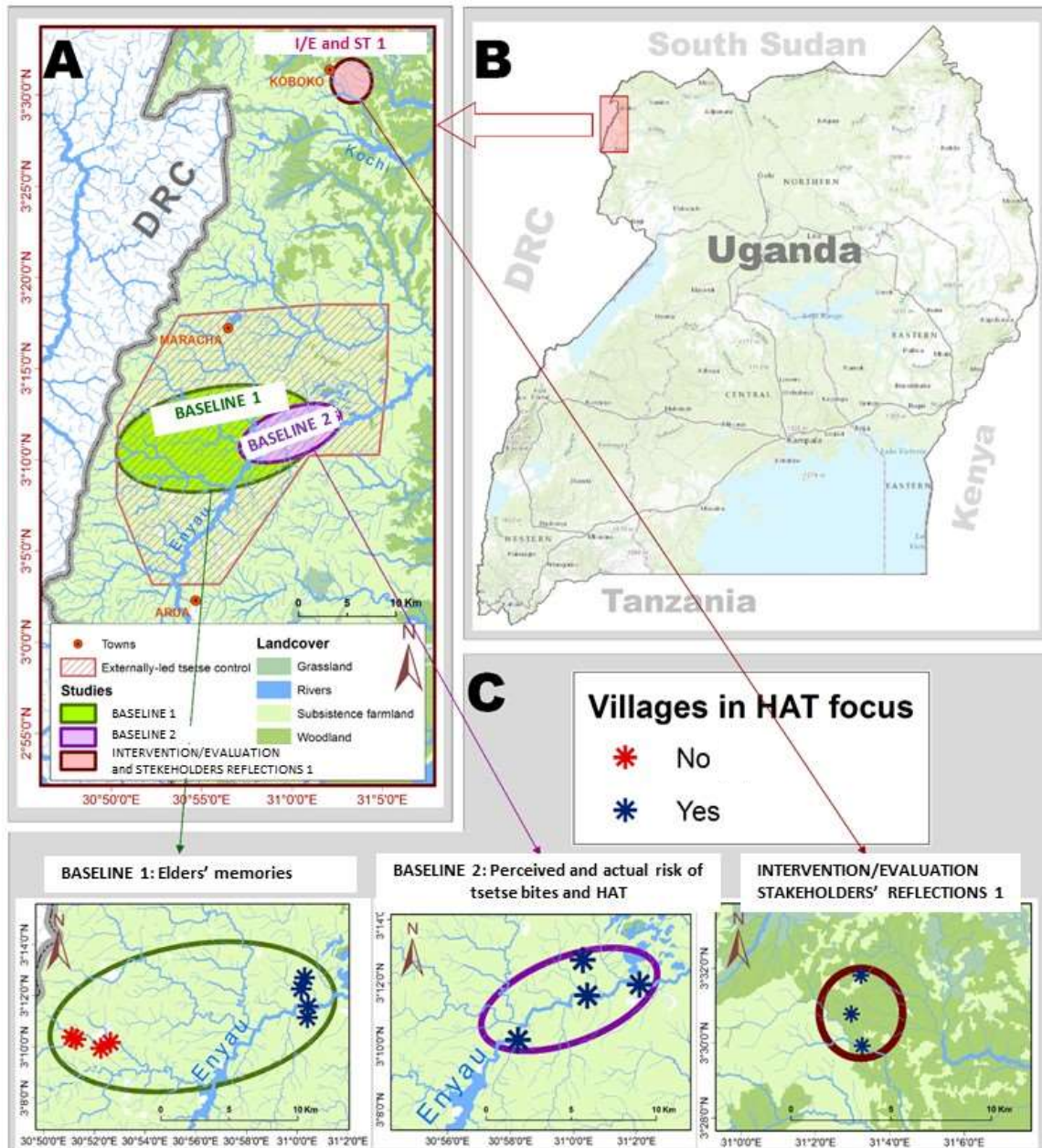


Figure 3.3: Map of West Nile and study locations

Study participants

The Lugbara ethnic group, which is the only ethnic group I worked with, settled in the territory of West Nile in Uganda, Democratic Republic of Congo and today's South Sudan [204]. Central Sudanic speaking Kakwa overlap with Nilo-Hemitic Lugbara territory on its northern side. It has been estimated that Lugbara and Kakwa ethnic groups have been neighbours for as long as three and a half centuries and Kakwans are gradually becoming assimilated with Lugbara group. The historic systems of inter-marriage between both groups are still common today. Today Lugbara represents one of the largest Nilotic groups in Uganda [205]. During the British rule, Lugbara was introduced in schools as the official language in the entire area [206]. Lugbara language has many different dialects, but people speaking them, are able to communicate fluently with each other.

Even before the introduction of the Christian and Muslim religions in this area, Lugbara believed in a single deity, called *adroa*, who created the world [205]. They still combine traditional beliefs, which are based on the importance of spirits and departed ancestors. Dead ancestors are still considered to be present in the world of living relatives and are believed to have protective powers or powers to bring sickness (*ibid.*). Over the past century, Christian (Catholic and Protestant) and Muslim traditions have also been assimilated by the community. Polygamy is still widespread particularly among communities that practice Islam. Mwakikagile in 2009 [205] reported that about one third of men had multiple wives, but that this trend is declining in recent years because of the Church being against it.

Lugbara are mostly agriculturalists. Their food crops include cassava, sorgham, millet, maize, sweet potatoes, beans, and some widely grown green vegetables locally called *dodo*. Maize is also used for brewing local beer. They plant cash crops sporadically, mostly tobacco in the northern part and groundnuts across of the West Nile. They mostly breed goats, chickens, some cattle and in non-Muslim areas, pigs.

A typical family compound comprises of a group of small round huts built from a mixture of mud and cow dung or, more recently, bricks, and arranged in a circle. Adults and small children sleep in one hut (each wife has her own hut in polygamous communities); older children are separated into another hut and the kitchen is usually separate as well. Clan names are given to all constituent lineages. The daily scenes in the villages are similar to the rest of rural Africa: adults working in the fields, women carrying water on their heads in plastic containers, goats and chickens wandering around, girls grinding peanuts, elders chatting under the tree, and children playing in the dust.

Women in rural West Nile hold relatively independent role in relation to the male members of community. In many examples I observed, women were, at least partly, in charge of the households' decision-making. This position is facilitated by women access to some financial resources, by selling crops and local beer at the village markets. Women who are in the roles of traditional authority (village heads) or administrative authority (district administrative officers) are well respected by the community.

The villages in Uganda are administratively recognized as units, comprising parishes, which are joined into sub-counties. All these levels of organization have administrative heads. Village chiefs, for instance, represent a local government. Similarly, village health teams (VHTs) each comprising two volunteers elected by the village are an extension of the formal health system in Uganda. MSF France and MSF Spain collaborated with VHTs during their sleeping sickness sensitization campaigns and most of the areas, where this research was conducted, received some information on sleeping sickness and its management.

Local communities in West Nile use pluralistic health services [207]. The term 'medical pluralism' is used to describe multiple treatment systems that spatially co-exist with bio-medicine. It is extremely common in the health seeking process, for people in the study area to use different treatment options. These options range from the formal health system, such as hospitals and health centres, to traditional methods, such as herbal treatment and traditional healers. Self-treatment with medications bought in local drug shops, often run by lay people, with limited or no formal medical education, is also very common [28]. In this pluralistic medical context and along with the common belief that sleeping sickness is caused by witchcraft and sorcery, HAT patients have frequently consulted traditional healers. A combination of prayer, amulets, application of herbal mixtures on the skin previously cut with razor, and oral intake of herbal infusions have been used as remedies (ibid.).

3.4 An overview of three research phases

An overview in Table 3.1 lists methods used to address objectives in each of the three research phases. The detail on number of participants and their profiles is also provided. In total 96 in-depth interviews and 49 focus group discussions were conducted with over 280 participants over four years of data collection. Specific methods related to each phase are further described in sections 3.5 to 3.7.

Table 3.1: An overview of three research phases: objectives, data collection methods, participants

| Research phase and objective | Specific objectives | Data collection methods | Participants (number) |
|---|---|--|--|
| <u>BASELINE</u> – factors influencing community involvement in tsetse control | To explore influence of past HAT control interventions | In depth interviews | Elders (24) in 8 villages (Va, Vb, Vc, Vd, Ve, Vf, Vg, Vh) |
| | To explore perceived risks of tsetse bites and HAT | Participatory methods within FGDs: <ul style="list-style-type: none"> - seasonal calendars, - participatory mapping | Men and women in (~98) in 4 villages (Ve, Vf, Vg, Vh) |
| | To examine actual risk of tsetse bites | <ul style="list-style-type: none"> - GPS-human tracking, - In-depth interviews, - Socio-demographic questionnaire | Men and women (58) in 4 villages (Ve, Vf, Vg, Vh) |
| <u>INTERVENTION AND EVALUATION</u> – pilot and evaluate a women-led tsetse control intervention | To implement a women-led tsetse control intervention | <ul style="list-style-type: none"> - Action research cycles of planning, action and reflection - FGDs | Women: (~65) in 3 villages (Vi, Vj, Vk) |
| | To evaluate i) the impact on community and ii) the impact on operation (quality of target deployment and maintenance; cost effectiveness) | <ul style="list-style-type: none"> - FGDs and participatory voting - Field assessment - Cost effectiveness analysis | Women (~65) in 3 villages (Vi, Vj, Vk) |
| <u>STAKEHOLDERS' REFLECTIONS</u> - perceptions of community, policy and programme stakeholders on community involvement in HAT control | To examine community perceptions of decision-making processes | Role play | Women (24) in 3 villages (Vi, Vj, Vk) |
| | To explore programme planners' and policy makers' views on community participation as a component of HAT control strategies | In-depth interviews | Policy and programme decision makers (14) |

Research team and data collection process

My research team was composed by myself, the field interpreter/facilitator and office-based transcriber of the audio files. All interviews and FGDs were conducted in Lugbara (apart from interviews with decision makers which were conducted in English) and directly translated to English by the field interpreter. All interview and FGD topic guides were pretested and questions were discussed with the research team prior to data collection. After discussion, questions were readjusted to ensure that the meanings in Lugbara were as close as possible to the meanings in English. All interviews and FGDs were audio recorded, using Olympus L11 digital recorder.

To ensure high quality of data collected and accurate translation, I carefully selected interpreters, based on their previous work records as translators and facilitators. A test of back translation (written English text is orally translated to Lugbara and independent person translates it back to English) was performed during translator selection process to confirm good professional skills. An additional quality control on translations was ensured during the transcription process which was carried out by an independent member of research team fluent in Lugbara and trained in social sciences. A series of training sessions were organized, in particular on data collection methods, ethical principles of research, methods of transcription and translation, for my research team before the data collection process was begun.

During intervention and evaluation phase, a female Ugandan journalist joined the mentoring meetings with the participants (starting from the third mentoring meeting). She recorded parts of the discussions and tasks carried out by participants (more details under section 3.8/‘Ethical considerations’). Videos were not considered as ‘data’ (no visual anthropology methods were employed), since the main purpose of video recording was to illustrate engagement of participants with intervention (similarly to the use of the photo materials). Potential repercussions for the research and the use of videos as an example of community advocacy tool are discussed in section 7.2.

3.5 Baseline phase: research methods

A mixed methods design, was used in two parts of this study: part one used interviewing and participatory qualitative methods; and part two used quantitative methods with a particular emphasis on the use of Global Positioning Systems (GPS), combined with in-depth interviewing and a socio-economic questionnaire.

Elders' memories of HAT interventions (interviews)

In-depth interviews were conducted with 24 elders (16 men and 8 women) from eight villages (Baseline 1, Figure 3.3). The villages were selected through purposive sampling methods, based on their location in known local HAT foci. Four villages were selected in the area where, in 2010 (i.e. within 12 months of the study) Médecins sans Frontières (MSF) still detected HAT cases (HAT foci) during an active screening and treatment campaign. The other four villages were selected from the area where no recent or historical cases have been reported (non-HAT foci) [72]. Participants were selected using snowball sampling techniques [208]: starting with an initial small sample of elders in each location, who were subsequently asked to identify others who may be willing to be interviewed. This approach led us from one elder to another in each village and finally eight women and fifteen men were interviewed until we reached data saturation point [208]. The average reported age of the participants was 71 years albeit most of them were unable to state their exact year of birth. Interviews were conducted at participants' homes using an interview guide with several general open-ended questions, and probes to obtain further details on their memories of HAT and disease control interventions.

Community risk analysis

Perceived risk to tsetse and HAT (seasonal calendars, participatory mapping)

Sixteen focus groups discussions (FGDs) were held in four villages (Baseline 2, Figure 3.3) using two different participatory approaches: i) seasonal calendar (discussed in eight FGDs) and ii) participatory mapping (discussed in eight FGDs). To capture gender-specific views, groups were organized according to gender and on average, each group (regardless of gender), had 11 participants. Each group drew symbols in order to identify different seasons of the year, and based on these calendars, discussions on gender-related activities implemented throughout the year were held. When the calendars were completed, three petri dishes with different numbers of tsetse (some containing a few, some many, and some many more) were distributed to the groups. They were instructed to place each petri dish on the top of each season depending on the experienced intensity of the contact with the tsetse in each season (Figure 3.4). Discussion on gender related activities that facilitate this contact were introduced in due course.

Participatory mapping techniques were used to explore patterns of daily and seasonal movements within the village and its surroundings. This was carried out to explore if there are any additional special zones of human-tsetse contact which may have been missed in more temporally-oriented seasonal calendars. Each group was asked to draw a map of the village with important landmarks within and outside the villages (Figure 3.5). The discussions which followed were focused around frequency and patterns of

human migration within the village and its environs.

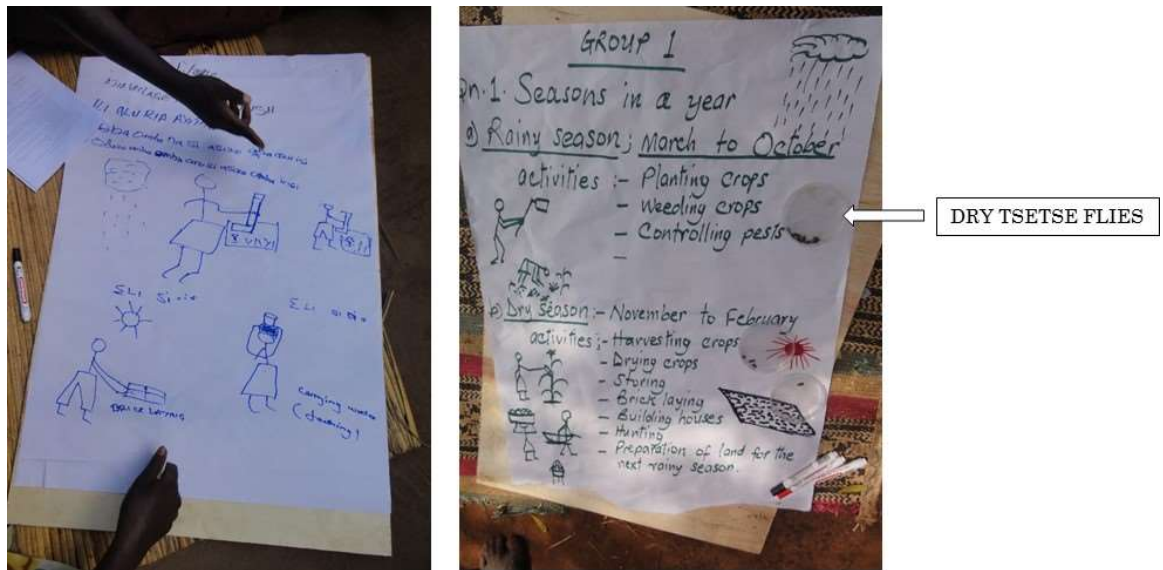


Figure 3.4: Seasonal calendars as drawn by participants



Figure 3.5: Participants drawing maps of their villages

Exploring actual risk of tsetse bites (GPS techniques, in-depth interviews, socio-demographic questionnaire)

Actual risk of tsetse bites among men and women was evaluated using GPS mapping together with in-depth interviews and demographic questionnaire to help interpret the GPS data. Sixty households were

randomly selected in four villages (Baseline 2, Figure 3.3). Randomisation was carried out using a household village list which was obtained from the village chiefs. Households on the list were numbered and numbers selected randomly. A single volunteer from the household was approached and after the baseline acceptance interview, the time for the next visit was agreed upon; if no participant was obtained from a selected household a neighbouring household was approached until the final number of participants and equal gender distribution was obtained. The socio-economic information was collected, prior to the distribution of GPS trackers, using a questionnaire. At sunrise, participants were given small light GPS trackers (I-GotU GT-120, Mobile Action U.K., dimension 44.5 x 28.5 x13 mm; weight 20g) to carry on their upper arms (Figure 3.6) from sunrise to sunset (~11 hours on average). Participants were instructed to carry on with their usual duties through the day without changing their usual routine. Trackers were recording and storing participants' location every 3 minutes. At sunset, I collected tracking units to download the data onto my personal computer. Individual movement maps were created for each participant using Google Earth [209]. The research team returned the next morning with the individual maps and carried out in-depth interviews with participants about their previous day's activities.



Figure 3.6: Two participants carrying the GPS tracker on their upper arms

Data analysis

Qualitative analysis

Discussions and interviews were analysed using a thematic analysis approach [208]. All audio recordings

were translated and transcribed by trained field assistants with backgrounds in social sciences. Transcriptions, saved as Word documents, were read numerous times until the obvious codes were identified. Text was then coded using MAXQDA software [210] and participants' quotes, organized by codes, were collated into a matrix table, which allowed further examination of themes and silent messages. This analytical method was applied to all other interviews and FGD data collected in my research, including data gathered in the implementation and evaluation phases and the stakeholders' reflections phases, unless otherwise described in relevant sections.

Quantitative analysis: socio-demographic questionnaire; GPS trekking and mapping analysis

Data from the socio-economic questionnaires were analysed by social and economic categories to obtain an average profile of my participants.

Tracking data was successfully downloaded from 58 GPS units (28 women, 30 men). These data were saved in gpx format and imported into ArcGIS 10.1 (esri 2012) for analysis. Using the same software, 'risk zones' were defined as being 10, 20, 50 and 100 m on each side of the river in order to delimit areas where riverine tsetse concentrate. Henceforth, these buffers are termed "tsetse risk zones". Tsetse risk zones were chosen as a standard measure since according to the published literature [211] on the same tsetse species found in the study area (*Glossina fuscipes fuscipes Newstead*), flies are found largely within 10 m of river banks and no flies were caught further than 100 meters away. Individual movement maps were then overlaid on the top of tsetse risk zones. The areas of intersections between individual movement maps and tsetse risk zones were identified by appearance of waypoints and used for further analysis.

All the movements in each village were plotted to examine potential zones of aggregation of movement within the village. A convex hull polygon (the smallest area that contains all the waypoints) [212] was drawn for each village to mark the area covered by participants' movements. The maps were overlaid with land use layers⁵ [213] in ArcGIS to determine what kind of land-use zones the participants crossed in the course of their daily movements.

The effect of gender on the proportion of time that a person was in a 'risk' zone was statistically analysed by fitting general linear models (GLM) with a binomial error structure and a logit link. The total number of points recorded by the GPS carried by each person was specified as the binomial denominator and the number of points within the risk zone was the response variable. Gender was specified as a factor. If the

⁵ An aggregated 1:250,000 scale land-cover map derived from Landsat TM Imagery (part of the Africover project) was used to overlay tracks.

data were overdispersed then a quasibinomial model was fitted to the data. Analyses were carried out using R [214].

3.6 Intervention and evaluation research methods

Selection of the villages and participants

Two villages were invited to participate in the study (Village 1, population: 404; Village 2, population: 310); an additional village (Village 3) (Intervention and Evaluation, Figure 3.3) joined in for the training and deployment phase after the women there learned about the study and expressed interest in being part of the intervention. Village 3 was represented by fewer participants compared to the other two villages and was therefore only assessed for the target deployment and maintenance parts of the study. The selection criteria for the villages were as follows: i) location in known HAT focus [72], ii) no previous tsetse control operation carried out within the village prior to intervention, iii) perennial rivers flowing through the village providing permanent tsetse habitats, and vi) the research is given permission by village chiefs.

Participants were exclusively women, mobilized initially by the village chiefs before the first meeting and over time they arranged themselves into groups. Their participation was voluntary throughout action research (AR). On average between 18 (village 1; 7%, n=257) and 22 (village 2; 14%, n=157) women participated in the meetings. Village 3, which self-initiated participation at the trainings, was represented by 2 to 4 participants.

Intervention

Action research

The tsetse control intervention was conducted through planning, deployment and maintenance phases using action research (AR) as the principal methodology. These phases were supported by mentorship, consisting of discussions and training sessions carried out by the research team, which included myself and a trained interpreter. In all, we held seven mentoring meetings over six months. Mentoring meetings⁶ (Figure 3.7) were conducted in the usual village meeting places. The main tasks planned and executed during these meetings and how they fit into the AR phases are summarized in Table 3.2. AR included: four weeks of preparation; two weeks deployment (this was extended to six weeks); and two weeks of reflection in follow-up visits. The initial 12 week interval between the beginning of planning and target

⁶ Mentoring meetings comprised delivery of technical information delivered by the research team and discussions with participants to provide opportunities for feedback, organize intervention and gather their view of the process.

deployment, and the seven week period between start of deployment and reflection provided an opportunity for information distribution within the community and its surroundings and prolonged exposure to tiny targets without any external interruption from the research team.

The research team facilitated the process in three repetitive phases: i) planning, ii) action, and iii) reflection. Lessons learned in the reflection phase were incorporated into a new planning phase. A series of micro-cycles: planning-action-reflection were also run for each separate task, such as mapping of the rivers, measuring river length, sensitization of community and target deployment (Table 3.2).



Figure 3.7: The mentoring meeting with the demonstration of targets

Table 3.2: An overview of action research phases and mentoring meetings (March to August, 2013)

| Action research phase | Mentoring meeting | Content of focus group discussion | Activities carried out / technical information provided |
|-----------------------|--|---|---|
| PLANNING | 1. Identifying priorities | Women's experience with HAT; views on prioritising tsetse control | Discussion of past HAT cases in their village. Introduction to tsetse trapping. |
| PLANNING | 2. Detecting tsetse habitats | Methods to identify tsetse flies and their habitats within villages | Discussion on where tsetse are observed. Demonstration of trap deployment. Accompanying women to deploy two traps in selected sites within each village. |
| PLANNING | 3. Identifying and measuring rivers | Locations for target deployment; community sensitization | Accompanied women to measure stretches of river to a) calculate number of targets required and b) identify where to deploy targets. Women identified rivers in the village where they observed tsetse and mapped them on a hand drawn chart using marker pens. Research team provided information on deployment requirements (every 50 m on one side of the stream) and women were asked to bring back data on measured length of the rivers. |
| PLANNING | 4. Planning deployment | How best to deploy targets, roles and responsibilities during deployment; how to convey information about deployment to other community members (sensitisation) | Agreement on number and design of targets needed for each stretch of the river; participants chose to deploy either a target supported by two vertical sticks placed in the ground (ground target) or a target suspended from the branch of a tree (hanging target). |
| ACTION | 5. Carrying out deployment | Organization of deployment groups | Women were asked to bring tools for cutting back vegetation around targets. The research team demonstrated the deployment of two targets and left the remainder for the women to deploy targets themselves. |
| REFLECTION | 6. Reflecting on deployment | Organization of deployment and discussion on challenges encountered. | Women reported how they organized themselves for deployment, they described the time they spent to complete deployment along different stretches of river and provided comments on challenges encountered. The research team provided information on target maintenance: regularly clearing vegetation ~1m around targets and keeping targets in an upright position. |
| REFLECTION | 7. Reflecting on target maintenance and overall experience | Organization of target maintenance; view on participation of women. | Women reported how they organized themselves for target maintenance and their observations on target conditions. They provided their views being involved as women and reactions they received by their male members of family and wider community. |

Focus group discussions

The implementation and evaluation phases occurred simultaneously throughout action research and focus group discussions (FGDs) were used to carry out data collection in both phases. Nineteen FGDs were run within the mentoring meetings to facilitate the planning phase, leading towards target deployment and follow-up reflections. Village 1 participated in eight FGDs and Village 2 in eleven FGDs; the additional three FGDs were run in Village 2 to explore the reasons for delay in the deployment of targets. In each subsequent FGD, we discussed and carried out the various planning activities as described in Table 3.2. In all these activities, participants led the decision-making processes but technical information on deployment procedures and functionality of targets was delivered by the research team. After an agreed period of 'action', during which targets were deployed, the research team returned to the villages to carry out the remaining mentoring meetings. During these last 2 meetings, the research team facilitated 'reflection' on the entire process from planning to target deployment. The team also facilitated discussions on target maintenance and recommendations from women for sustainability of target deployment.

The FGDs gathered data on: organization of activities, distribution of tasks among participants, feedback from other members of community, challenges of performing tasks and discussions on potential solutions. The levels of evaluation and specific methods used are described in the section below.

Evaluation

Evaluation was conducted at two levels: I) participation of women and II) operational evaluation. The participation of women was assessed through: i) evaluation of their engagement with interventions, in particular on perception of motivation, ownership and empowerment; ii) their organizational capacity, demonstrated through leadership, mobilization of resources and implementation of tasks; and iii) perceptions of effectiveness and feasibility of intervention. Many community-based health programmes attempt to empower and motivate communities and strengthen community ownership [215-218], yet there is no consensus on the exact meaning of these concepts or how they can be used to measure community engagement [219]. To overcome this, I used a novel approach whereby participants' own definitions of empowerment, ownership and motivation were identified and used to evaluate their engagement with the intervention. The operational evaluation was measured through evaluation of the quality of deployment and cost-effectiveness.

Participation of women

Measuring participants' engagement with the intervention

Changes in motivation, empowerment and sense of programme ownership were measured using participatory methods. I asked participants to define the concepts of empowerment, ownership and motivation and to suggest criteria for measuring each. In this process, they compared use of tiny targets with mosquito nets, which were already in use in the villages; this helped women to develop definitions during focus group discussions in each village. The descriptions were then used for self-assessment of empowerment, motivation and ownership indices, which were measured using a participatory voting method in subsequent mentoring meetings and group discussions.

Eight participants were chosen from those seated at the first row of the group of ~20 participants and each was given three stones. They were asked to vote by placing different number of stones on the ground (from 1 to 3 stones) depending on how strongly they agreed with various statements, for example: 'agree strongly' -three stones, 'agree mildly'-two stones, 'disagree'-one stone (Figure 3.8). The statements were variations of the definitions that participants initially developed to describe motivation, ownership and empowerment. The total number of stones placed on the ground by all participants in each village was counted for each index. The total number of stones was then translated into different numbers of scores (from 1 to 4) (Table 3.3). Participatory voting was carried out at three different points in time: baseline, pre-deployment and post-deployment (Table 3.5).



Figure 3.8: Participants voting with stones

Table 3.3: Scoring system used for self-assessment of participants' engagement

| A. PARTICIPANTS' ENGAGEMENT | | | | | |
|---|---------------------|----------|--------------|-------|----------------|
| Scores used in spider ⁷ diagrams | 0 | 1 | 2 | 3 | 4 |
| Responses to the statements defining levels of ownership, motivation, empowerment | Completely disagree | Disagree | Agree mildly | Agree | Agree strongly |
| Total number of stones voted during participatory voting | up to 8 | 9-12 | 13-16 | 17-20 | 21-24 |

Participants' organizational capacity

Organizational capacity was assessed in relation to the tasks carried out by women during the AR intervention. This was carried out through a number of indices: i) leadership, ii) contribution of resources: material and time and iii) implementation of tasks. For example, after the third mentoring meeting when women mapped and measured the rivers, we asked them to indicate the extent of leadership, resources mobilised, and the extent to which tasks were completed. These indices were scored by myself using

⁷ Results of scoring were illustrated in spider diagrams (see section 5.3).

assessment forms and pre-defined criteria (Table 3.4). The measurement of participants’ organizational capacity indices was recorded at baseline, pre- and post- deployment time points (Table 3.5).

Analysis of participants’ engagement and organizational capacity data

Data on motivation, empowerment, ownership, leadership, resource allocation, and task performance, were plotted on spider diagrams using a 4-level scoring system as shown in Table 3.3 and Table 3.4. Spider diagrams and scoring systems were adapted from Draper et al [220]. Data from different villages were analysed separately to explore differences between villages. Three different diagrams were created for different time points to illustrate changes in perceptions of community engagement and feasibility over time.

Table 3.4: Scoring system used to assess participants’ organizational capacity

| B. PARTICIPANTS’ ORGANIZATIONAL CAPACITY | | | | | |
|--|------------------------------|--|---------------------------------|--|---|
| Scores used in spider diagrams | 0 | 1 | 2 | 3 | 4 |
| Leadership scoring definitions | Leader not identified | Leader identified (selected) | Leader assumes leadership | Leader is able to mobilize others | Leader’s skills contribute towards successful task performance |
| Mobilization of resources (material, time) scoring definitions | No attendance at the meeting | Participants provide meeting space and equipment e.g. tables, chairs | Participants attend the meeting | Participants dedicate sufficient time to perform tasks | Participants provide materials to perform tasks e.g. slashing tools |
| Task performance scoring definitions | Task not completed | Task 25% completed | Task 50% completed | Task 75% completed | Task 100% completed |

Participants’ perceptions of effectiveness and feasibility of intervention

The perceived effectiveness and feasibility of interventions were recorded during the last two meetings with women (Table 3.2). Women’s views on feasibility of interventions were recorded through FGDs in each village through discussions on practical challenges in implementation of tasks as well as on how the broader community responded to their role as implementers of intervention

FGDs were also used to discuss any observed changes in tsetse densities after tiny targets were deployed. Participants’ perceptions were verified using tsetse monitoring traps. Five pyramidal traps were deployed in women-led intervention areas and five additional traps were deployed about 7 km from the women-led intervention, and they were used to check if there was any observable difference in relative tsetse

density during the same days. Trap catches from both groups of traps were collected by the research team at 24 h intervals over a period of three days (from 13/03/2014 to 15/03/2014).

Operational evaluation

The operational evaluation of women-led intervention was assessed through comparison with an 'externally led' tsetse control operation. The later is considered a standard method of tsetse control; in this case tiny targets were deployed and maintained by trained technicians and operations were managed by an expatriate team [47]. This intervention was conducted in the southern area of West Nile (Figure 3.3) during the same period as the action research intervention. The following categories were compared: i) quality of deployment; ii) level of target maintenance; and iii) cost.

Quality of deployment and target maintenance

To measure the quality of target deployment and the community's capacity to maintain targets, the distribution of deployed targets was mapped using a global positioning system-GPS (GPSMAP 78; Garmin, USA). A trained field assistant also evaluated the site and target condition; a field assessment form was used to record the state of targets visited (cloth intact, damage to the cloth; wooden frame with both horizontal poles inserted, or poles missing, damaged; target in fully standing position, twisted or fallen) and the degree to which vegetation obscured the targets (target fully visible, target partly shaded by vegetation or target completely shaded). Evaluation and mapping of targets, using a GPS, was carried out three times: immediately after deployment and at three and six months thereafter (Table 3.5).

All GPS data (location of targets) were analysed using ArcGIS 10.0. to produce maps of the distribution of targets. The proportion of fully functional targets (cloth intact and in fully standing or hanging positions) and appropriately cleared proportion of deployment sites (target fully visible) was calculated in relation to initial deployment of targets. The proportion of fully functional targets in women-led interventions was compared with proportion in interventions implemented by trained technicians in the externally-led intervention.

Cost-effectiveness

The overall objective was to produce an estimate of the total cost of a women-led tsetse control operation. The costing of the action research included numerous research elements as some of the contact with women was conducted purely to evaluate the action research process. My analysis, however, allowed me to separate the research and operational costs and hence estimate the likely cost of a

community-based intervention. Accordingly, two different parts of costing analysis were carried out: i) analysis of the action research and ii) likely cost of community based tsetse control interventions lasting three years. Both calculations were based on the tsetse control programme using tiny targets undertaken in north-western Uganda.

This cost analysis followed the protocol published by Shaw et al. [49], which analysed 'externally led' tsetse control operations. In this analysis, the likely cost of the government-run tsetse control programme, using tiny targets in Uganda, was estimated. However, my analysis of women-led interventions involved important inputs from participants; therefore, the opportunity cost of their time was estimated and included in the analysis. All the costs were categorised as either external resources (those contributed by research team) or internal resources (those contributed by participants). I recorded five resource categories: staff, transport, equipment, refreshments, and gifts given by participants to the research team. Staff costs were based on Ugandan civil service rates to make this analysis comparable to the 'externally led' intervention [49]. A percentage of depreciation was applied to all equipment including the vehicle, which was the only major capital item.

Data on opportunity cost was recorded during the mentoring meetings and focus group discussions. This included data on: a) the duration of various tasks and b) number of women performing them. During group discussions we asked women about the most common income generation activities they would ordinarily be involved in, the range of payments received for these activities, and the usual payment methods. These data were used to develop a crude estimate of opportunity costs.

Expenditure was either in Ugandan shillings (UGX) or United States dollars (USD). The conversion rate used for all calculations was 1 USD = 2595 UGS, which was applicable for the study period [221]. The data were used to estimate overall costs and opportunity costs.

Assessment time points in implementation and evaluation phase

Table 3.5: An overview of assessment time points in action research process (years 2013 and 2014)

| Month | | Mar | | | | Apr | | | | May | | | | Jun | | | | Jul | | | |
|---|---|-----|---|---|---|-----|---|---|---|-----|---|---|---|-----|---|---|---|-----|---|---|---|
| Weeks | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| MENTORING MEETINGS TIME POINTS | | x | | | | | | | | | | | | x | x | x | x | | | | |
| EVALUATION OF PARTICIPATION-TIME POINTS | Participants' engagement | x | | | | | | | | | | | | x | | x | | | | | |
| | Participants' organizational capacity | x | | | | | | | | | | | | x | | x | | | | | |
| | Participants' perceptions of efficacy/feasibility | | | | | | | | | | | | | | | x | | | | | |
| OPERATIONAL EVALUATION TIME POINTS | Targets' and site condition | | | | | | | | | | | | | | | x | | | | | |
| | Costing data collection | x | x | x | x | x | x | x | x | x | x | x | x | x | x | x | x | x | x | x | x |
| Months | | Aug | | | | Sep | | | | Oct | | | | Nov | | | | Dec | | | |
| Weeks | | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| MENTORING MEETINGS TIME POINTS | | | x | x | | | | | | | | | | | | | | | | | |
| EVALUATION OF PARTICIPATION-TIME POINTS | Community perceptions of efficacy/feasibility | | x | | | | | | | | | | | | | | | | | | |
| OPERATIONAL EVALUATION TIME POINTS | Targets' and site condition | | | | | | x | | | | | | | | | | | | | x | |
| | Costing data collection | x | x | x | x | | | | | | | | | | | | | | | | |
| Months | | Jan | | | | | | | | | | | | | | | | | | | |
| Weeks | | 1 | 2 | 3 | 4 | | | | | | | | | | | | | | | | |
| EVALUATION OF PARTICIPATION-TIME POINTS | Tsetse density using traps | | x | | | | | | | | | | | | | | | | | | |

3.7 Stakeholders' reflections

The stakeholder reflection phase was divided into two parts: in the first part, community perceptions of decision-making processes were recorded through role play; in the second part, actual decision makers were interviewed and their views of future HAT control strategies, including the potential for community-based tsetse control interventions, were explored.

Community reflections (role play)

Role plays were conducted with female participants who participated in action research in two AR villages (Village 1, Village 2). The research team distributed six 'role tags' to participants. Role tags carried the following roles: (i) Village chief, (ii) Sub-county chief, (iii) District representative, (iv) Ministry representative, (v) WHO representative and (vi) Donor (Figure 3.9). Other participants were asked to 'play' members of the local community. Roles were explained to participants by providing information on the position of the role in the decision-making hierarchy: local/national/international and on the roles' access to resources and decision-making power. Participants acting as community or decision-makers were asked to present the problem of tsetse flies and sleeping sickness and demand assistance of the next role in the decision-making chain in the following order: community-village chief-sub-county chief-district chief-Minister-WHO-Donor. The decision-maker addressed was required to present obstacles in including HAT control on their agenda and then required to accept or refuse the assistance, before moving to discuss it with the decision makers at the next level.

Data collected during role play was analysed using thematic analysis approach (already described under 'Qualitative analysis' above) and discourse analysis approach. The former was used to focus analysis on the use of language in construction of arguments and to help interpret interactions among participants during performance [197].



Figure 3.9: Participants during role play

Reflections of decision-makers (interviews)

Following the role play, I approached actual decision makers. I conducted fourteen in-depth interviews with the following stakeholders: village chiefs from Ludara sub-county (2), district entomologists from Arua, Maracha and Koboko districts (3), district health officers from the same districts (3), and senior national representative of HAT control-MoH (1), national representatives of tsetse control-COCTU (2), WHO representatives (2), and a representative of African Union (1). Interviews were focused on exploring their personal and professional motivations and work-related obstacles. Their views on future community involvement, with a focus on involvement of women, were also examined.

3.8 Ethical considerations

Throughout my research, the ethical principles of informed, voluntarily, free, confidential and anonymous participation were respected. As part of these research ethics, all the members of research team (translators, transcribers, FGD facilitators and the driver) were aware of the absolute necessity to respect confidentiality. Local district and sub-county administrative authorities and village chiefs were informed about the studies and their permission sought prior to data collection.

All participants were informed about the objectives of the studies and data collection procedures and were encouraged to ask questions. The use of data as well as the use of visual materials (photos, videos) was also explained to participants and their consent was sought. This information was delivered to participants before data collection started, both orally and through written information sheets.

Information sheets were produced in English and Lugbara (back translation from English to Lugbara was carried out to ensure the accuracy of information translated) and participants chose whichever version they found more convenient to follow. Their voluntary participation and right to withdraw from the studies were clearly explained and their written consent was obtained. In case of illiterate participants, a fingerprint was collected in the presence of a literate witness.

A special precaution was taken when participants discussed personal experience with as HAT patients or care takers. Emotional distress could have arisen when discussing any potential traumatizing situations experienced during disease or treatment. Occasionally sleeping sickness results in irreversible mental symptoms, which is emotionally draining not only for the patient, but also for other family members. If any cause for distress was observed, the interview would be terminated and de-briefing with informants would be offered.

Studies involving geo-reference tracking of individuals have potential discomfort of invading privacy. To manage this, volunteers, who agreed to carry GPS units were explained in detail how the units work (connect with the signal similar to the mobile phones and record volunteer geographic position every three minutes). The example of the geo-tracking map was shown to them, so that they were fully aware of the nature of data that was collected and how it was plotted. They were informed that similar maps, recording all their movements throughout the day will be produced when they carry around the unit. At the end of the interview each participant was given a copy of their individual map.

A special care was taken to insure that ethical principles were respected during short filming sessions. Myself and field interpreter held a preliminary meeting with potential participants explaining them what the video recording will involve and their right not to participate if they didn't wish so. We also explained them how the videos were to be used (to make a short documentary which will be presented to decision makers, for LSTM promotional purposes and presentations on events relevant to HAT control). All the participants who agreed on participating in filming were asked to give their written consent. Filming was carried out by professional Ugandan journalist (Ms Evelyn Mwangalwa) who was contracted by LSTM. Copies of all the raw filming materials were handed over to the LSTM research team after production process was completed. These were stored in Arua research office (locked) and later transferred to LSTM. After the short documentary was completed the screening session was organized for participants in their village (using a generator, a projector and a white screen) and their additional verbal permission was given for the final product to be shown publically.

All hard copies of consent forms were organized in a folder and are currently securely stored at the offices of the Liverpool School of Tropical Medicine tsetse research project in Arua, Uganda. All personal information collected during the studies remain anonymous and strictly confidential. No names on participant's study forms or any reports resulting from the study were recorded. At the beginning of the study, each participant was given an identification number and this number was used on the forms. All the digital recordings were computerized and password protected on my personal laptop.

The study protocols and procedures for obtaining participant consent were approved by the Research Ethics Committee of LSTM (ref: 11.73) and Uganda National Council of Science and Technology (UNCST) Ethics Committee (ref: SS-2561) (additional supportive documents in Appendix A).

Chapter 4: BASELINE RESEARCH FINDINGS

4.1 Chapter overview

The findings described in this chapter provide a detailed context of factors influencing community participation in tsetse control. This chapter begins with findings from elders' interviews, which examined if any traumatic memories related to previous HAT control interventions persisted in the community's collective memory. Next, the community's risk analysis to tsetse and HAT was examined through perceived and actual risk to tsetse and HAT, with particular focus on differences between men and women. The working hypothesis, is that if women perceived themselves to be at greater risk of HAT, then their willingness to seek preventive actions could be higher⁸ and male members of community might be more supportive of their active participation in tsetse control operations. The chapter concludes with a summary of key findings, including an explanation how they relate to the women-led tsetse control intervention piloted and evaluated in the second research phase.

4.2 Elders' perspective on the influence of past control interventions

Specific areas examined were related to: i) experiences preserved in the memories of elders in relation to sleeping sickness and past HAT control interventions; and ii) the potential impact of these memories on community engagement with HAT control programmes. These results are obtained from 24 in-depth interviews with Lugbara elders living in HAT endemic villages (HAT+) and non-endemic villages (HAT-) (section 3.4). The five main themes under which I discuss my findings (subheadings in bold) were derived from the categories explored. Themes are illustrated with participants' quotes organized in boxes at the end of description of each theme (Boxes 4.1-4.5).

Disease associated with examination of neck glands (Box 4.1)

As soon as sleeping sickness was mentioned to the participants in relation to the past, many of them lifted their hands to the side of their necks, their gestures indicating examination of lymph nodes (Figure 4.1). Regardless of the location of the village in endemic or non-endemic area, all participants remembered neck examination and many of them participated in this type of testing. These memories are drawn from the early 1940s to 1960s period, when most of them were children but some from the younger generation

⁸ This hypothesis is based on 'health belief model' discussed in section 3.2.

referred to the stories they heard from their parents. Mostly, they did not know at the time what disease they were tested for and indicated that they received knowledge on sleeping sickness when ‘whites [white foreigners] arrived in the area’. Some mentioned that the disease was called ‘gland’ and one participant thought they were testing two different diseases: ‘gland’ and ‘sleeping sickness’.

Elders from the current HAT-affected (HAT+) villages had vivid memories of the severity of sleeping sickness in their area in and many remembered the last epidemic in the 1990s and attributed it to the migration of refugees from South Sudan. In contrast, participants who do not live in a current HAT focus (HAT-) reported that HAT had not been a major problem for them, even in the past.

Box 4.1: Disease associated with examination of neck glands

“This disease started a long time [ago] and many people died of it. (...). They did not know what was happening to people, and they didn’t know what kind of disease [it was] since they [people] lived in remote areas. And this was before the whites [white foreigners] came to this area, so they [people] didn’t have the knowledge” (Elder 7, HAT+).

“When your neck was checked that time, they would get [diagnose] two things; [first] one, they would find that you have sleeping sickness and the second [one] would be called gland whatever it meant” (Elder 17, HAT+).

“They would say they were checking the neck-it was the disease of the neck; but we didn’t know the name” (Elder 24, HAT-).

“In the old days they used to check neck and it was called ‘gland’ which now is called sleeping sickness” (Elder 21, HAT+).

“People brought this disease from Sudan, to where they escaped during liberation war [as refugees] (Elder 16, HAT+).

“No, not many cases [of HAT] were here in our area” (Elder 1, HAT-).



Figure 4.1: An elder gesturing examination of neck lymph nodes

Recall of colonial medical interventions: fear in children, but not in adults (Box 4.2)

The elders recalled that mobilisation for ‘gland examination’⁹ happened once a year and was carried out by medical teams who moved from parish to parish. Villagers were informed about the time and place of gathering by government representatives. Participants commented that testing was compulsory and the entire village, including children, gathered. Families lined up for neck examination, their names were called, and the sides of their necks checked manually. Participants recalled that positive cases were separated from negative ones. Those who were young children at the time or were not diagnosed as positive had no recollection as to what happened with the positive group. Most of the participants from non-HAT foci speculated that positive cases were injected on the spot and then sent home. In HAT foci some participants remembered a treatment camp where there were houses built of clay and where people were treated (injected) at the same site where they were examined. Most participants recalled that in recent times, patients were transferred to Arua hospital.

According to the participants, sleeping sickness testing was mandatory. In cases of non-compliance, there were different sanctions in place including interrogation, imprisonment, levy of fines and physical punishment. Despite these disciplinary measures, the vast majority from both areas reported that they willingly participated; they did not report or remember any fears associated with testing or treatment. Positive attitudes towards examination were also associated with the non-invasiveness of the neck

⁹ Participants refer to examination for Winterbottom’s sign, an enlargement of lymph nodes on the neck [213].

examination which did not require collection of blood samples. They associated the examination with offers of help, also a positive association and perception. Some participants reported their childhood memories as being associated with fear of white foreigners and injections, but none of them reported their parents being fearful. Many participants remembered that the fear was not of examination but rather that the fear among adults was that they would get the disease and not be able to receive treatment.

Box 4.2: Recall of colonial medical interventions: fear in children, but not in adults

“They [positive cases] remained in Chilio [where neck examination was happening] and there were structures of camps raised to admit them in (...).They were built like these grass thatched houses and many in numbers [that's how a treatment camp looked like]” (Elder 21, HAT+).

“If someone refused to go [for testing], after the exercise [testing] ended, they would send a sub-parish chief to ask, to question the person. Because sub-county chief had a list of people and he would see who did not go... They would question that person- why he didn't go? And they would fine him, and the fine would be... Maybe you would need to pay a goat” (Elder 7, HAT-).

“Eeah! It would be so bad if someone refused to go for gland examination! If you didn't go, they would say you have brought the disease in the place, so you were taken to prison. They would assume that you are the one bringing more infection or disease in the area” (Elder 16, HAT+).

“And if you rebelled against the message [about testing], they would come to get you and take you [away] to be caned [beaten by stick]” (Elder 21, HAT+).

“Those were whites [who were involved in neck examination]; so we [children] wondered: are they coming to eat us? We feared, we didn't know the reason [for them being there], so we feared. (...). In our thinking was, maybe they will even retain us there; why are they calling us there? And the colour, they are people of different race [white], they are different. So that was the essence of fear [for us, children]” (Elder 13, HAT+).

“Only the kids of my age at the time would run away [were afraid of neck examination] (...). What were you afraid of as a kid was just the injections. Syringe entering your body. I didn't like that. If you are a child and you see that blood [with injections] you cry so much. You don't like any injection in your body” (Elder 3, HAT-).

“People from the village didn't fear [neck examination]. The fear was of not [getting] tested! It was better to get tested... They were saying that there is a disease which has come. People didn't know which disease, but they wanted to be tested” (Elder 2, HAT-).

Reluctance and fear associated with more recent medical interventions (Box 4.3)

Participants who were not from a HAT focus stated that after the period of 'gland examination', no more medical interventions related to HAT were carried out in their area. Thus, only memories from inhabitants living in HAT foci are reported. Participants remembered that after independence in 1962, there was a

period without any intervention until MSF France started their campaign in the late 1980s and 1990s at the peak of the epidemic with active village-based screening and treatment of patients in regional hospitals. The organization of active screening and spread of information was in elders' memories, which echoed those of earlier times. Village chiefs were involved in informing the village members and they ensured that villagers were present at the screening.

Elders reported that the use of new medical approaches created some reluctance among community. At the time, this reluctance was associated with the length of treatment, side-effects of treatment and drug resistance, and high patient mortality. One participant was convinced that in the old days, people could live with HAT and it would just 'make them dull', but that once treatment was provided, the disease 'changed form' and caused people to die. Many negative associations were also related to diagnostic procedures, such as collection of blood samples and lumbar puncture; and rumours associated with them that caused suspicion. Blood collected during diagnostic procedures, for instance, was believed to be collected and sold for transfusion purposes. One participant told of a rumour that the medical team was believed to be involved in the release of tsetse in order to gather people for testing bloods; then they could use the blood collected to sell it. However, despite these complaints, many of the elders reported that most of the community still participated in active screening.

Box 4.3: Reluctance and fear associated with more recent medical interventions

"What I remember is that community participated in work when the health centre coordinated [and announced] that they are coming on such and such day for testing. So the information is sent to us as the government representatives¹⁰. Then for us we would take the information to churches, schools where people gather, and then we would announce whereby such a day, the community would gather, the congregation would be there" (Elder 14, HAT+).

"And in those earlier times [in the 1990s during MSF France treatment campaign] you were kept long [in the hospital]. And for you to get well, it may take six months" (Elder 14, HAT+).

"What scared the people is that: the treatment, the help [they received], it was not good (...). Sometimes you grow fat [you swell], when given the medicine. Yes. You grow fat! And then you became normal [again after side effects are over]" (Elder 10, HAT+).

"That treatment was not all that good. For example, if I got that disease [HAT], it [the disease] could come back again [after treatment in relapsing cases]" (Elder 10, HAT+).

"The people were admitted to the hospital and next time they would be brought back [to the village] as corpses. So that created fear in people" (Elder 14, HAT+).

¹⁰ Participant is a village chief.

“During earlier times people used to not to die from that disease; they used to die when they were old; it would just make them to be dull [mentally compromised], but you would die at the old age. But now, recently, when they started giving drugs, the disease changed the form. It is making people mental and then they die” (Elder 13, HAT+).

, which contributed to “They take blood from here [points at the finger], put it in machine and the worm [parasite] will appear there. But if they don’t get it here, then they would come and take blood from here [pointing at the upper hand] (...). They remove big amount of blood. People feared because (...) they were saying that people taking blood [medical team], they will go and sell it “(Elder 13, HAT+).

OPPOSING VIEW:

“Those who were ignorant had many stories [rumours about testing]. But eventually many people come for testing” (Elder 12, HAT+).

New treatment approaches and increased knowledge improved community perceptions (Box 4.4)

The second medical campaign, carried out by MSF Spain (2010-2011) is remembered differently. Elders noticed improvements in treatment¹¹, which seemed to improve community trust and reduce general reluctance towards medical interventions. They specifically noticed that durations of hospitalization were shorter, there were no relapse cases, treatment had fewer side-effects and that no deaths occurred in the process. Most participants declared that the community response to testing was better during this campaign, and also that fewer cases were diagnosed compared to the previous intervention period. They also reported that there were attitudinal changes within the community itself, having already been sensitized in previous campaigns. Also, many participants had personally witnessed development of the disease in their family members and were therefore aware of the importance of testing and treatment. In general, participants reported that negative associations and fear were lower during the last treatment campaign.

Box 4.4: New treatment approaches and increased knowledge improved community perceptions

“And when the first group came [MSF France] and you were taken to Omugo [hospital], the duration [of treatment] was long- two weeks. But with the second group [72], recently, the duration [of treatment at the hospital] is three to four days and then you are back” (Elder 10, HAT+).

“But today, if you are treated, disease will not come back again (...). In the recent treatment [campaign], the same people [who were tested and treated years ago] were found with disease again. That one [information] tells me that the medicine they were using first is not the same they are using now” (Elder 10, HAT+).

¹¹ MSF Spain carried out sensitization campaigns in this area, which also contributed to the improved knowledge of elders. New treatment regime, i.e. Nifurtimox / Eflornitine combination therapy, was indeed introduced in this second MSF campaign [70].

“They are all right [all the members of community who were diagnosed]; no cases of death [occurred with the Spanish section of MSF] (...). These days it [HAT] is treated easily, it is treated easily! Because if you are treated you will be all right” (Elder 10, HAT+).

“The [community] response was better [when MSF Spain arrived]! Because people have already known about the disease, some have lost their dear ones. They got to know that disease needs to be treated” (Elder 12, HAT+).

“The fears have reduced and also the rate of death [due to HAT] is slowing [is reduced]” (Elder 14, HAT+).

Previous tsetse control programmes were not recalled as imposed (Box 4.5)

Only participants from the current HAT foci remembered organized activities related to tsetse control. Therefore only views from this group were collected. Elders remembered cutting vegetation of the river banks—an activity which was organized in from the 1950s until Ugandan independence (1962). Some of them reported that their parents or relatives participated in these activities. Clearance of vegetation along river banks was first organized as forced voluntary labour, but was later transformed into paid employment. Re-settlement from the river banks to higher level sites in the village was also reported, but one of the elders commented that this was done willingly by community members, who were aware of seriousness of the disease and also not concerned about the land ownership ‘since the land was free’. During this time, information about the link between tsetse and sleeping sickness started to spread within the community. Elders also commented that vegetation clearance significantly contributed towards control of sleeping sickness at the time, and so there appeared to be no negative associations with these interventions.

Box 4.5: Previous tsetse control programmes were not recalled as imposed

“The work [of vegetation clearance] was given in hands of local government representatives. So they would just get people in the village, whether you are willing or not, they put you in front to do the work; whoever you are, whatever your status, as long as you are in that village” (Elder 13, HAT+).

“Vegetation clearance started as voluntary, but there were some people who were weak while others were able-bodied; the weak began to withdraw [from the programme] and some people were sick to do the work. So the white- District Commissioner suggested that, it was better if they would employ people who were able bodied to do this work as their daily routine. So they started to get paid, and the voluntary work was left out (...). The payment was six cents per month” (Elder 16, HAT+).

“They discovered this disease, and government came in to organize the slashing [clearing of vegetation]; the people who were living along the river side, whose houses were along the river side, were transferred away, they were brought instead up here [on the hill away from the river] (...). People did not complain [about being resettled] since the disease was real. During that time, land

was free, people were using it [the lower parts next to the river] for cultivation and grazing of the animals; nobody would complain” (Elder 16, HAT+).

“They [people involved in slashing] were informed that they were slashing to keep off the tsetse flies that spread sleeping sickness” (Elder 17, HAT+).

“It was clean... When they maintained the river banks it maintained the rivers clean and this disease called sleeping sickness disappeared at that time” (Elder 11, HAT+).

In summary, elders’ memories spanned from times of colonial examination of lymph nodes to more recent times of active screening and treatment campaigns. Some negative memories dating back to the 1990s were associated with diagnostic procedures, treatment duration and treatment side effects. These memories, however, were combined with memories of negative impacts related to sleeping sickness epidemics particularly in HAT foci. More positive associations and memories from the recent treatment campaigns were reported, especially because of their observations regarding improvements in treatment. Similarly, no negative memories were associated with past tsetse control interventions.

4.3 Community risk analysis

In this section, the following findings are reported: i) community perceived risk to exposure to tsetse and HAT explored through seasonal calendars and participatory mapping; and ii) community actual risk of tsetse bites assessed through GPSing techniques, interviewing and socio-demographic questionnaires. Special attention was paid to the differences in risk in relation to gender and how this difference influenced community willingness to be involved in tsetse control intervention.

There were large over-laps in the results from seasonal calendars and participatory mapping, so they are reported together. Identified themes emerging from qualitative data are described and illustrated with quotes organized in boxes (Box: 4.6-4.9); how main themes relate to each other is illustrated with the Figure 4.5. Table 4.1 summarises information related to activities in tsetse risk zones collected via interviews with participants, whose daily movements were followed using GPS methods. Figures 4.6-4.8 illustrate data from qualitative individual tracking and mapping data.

Perceived risk of tsetse bites and HAT

Gender-related activities create a difference in perception of exposure to tsetse (Box 4.6)

In developing seasonal calendars and maps of activities, all participants described specific activities that were related to exposure to tsetse. Women, for instance, mostly reported that they encounter tsetse

while fetching water, washing clothes, and working on the fields. Firewood collection, picking wild fruits and vegetables, extracting sand from the river and grazing goats were also mentioned as activities where they encounter tsetse. Both male and female participants agreed that female roles are associated with providing water for the households. Boreholes are only used for collecting water for drinking and cooking - this is because of the payment of user fees for such facilities. Rivers and streams are commonly used for collection of water for bathing, washing, and providing water for livestock such as cattle, goats, sheep and poultry. Women, teenage girls and children of both sexes were reported as the groups who usually undertake these tasks (Figure 4.2). It is generally accepted by both sexes, that bathing at home in a bathing shelter is preferred, and women are in charge of collecting/ providing water for the entire family for bathing.

Men mostly reported being in contact with tsetse while they worked in the fields. However, bathing in the rivers, fishing, and grazing cattle were reported as male-dominated activities. Cutting reeds for house construction, hunting and washing vehicles in the rivers were other activities mentioned as part of those that expose them to tsetse. However, both male and female groups, mostly agreed that women's daily activities make them more prone to being bitten by tsetse.

Box 4.6: Gender-related activities create a difference in perception of exposure to tsetse

"When you go and dig [work in the field] and the place where you dig is bushy, tsetse flies can bite you there; and also when you go to the river to wash your clothes, that's when you can have tsetse flies attacks. And also when you're going to collect firewood, that's when you can get tsetse flies bites" (woman, FGD 5).

"At times it's the management of the homes. If there is conflict [at home], you don't understand each other, you [as man] may construct a [bathing] shelter; but if your madam [wife] is weak and doesn't go and fetch water for you to bath, you will be forced to go and bath at the river (...). It's our African culture that only madam [woman] fetches water at the river" (man, FGD 6).

"Fishing, taking cattle for grazing takes us [in proximity] to tsetse flies; when you go and bath in the valleys [as well]" (man, FGD 16).

"Women [are more exposed to tsetse] because they do a lot of washing; they spend [long] time in washing [at the rivers] and in a day she may fetch water two to three times [for the household]. So they [women] are more at risk [to contract sleeping sickness]. For men you just go and bath; you come back [home soon after] you take animals to take water and bring them back" (man, FGD 16).

"In our place here it's very common for women to wash at the river [not at home], because women have a lot of work to do. If you keep on fetching water from the river to bring it home, you will be adding more work, yet you have a lot of work to do [already]. So here most of our women wash at the river [and get exposed to tsetse]" (woman, FGD7).



Figure 4.2: Girls and women arriving to the village with filled water containers

Dry season increases exposure of women to tsetse (Box 4.7)

Participants mostly described two main seasons of the year: rainy (from April to September) and dry (from January to March) with an intermediate season of moderate rains between October and December¹². They reported a strong division of activities between the seasons: the rainy season is reserved for planting and maintenance of fields; the dry season is for farming in the river valleys, brick laying, sand extraction, house construction, fishing and hunting. During the intermediate season community members mostly occupy themselves with harvesting. Participants recognised strong differences in gender-related roles across the seasons, because different activities are carried out predominantly by women or men.

Both men and women groups inconsistently reported the season in which they observe more tsetse flies; some reported seeing more tsetse in the dry season, while others described observing more in rainy season. However what they generally recognized was that activities and the time of the day at which these activities are performed pose a risk of exposure to being bitten by tsetse. What was consistent among participants regardless of gender was an observation that in the dry season they observe an increase of tsetse along the river valleys.

¹² This accords with meteorological records for the area [214].

Besides the usual activities, which take place on the river banks, such as washing clothes and water collection (carried out by women), and grazing (carried out by men), some additional occupations were reported to occur at the river banks in dry season. Some of these activities were explained to be shared between men and women, such as gardening activities in the river valleys, and brick-making, but some activities, such as sand extraction are carried out only by women.

In the dry season, most cultivation occurs in the river valleys. Drought-sensitive vegetables such as tomatoes, cabbage, onions, egg plants and local greens were mentioned as crops cultivated at this time of the year, along with tobacco. Maintenance of tobacco nursery beds, which are located next to the rivers, was described as a very time consuming activity, since young tobacco plants require daily watering. Figure 4.3 shows men working on tobacco beds and women bringing water.

Sand extraction is another dry-season activity carried out by women predominantly. About half of the women groups in one of the villages reported participating in this income-generating activity from time to time. Women enter the river, sometimes until they are chest deep and dig out sand, which is carried out to the river banks and later sold to builders. Another related activity is brick-making, which involves mixing of clay with water, using wooden frames to lay bricks, sun drying and baking them in the outdoor earth-oven. While men are involved in most of these procedures, women are responsible for providing needed water for mixing brick materials. Male and female groups, agreed that women, particularly in dry season, spent a longer duration and had more frequent contact with the riverine areas where tsetse concentrate.

Men reported only occasionally engaging in fishing and hunting trips during the dry season. The reason for this was mostly described as reduction in intensity of fieldwork compared to the rainy season and more leisure time. Traditional fishing, however, requires lower water levels since it involves using herbal mixtures to paralyse fish.

Box 4.7: Dry season increases risk of tsetse bites for women

“Like from January to February [dry season], it’s dry there, outside the places [river valleys]; there are no bushes and when you go down waters like around the valleys, there it’s a bit wet. Also, the tsetse flies do go there” (men, FGD 4).

“According to me I think women do expose themselves too much to tsetse flies during December [dry season]; then they go down to the waters [rivers]; they go and dig to clear some piece of land for planting their vegetables, greens like osubi [local vegetables]. Men also do go there to put some small seed beds, nursery beds for their plantations of tobacco. But also women go there to fetch water and also to wash clothing; that’s why I think we [women] are so much exposed to tsetse flies”

(woman, FGD 1).

“Digging of sand happens like this: if you begin at 9 am, you are soaked by the water [entering the river]. And then from 11 [am] to midday you get out from there to go home and to prepare meal. Then we return back to dig sand in the afternoon, up to 6pm (....). The peak [of sand extraction] is in dry season, because during the wet season, the rivers over flood [so there is less sand extraction work]” (woman, FGD 11).

“Men lay bricks and ladies fetch water for mixing the soil and for laying bricks. In a day sometimes, it normally takes you-if you use this big source pans [with which] you pour into two jerry cans [water containers], two twenty litre jerry cans-it means you fetch like thirty source pans, thirty times per day” (woman, FGD 3).

“If men begin to build the house, you will fetch water from the time they begin to build the house, from the morning up to sun set and it can even be over 30 times. I would say, it’s unaccountable the number of times, you fetch up to when they go on with the construction” (woman, FGD 10).

“When there is a lot of water during rainy season, you can’t find fish; it would be hard to fish! There is a local way of trapping the fish [in dry season]; there are some [poisonous] leaves which we use here locally. You crash them, then you put them in the water, so it [the poison] will affect the fish, so they will come up [floating] at the surface of the water. Then you trap them around that site” (man, FGD6).



Figure 4.3: Tobacco beds along the river banks in dry season

Local travel is frequent but it is not perceived to increase the risk (Box 4.8)

Distant daily travel to other sub-counties were mentioned less frequently, compared to the daily movement between neighbouring villages. The most common reasons described for traveling to other

sub-counties, for both men and women, were paid farming activities, visiting markets and social affairs. Men also mentioned travelling to more distant places in search of pasture for livestock or for fishing. Some locations that participants mentioned in this regard, such as Madi, Ayivu, Kubala and Rhino camp, are known local historical HAT areas. None of the participants, however, associated these visits or movements to local HAT foci with increased disease risk. Most of the participants reported travelling for paid agricultural activities in the rainy season, when there is demand for additional labour. Frequenting markets, however, was reported by men and women, to be more common in the dry season when working in the fields is reduced (Figure 4.4).

Box 4.8: Local travel is frequent but it is not perceived to increase the risk

“Because the [farming] land is not enough [to support us], we go and look for land to dig [farm] in Aripa, Uriama sub-county, and also Madi. And we also go and try to get ways of fighting poverty in other divisions. Like me I can go to Ayivu and I look for work there so that I can earn wages. And also from here [our village] we go up to Madi to get fish [sell them] and make money. And then we can also follow our girls to go and pick bride wealth from them [in those areas]” (man, FGD 16).

“Especially digging [working in the fields takes us to other districts]; you can go and dig at Madi, particularly sim sim [on sesame plantations]” (woman, FGD 15).

“At times we can go to distant places, like Rhino camp to look for grazing land for our cows; here the land is not enough for grazing them” (man, FGD 8).

“For markets like Kubala at times someone can go on Tuesdays and then skip a market day on Friday [the same week]. Our women here they also go and pick the vegetables that they grow in the valleys, some greens we call awubi, and take them to markets like Kubala, for sell” (man, FGD 14).

“During rainy season, most people [spend] most times in the gardens, digging and working in their gardens; they don't go to the markets that often” (woman, FGD 13).

“In dry season, people mostly, if they work, they work for few hours in the valleys [gardens next to rivers] and then in the evening they go out to rest in market places” (men, FGD 14).



Figure 4.4: People traveling to Kubala market on a market day

Both male and female participants are willing to be involved in tsetse control, but women claim to be better positioned for it (Box 4.9)

Regardless of gender, participants expressed willingness and appeared motivated to be involved in tsetse control programmes. There was a difference, however, how female and male participants rationalized what would be needed for these interventions to work. Women expressed greater need for empowerment and requested access to traps more often, while men expressed greater need for village decision-making, financial motivation and government involvement in tsetse control programmes. Some women reported that they were already contributing to tsetse control by voluntarily slashing vegetation around watering points. They also felt that compared to men, their motivation was higher, and they associated it with higher risk of contracting sleeping sickness.

Box 4.9: Both male and female participants are willing to be involved in tsetse control, but women claim to be better positioned for it

“For us to work effectively, to cooperate in tsetse fly control; it’s good when we are given these traps, enough of them; we are ready to do the deployment. But for us to look for these traps by ourselves, it is impossible” (man, FGD 8).

“The distribution of traps would be effective if they are given to each village; so that the village will decide where to distribute the traps, especially in areas which are not targeted [with the current programme]” (man, FGD 12).

“In my thinking if the community [here] is cooperative, they can do the work of deploying the traps (...). But what challenge is, these people who are doing the work, they will need some ‘soap’

[financial contribution] to maintain them, to motivate them (...). Because you get up early in the morning to go and do the work in the valley; you don't have time; it [tsetse control] will be like your daily activity so at the end of the day your input to the family is less [then usual] (...). Even if this is to prevent disease, it is very hard! You are risking your life to approach the flies while other people stay at home (...). So this is why one needs 'soap' to do that work" (man, FGD 10).

"Yes. We can participate doing the tsetse control work [here]. For example here [in our village], we have a village health team [volunteers]. So if enough traps were given to us, the village health team would look for more, let's say six people to add to the team of two [already recruited as village health team], so that we become eight, and we would unite ourselves to do the work with the team; to do tsetse control intervention" (woman, FGD 9).

"Us, as community, we go to clear areas where we are fetching water. We have been doing it, us the women, who fetch from that river. We [women] organize ourselves. It's sometimes four, five to six women who do the work" (woman, FGD 15).

"Men are not so much bothered about these things [tsetse control]; it's women who suffer most from sleeping sickness; so much because they are the one doing kitchen work [which includes water collection]" (woman, FGD 11).

To summarize main findings, Figure 4.5 illustrates the main themes identified in FGDs and highlights differences in male and female views. The four main themes (green boxes in the middle) were: i) gender related activities, ii) seasonality (dry season), iii) local migration to other HAT foci and iv) willingness to be involved in tsetse control. Examples, related to each theme, are organized by gender: female views at the top row and male at the bottom row to emphasise on the gender differences in perceptions (in bold).

Perception of risk to tsetse bites and HAT, expressed by both male and female participants, was higher for women compared to men. This was related to activities traditionally performed by women and to activities being shifted to the river banks in the dry season, which are also mostly carried out by women. Local travel, however, which sometimes occurs between historical HAT foci, did not increase perceived risk for either men or women. Finally, women perceived themselves to be more motivated for activities related to tsetse control compared to men.

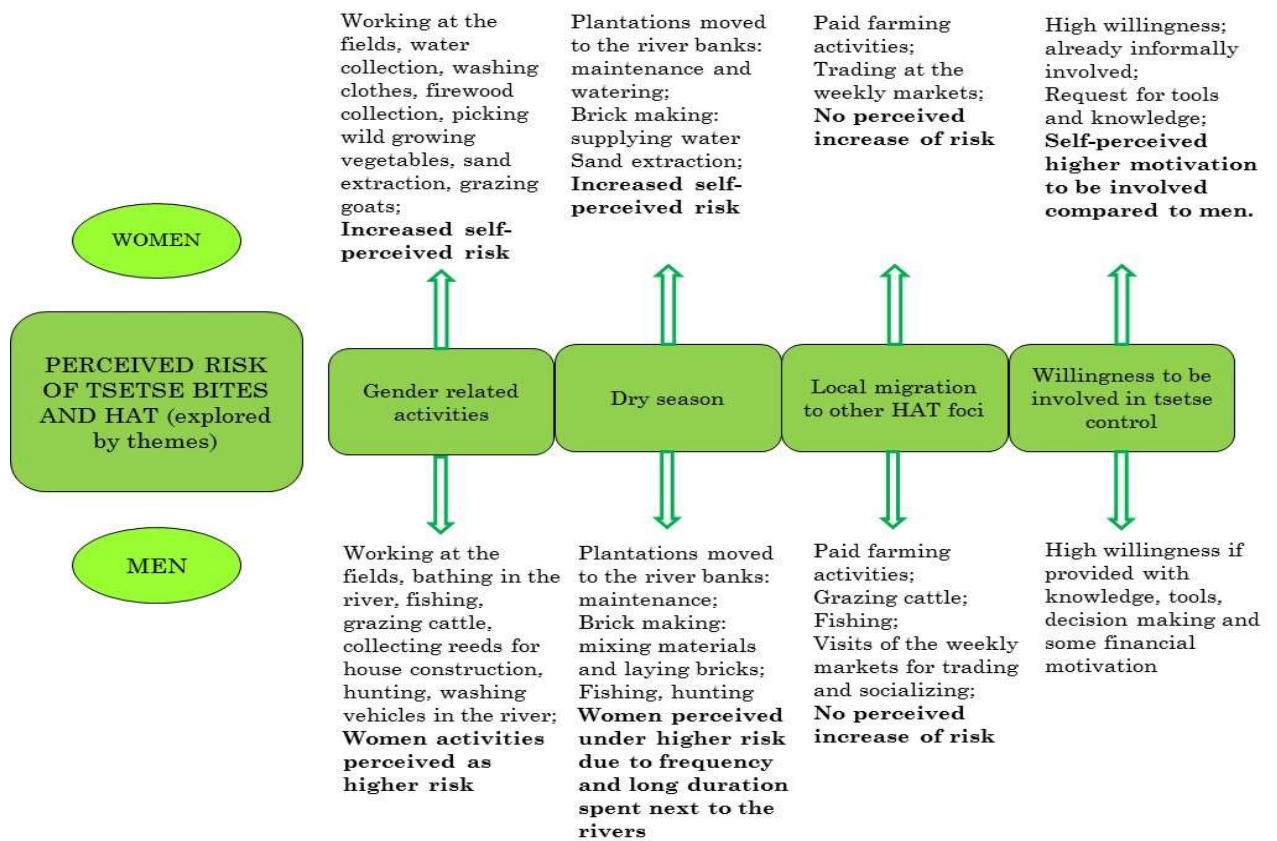


Figure 4.5: Perceptions of risk explored by themes and organized by gender

Actual risk of exposure to tsetse

Socio-economic profile of participants

To determine whether there are any major socio-economic differences, which could potentially influence daily behaviour of participants selected for carrying a GPS tracking unit, an analysis of participants' demographic and economic data was carried out. Below is a description of the average profile of participants. In total, 28 women and 30 men participated in GPS mapping, with an average age of 33 years and 39 years respectively. The majority of participants (97%) were Christian (Roman Catholic or Protestant). They were mostly married (81%) (monogamously or polygamously).

The highest proportion of participants (70%) had had some primary school education, 20% attended secondary school or college, and 10% were illiterate. The majority (93%) were farmers (Appendix C, Table C1). On average, participants' households comprised nine family members, four of whom were adults (over 16 years old). An average household owned livestock, with goats being the most common (mean = 4 per household), followed by cows (1 per household) and sheep (1 per household). More than half (60%)




























of the participants own at least one bicycle, but other vehicles are rare (only 5% own a motorbike and 3% car). The majority of the houses (93%) were grass-thatched and an average household receives the equivalent of about USD 14 a month in cash (~UGX 40,000; range: UGX 1000 to UGX 300,000) mostly by selling farm produce at the local markets (Appendix C, Table C2). All this indicates that in terms of socio-economic characteristics, a relatively homogeneous sample of volunteers was selected for carrying GPS trackers (all variations in Appendix C).

Daily access to tsetse zones



Analysis of the interviews with men and women who carried the GPS trackers for a day on their daily movements, confirmed findings recorded in FGDs that in the course of the day men and women have different reasons for accessing rivers. Table 4.1 illustrates the most commonly occurring activities reported during interviews. The results are arranged by gender and time of the day when these activities were most commonly carried out. Activities marked with the tsetse sign are associated with access to rivers and demonstrate a putative higher risk of exposure to tsetse.

Female participants reported accessing rivers for processing harvest, particularly cassava and beans. Male participants described commonly following rivers on the way to visit friends or relatives or in order to attend social functions (in Table 4.1, under “social activities”). Unlike women, who prefer to carry water and bathe in the bathing shelters at home, men commonly reported bathing in the rivers throughout the day.

Table 4.1: Daily activities of men and women organized by the time of the day

| TIME OF THE DAY/ ACTIVITIES | WOMEN | | | | MEN | | | |
|--------------------------------|---|---|---|---|--|---|---|---|
| | 6am - 12pm | 12pm -3pm | 3pm- 6pm | 6pm- 10pm | 6am - 12pm | 12pm - 3pm | 3pm- 6pm | 6pm- 10pm |
| Cleaning | | | | | | | | |
| Cooking | | | | | | | | |
| Fetching water |  | |  |  | | | | |
| Collecting firewood |  |  |  | | | | | |
| Gardening |  |  |  | |  |  |  | |
| Harvest processing |  |  |  |  | | | | |
| Child care | | | | | | | | |
| Social activities | | | | |  |  |  |  |
| Selling/buying items | | | | | | | | |
| Grazing goats/cattle | | | | |  |  |  | |
| Bathing | | | | |  |  |  |  |

Legend

-  Most frequent activity times
-  Activity increases risk of exposure to tsetse bites

Aggregation of participants' movements within the village

GPS tracking data showed that the total area covered by participants' movements within a single village varied between 5 to 21 square kilometres¹³ (Figures 4.6 and 4.7). Each colour polygon indicates the total surface area covered by participants in their village and surroundings. Figure 4.7 zooms into each village and illustrates concentration of movements by clusters of black dots (waypoints). When movement tracks were covered by the land-use layer, the single layer, namely "agricultural land" was shown on all the maps. Examination of waypoints (Figures 4.6, 4.7) showed that, not surprisingly, most movements were

¹³ All participants were moving on foot.

clustered around participants' homes¹⁴.

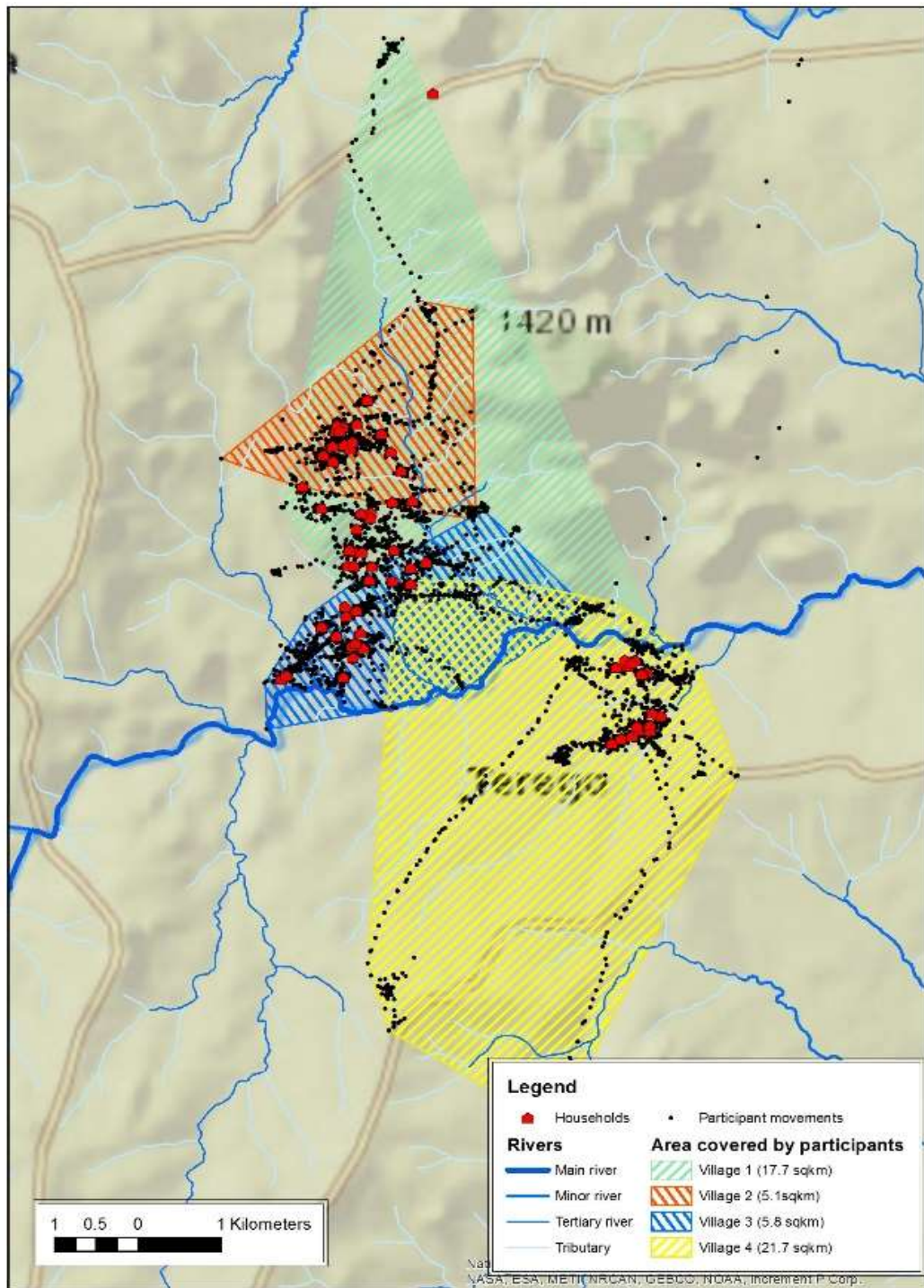


Figure 4.6: Map of the area covered by GPS tracked participants in all the villages

¹⁴ The area between rivers and households are mostly occupied by fields (personal observation).

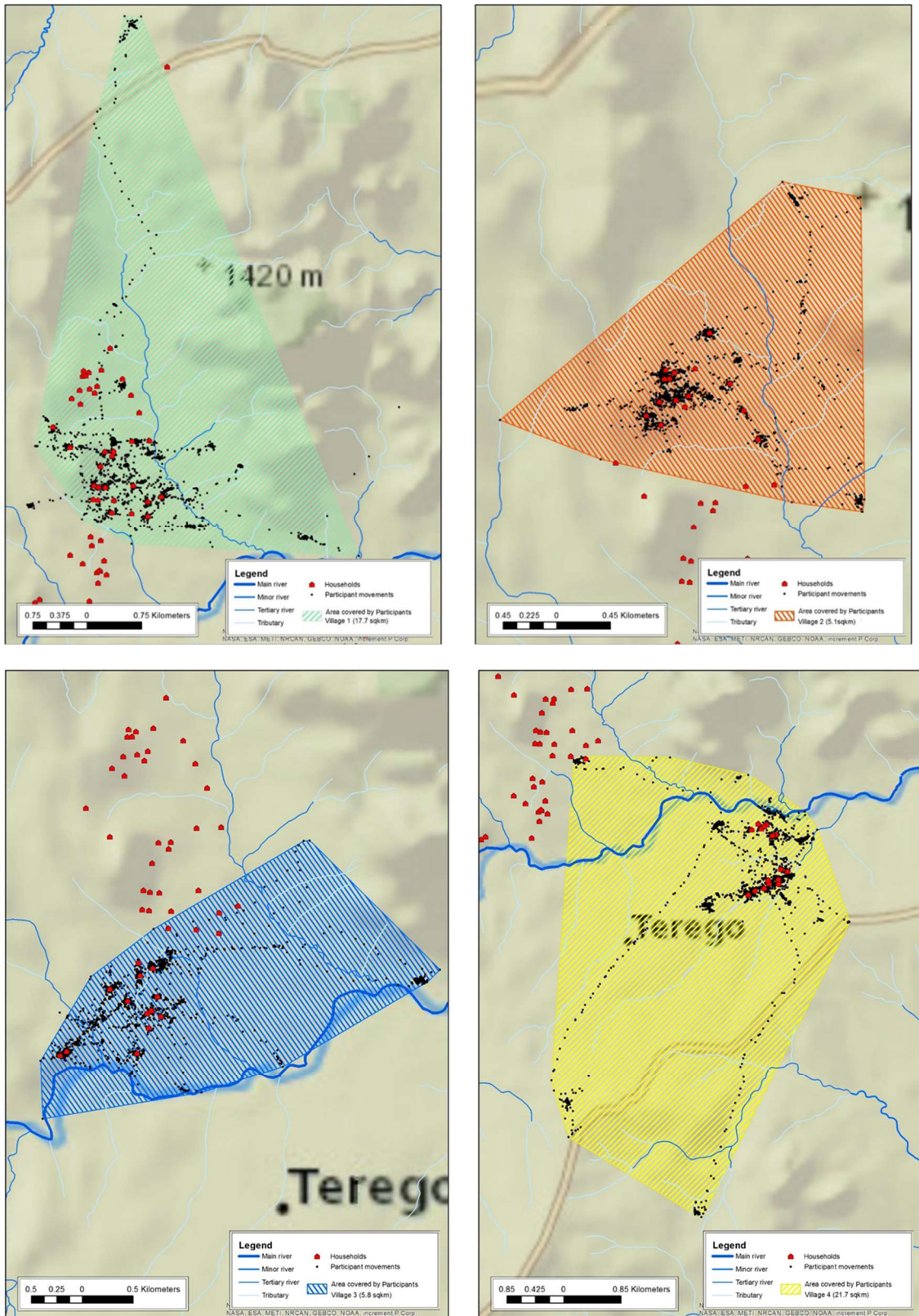


Figure 4.7: The area covered by GPS tracked participants in each village

No difference between men and women in assessing tsetse risk zones

Four potential risk zones were defined as being within 10m, 20m, 50m or 100 m of the river bank (Opiyo M., unpublished). Analyses of the percentage of waypoints recorded within each risk zone showed that male participants spent more time there than female, albeit the difference was only significant ($P < 0.05$) for the 100 m data (Figure 4.8).

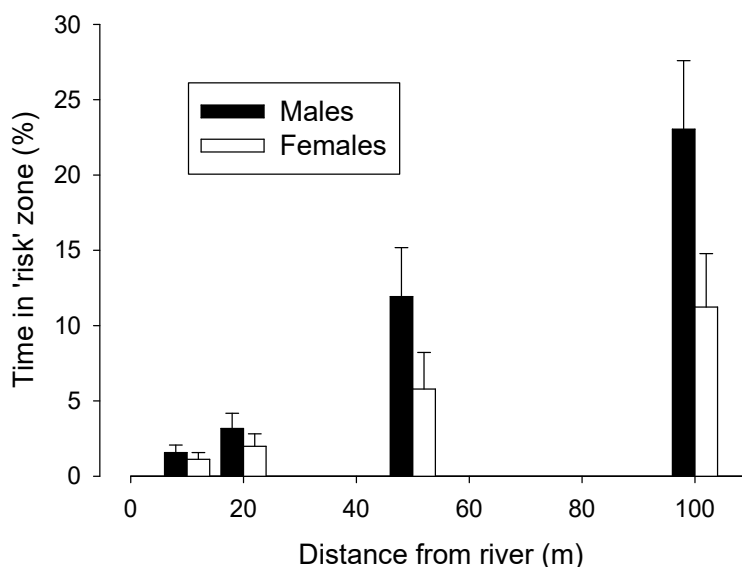


Figure 4.8: Mean percentage (+SE) of time spent in biting risk zones (10, 20, 50 or 100 m of a river)

The proportion of time spent in the risk zones was low, ranging from 1% for females and 2% for males in the 10 m zone up to 11% and 23% respectively in the 100 m zone (Fig 4.8). Whilst the times spent in the risk zones were low, most individuals entered them at some point during the day, which presents an important cumulative risk to tsetse bites. For instances, 82% of all participants (males and females pooled, $n=58$) entered the 100 m zone and 65% entered the 10 m zone. Three participants spent a particularly long time in the 100 m risk zone and the reasons for this were discussed in subsequent interviews. One male (95% of time in the 100 m risk zone; $n=392$ waypoints) reported walking to visit his brother's and his son's households; he spent time harvesting maize, green papers and eggplants; he approached river to check on drying cassava and went to inspect the field planted with beans; he also made some movements while grazing cattle. A second male (88%; $n=215$ waypoint) reported harvesting cassava, visiting friends, walking to the distant home to deliver money for the purchased field and cutting sticks in the bushes for harvesting mangoes. The female participant spent most time (72%; $n=214$ waypoints) checking her peanut crop, cleaning harvested beans in the river, fetching water and searching for wild vegetables.

4.4 Key findings from the baseline phase

- Details related to disease control programmes remain in the collective memory of the community over a long period. Despite some negative associations with HAT control campaigns, particularly the early ones, it appears, from the views expressed by elders, that sleeping sickness interventions in the research area did not create any permanent traumatic memories. Hence, previous HAT control interventions are not likely to be an impediment to community involvement in tsetse control.
- When gender related factors were examined, men and women perceived women to be at higher risk due to daily activities that take women to proximity of rivers. This perception of increased risk was associated with the dry season when women shift to the river banks to perform additional activities. Such activities include watering nursery beds, fetching water for brick material and carrying out sand extraction.
- Perceptions of risk, however, were not in general accord with actual risk, measured by GPS tracking and interviews with men and women. This data showed that actual movements in tsetse risk zones do not place women under greater risk than men. These findings further showed that both men and women are exposed to tsetse on a daily basis (82% of participants entered to the tsetse zones), despite the fact that they access rivers for different reasons and activities.
- In summary, perceived risk, is certainly higher for women and women themselves used this argument to explain that they are therefore better positioned to be involved in tsetse control compared to men. According to my working hypothesis, women and men, and their perception that women are at higher risk, create a supportive social-context for a women-led tsetse control operation. On the bases of these findings a community-based tsetse control operation was developed, led and implemented by women; the findings of this pilot study are described in the next action research phase.

Chapter 5: PILOT INTERVENTION AND EVALUATION FINDINGS

5.1 Chapter overview

This chapter reports results of the pilot tsetse control intervention implemented through participatory action research with women. The first part of the chapter reports findings related to planning the intervention with women. The remaining of the chapter reports on the impact of the intervention to both at community and operational levels. The findings related to operational impact, particularly the quality of target deployment, maintenance and cost effectiveness are compared with the operation managed by an expert team, referred to as 'externally-led' programme (section 3.3) which was operating concurrently with the pilot intervention in West Nile. Tiny targets were the primary control tools used in both the external programme and the pilot intervention; the main difference was in how tsetse control strategies were delivered. The externally run programme was managed by a team consisting of experts and locally trained field technicians, whereas the pilot intervention enlisted local women to implement a tsetse control programme through action research.

5.2 Intervention

Planning the intervention

A series of focus group discussions (FGDs) documented the early stages of the intervention, how women were introduced to tsetse control and the control tools (tiny targets), and how they prepared for target deployment. This section describes and illustrates the process based on the findings from group discussions.

Women demonstrated competence in planning target deployment (Box 5.1)

During FGDs, which were initiated at the beginning of the action research, women readily identified water bodies where tsetse were present. In both villages, women mentioned being 'attacked' or 'bitten' by tsetse flies. Specific riverine sites were described by referring to locations where women performed their daily activities, such as washing clothes, fetching water, drying cassava and collecting firewood. Women reported having local names for the river sections and tributaries where these activities took place and

they used these names in the planning process. Participants from both villages agreed that targets must be deployed along all these sites, particularly in places where their daily activities were performed.

Despite initial reluctance by one group, both villages created detailed maps (Figure 5.1) of the rivers running through their villages, which demonstrated a clear spatial understanding of the river system. Boundaries between villages were identified through landmarks, such as trees, big stones, and anthills, nearby paths or tributaries. Participants used these landmarks to divide the river into sections and individuals living in the vicinity were placed in charge of each section.



Figure 5.1: A participant drawing a map of the river system in their village

Participants were resourceful and made prompt decisions about the practical tasks involved in planning target deployment. For example, despite the lack of equipment to measure river lengths to calculate the number of tiny targets needed, women in both villages decided to count their footsteps (one hundred footsteps would equal approximately 50 metres). Some participants wrote the number of footsteps on paper while others, who did not have the use of pen and paper, used sticks¹⁵ (Figure 5.2) to record the numbers. Some women suggested marking target deployment location by using: a) a small hole in the ground, b) a mark on a nearby tree or c) knot tied in the grass.

¹⁵ Each provided stick was equivalent of the 100 steps walked along the river (~50 m).



Figure 5.2: A participant submitting a bundle of sticks after measurement of river length

Women discussed the challenges they faced while planning target deployment. The most common challenge was the nearby vegetation (tall grass, dense underbrush and thorns) as it impeded access to the river. Women also commented on the inappropriateness of ground targets because of their susceptibility to loss and damage due to flooding of the river. All women preferred hanging targets (Figure 5.3) since there was an abundance of suitable trees and bushes from which to suspend the targets.



Figure 5.3: Hanging (left) or ground (right) tiny targets

Participants in both villages were enthusiastic about the planning meetings and were willing to disseminate information about the tsetse control intervention to other nearby villages. Women generally shared information during normal daily interactions with their neighbours: they would ‘just talk about it

anytime, wherever we meet [with other community members]'; but some women specifically visited households to inform them about the programme. Women who missed a mentoring meeting were also briefed about the discussions and activities planned by other participants. In addition to their efforts to sensitize other community members, participants said that the news spread by word-of-mouth to neighbouring villages. On one occasion, a village chief made an announcement regarding the tsetse control intervention during a wedding ceremony that was attended by villagers from other communities. Before target deployment, all participants were confident that villagers were sufficiently informed and that consequently, nobody would tamper with the deployed targets.

Box 5.1: Women demonstrated competence in planning target deployment

"Keci, Arimbajo, most of the water bodies here even Peletu is where we see tsetse (...). We would like to place targets along most of the rivers we named; we get bitten by tsetse along all of them" (FGD 3b).

"Along the way, while I walk, when I reach hundred steps, I will just make some sort of mark on the ground; next time [when we deploy targets] I will show other women where to put the target. And also on the small paper for every hundred step I will make a small line" (FGD 3a).

"The grass was too long, the area bushy, there were even thorns [where we walked to measure rivers]" (FGD4b).

"We experienced difficulties measuring the length of the rivers. It was bushy, so it was hard for us, and we stepped on thorns so there were many challenges" (FGD 4a).

"There are [enough] trees there... So mine bunch of targets should be mixed [with ground and hanging], but mostly there should be hanging type" (FGD 4b).

"Sometimes, if it rains, like at night, sometimes the water level is very much [increased]; it comes even up to some [flooding] extent so that we will even find it very difficult to get to these targets; we may find them already swept away by the water. It's better this one [hanging type] so that we tie it up [and keep it safe]" (FGD 4a).

"Yes, people from this village know, every household knows what we are planning to do (...). When we start deploying targets around, when someone comes and sees them; someone who heard an information about it, they will know! They will know that, it's targets which have been given to prevent sleeping sickness (...). Nobody will remove them, as people have information about it and they are happy about it" (FGD 4a).

Target deployment and maintenance process

After the preparation phase was complete, women were given the appropriate number of targets, as estimated through use of river stretch measurements. Figure 5.4. shows images of participation on the

first day of deployment¹⁶. The research team accompanied the participants to the designated site and demonstrated two target deployments. The women then took charge and further organized themselves to proceed with target deployment and maintenance for the next six months (demonstrative video in Appendix D1). Women were instructed to keep targets in an upright position and ensure that they were clear of vegetation so as to position them in a manner fully visible to the tsetse.

Details on the efficacy of target deployment, target maintenance and women experiences during deployment are presented in sections 5.3 and 5.4.



Figure 5.4: The first deployment day

5.3 Evaluation: participation of women

Participants' engagement with intervention and their organizational capacity

Evaluation of how women engaged with the intervention was explored through a participatory scoring method. This method focused on evaluating women motivation, and their sense of ownership and empowerment. In discussion with participants through FGDs the definition of 'motivation' corresponded

¹⁶ Top left panel: women walking to the river with targets and tools; top right panel: clearing of vegetation at deployment site; bottom left panel: the first ground target is successfully deployed; bottom right panel: the day ended in good spirits.

with 'one being willing to do something'. The definition of 'ownership' was linked to 'taking something as their own'. The empowerment was linked with 'having a strong confidence to do certain activities; confidence to achieve something'. These terms were further discussed during FGDs to capture all the associated meanings (see below).

Participants' organizational capacity was assessed by a researcher-completed scoring system in relation to three categories: leadership, implementation of tasks, and resource mobilization. Information on these indicators were collected at three time points: baseline, pre- and post-deployment of targets¹⁷. The following sections describe findings from the participatory scoring and evaluation, illustrated with spider diagrams (Fig. 5.5-5.7) [220]. In addition, key themes from the focus group discussions held throughout evaluation period are presented using quotes to illustrate key points (Box 5.2-5.4).

Findings from participatory scoring and evaluation of organizational capacity

During participatory voting, women from both villages scored a maximum of 4 scores for their motivation level at each of the three time points (baseline, pre- and post-deployment; Figs. 5.5-5.7).

In both villages, women's perception of target ownership improved from baseline through to post-deployment. Initially scored 'low' (Village 1: 0.5 scores; Village 2: 0.75 scores) (Fig. 5.5) the sense of ownership assessed by women increased steadily from pre- to post-deployment phases (Village 1: 2 and 4 scores respectively; Village 2: 1.25 and 4 scores respectively) (Fig. 5.6 and 5.7). But in comparison to other indicators of community engagement (i.e. motivation and empowerment), ownership¹⁸ increased relatively slowly in both villages.

There were some differences between the villages in scoring of empowerment. In Village 1, empowerment scores were low at the beginning of the study (2 scores) (Fig. 5.5), but at the time of pre-deployment women's scoring of this index began to increase (3.5 scores) (Fig. 5.6) until it hit a maximum score (4) during the post-deployment phase (Fig. 5.7). In Village 2, women's scores reflected their feelings of a complete lack of empowerment at the baseline (0 scores) (Figure 5.5), but in the pre-deployment phase, it jumped to maximum (4 scores) (Fig. 5.6) and remained at maximum level (4 scores) until post-deployment (Fig. 5.7). The noticeable increase in empowerment scores in both villages during the pre-

¹⁷ At the baseline no information on targets or their use was given to participants. At pre-deployment participants received all the technical information, but have not had experience with target deployment yet. At post-deployment time-point participants already received all the technical information and completed target deployment.

¹⁸ Ownership was associated with received information and handling targets (more details in Box 5.3)

deployment phase is consistent with the information from focus group discussions which suggest that women are more likely to feel empowered when they: a) acquire knowledge and skills and b) are able to communicate this to other members of their community (as discussed below).

The identification of leaders and their ability to implement tasks successfully improved in both groups during the course of the action research. At baseline, leadership was not demonstrated. For example, in Village 1 no leader had been identified (scored 0) and in Village 2, despite identifying a group leader, no leadership was assumed (scored 1) (Fig. 5.5). During the pre-deployment time period (Fig. 5.6), female leaders were selected in both villages and they assumed leadership by actively contributing to the decision-making and organization of the group (both scored 4). Importantly, the scoring system showed that those women who were identified as leaders maintained an active leadership role (scored 4) in both villages (Fig. 5.7). All leaders organized groups, acted as spokespersons and influenced decision-making.

Performance assessments of specific tasks completed during the three phases demonstrated that women consistently completed the tasks discussed at mentoring meetings (scored 4 in all phases) (Fig. 5.5-5.7). Tasks introduced to women during the meetings on tsetse control included mapping rivers, sensitization of community members and target deployment (Table 3.2). These were fully completed, which allowed operations to seamlessly flow from one operational phase into another.

Right from the start of the intervention, both groups were able to mobilise enough resources to complete meetings and tasks discussed (scored 4 in all phases) (Fig 5.5-5.7). For each meeting, for instance, the women organized a venue and provided chairs, tables and mats for participants to sit on. Women attended all meetings agreed upon. They also dedicated their time and provided the requisite tools to perform operational tasks, such as vegetation slashing tools and to some extent, protective footwear (more details under 'cost-effectiveness' section below).

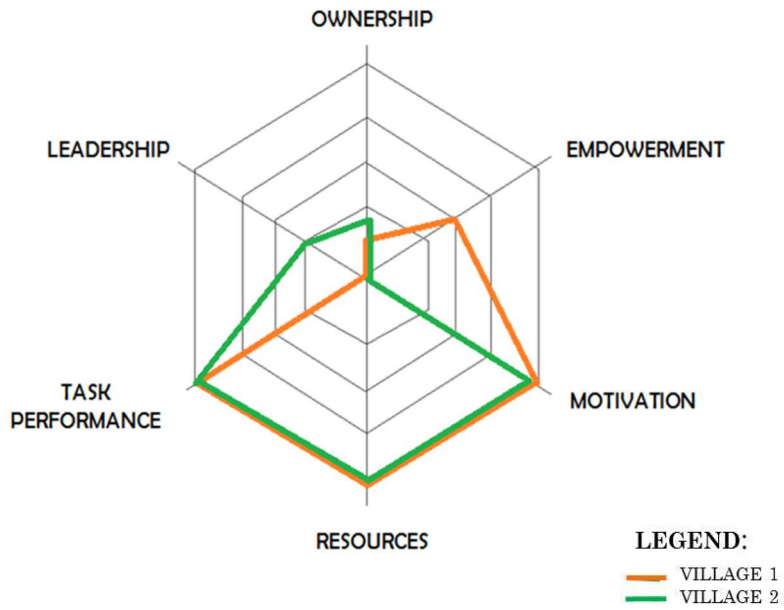


Figure 5.5: Baseline assessment of community engagement and organizational capacity

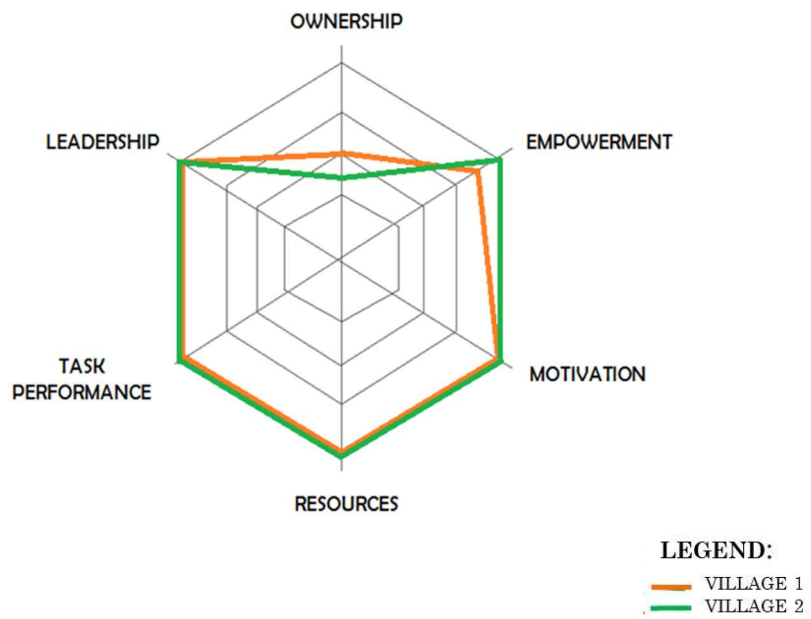


Figure 5.6: Pre-deployment assesment of community engagement and organizational capacity

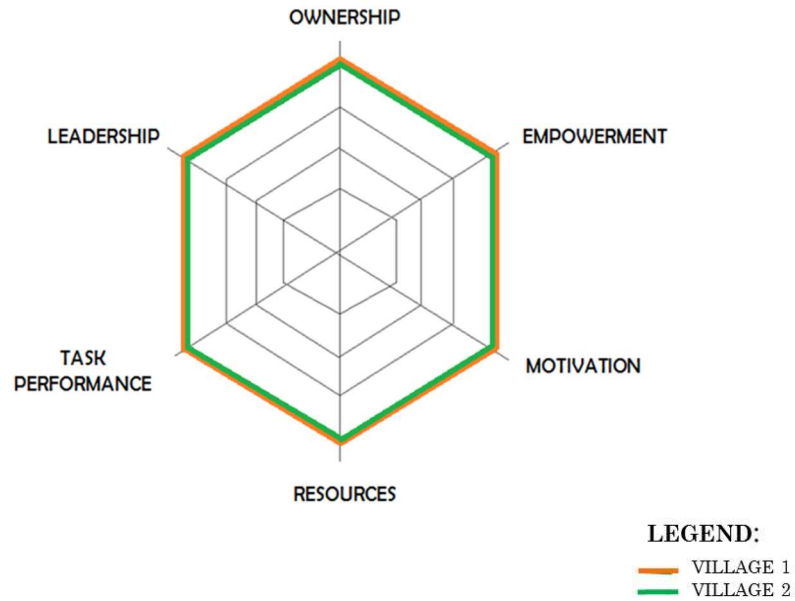


Figure 5.7: Post-deployment assessment of community engagement and organizational capacity

Women are motivated to prevent sleeping sickness and suffering in their villages (Box 5.2)

Group discussions revealed that participants from both villages declared their main motivation for involvement in the intervention was to prevent sleeping sickness. They gave testimonies of sleeping sickness cases that they had personally witnessed in their neighbourhood, and several participants were also survivors of sleeping sickness themselves. In both villages, there were some participants who expressed their gratitude to the research team for bringing the intervention to their village. They said that they were encouraged to participate in the intervention because they felt that they were at risk of contracting sleeping sickness. They also expressed concerns about the HAT treatment centre being located so far from their village and so felt that prevention was important.

Many spoke of ‘suffering’ from ‘that sickness’ and some hoped to prevent both tsetse bites and sleeping sickness. Participants from the second village also reported that reducing the nuisance of tsetse flies motivated them. Women from both groups reported feeling highly motivated to participate in target deployment and maintenance, and also to inform other members of the community about the programme. The second group were also motivated by a wish to learn new things and to inspire other members of the community to join the programme. Women in both villages re-confirmed their motivation to be involved throughout the action research process.

One participant in Village 1 raised the possibility that villages without experience with HAT may respond differently to the intervention. She explained that in villages where people suffered from sleeping sickness they would be more motivated to be involved, whereas those villages where the disease is non-endemic may not be as convinced.

Box 5.2: Women are motivated to prevent sleeping sickness and suffering in their villages

“Thank you! This sleeping sickness disturbed our area called Ludara [sub-county] so much. It had not yet attacked me that is why I am still in thoughts [not mentally ill]. But still the sickness is there [threatening us]. Since the testing facilities are not around, and to reach them one needs money (...). This thing has really affected us and it made us so scared! And I am so stressed of it! You should think of something to help us” (FGD 1a).

“Thanks, I give a lot of thanks to you. Here in our village there is no white [foreigner] who come to see us [before]. If it’s election time, some people come and sit [here], but if it’s other things, like good things [for the community], they don’t stop here, people just pass by. Thanks, thanks, for coming (...). They [health workers] tested many people [for sleeping sickness before], but they didn’t come here to our village [for a while] (...). it’s God who sent you here” (FGD 1b).

“We now want prevention, that’s why we are doing this [coming here for the meeting]” (FDG 1a).

“This work with targets will motivate us because tsetse flies will not bite us so much anymore” (FDG 1b).

“We get bitten by tsetse flies around water bodies, when we go down for fetching water. In this village we are really suffering from tsetse [bites]; that’s what we are saying, we are motivated!” (FGD 1b).

OPOSING VIEW:

“The thing is if one gets into that situation and they really suffered from sleeping sickness, one can easily do anything! That’s why we can willingly do anything [in our village]! But those ones who have not yet experienced this sickness, if they don’t have this experience, they can be saying like: -Aah, why should I go down there the river, why should I go and deploy targets, for what reasons? (...) But for us who have experience we shall not even think of that. For us we shall do the work in order for us to protect ourselves” (FGD 8a).

Women associated ownership with information and contact with targets (Box 5.3)

When discussing ownership of the tsetse control intervention, women remarked that ownership was synonymous with information and contact with the control tools. This included having sufficient information on the design and functionality of the tools and opportunities to handle and familiarize themselves with the tools. The first group also added that it was important to have enough information on sleeping sickness and how the tools are used for disease control. Participants in both villages compared their sense of ownership of the tiny targets, introduced in the intervention, with the use of bed nets. They discussed how they are ‘familiar’ with bed nets because they were ‘taught that bed nets are for

mosquitoes' and 'talked about [nets] extensively'. Others said they would be willing to 'take targets as our own thing' if given sufficient information about them.

As the action research progressed through the series of mentoring meetings, participants from both villages demonstrated increased knowledge of targets and confidence in handling them. For example, participants were able to easily provide the rationale for using the small size of the targets, explaining that '...the tsetse fly doesn't fly very high, it doesn't fly very low [either] so just at that medium height [where the cloth is]'

Women showed positive attitudes towards both types of control tools (traps and targets). They perceived the value of each type of control tool differently. For instance, traps were valued for their capacity to catch tsetse and for participants to 'see them', but targets were appreciated for their ability to kill tsetse. Participants mostly agreed that they liked both types of tools.

Ownership also seemed to be associated with taking responsibility for control tools. This was evidenced by the identified leaders of women's groups, who took personal responsibility for checking and maintaining targets at their section of the river and referring to those particular targets as 'mine'. There was no difference between both villages in this respect. Participants in both villages also observed that because of a sense of local ownership, the targets had been looked after and were not 'destroyed' or 'tampered with'. Many commented that people in the village were 'happy' with the tsetse control programme.

Box 5.3: Women associated ownership with information and contact with targets

"At that space where they have made it [the cloth], the size is developed for tsetse flying pattern" (FGD 6a).

"As we are now used to them [targets], we touch them whenever we are going to the stream, where we deployed them" (FGD 7a).

"For us they are all good [traps and targets], for the changes we have seen, they have reduced the bites" (FGD 8a).

"One by one we were checking deployed targets. Each person goes to her own [targets] at the place where she had fixed [deployed] them" (FGD 8a).

"I checked my targets thrice until today" (FGD 8a).

"Since it is to protect them from sleeping sickness, no-one will be removing them [targets]" (FGD 3a)

“What we experienced here is that people [in the village] are happy because of this programme. So they don’t even tamper or remove targets” (FGD 8a).

Women feel empowered through the communication of knowledge and skills (Box 5.4)

Regular group discussions with women in both villages revealed that women’s sense of empowerment came from the interaction between them and the research team. For instance, the ability of the research team to impart specific knowledge and skills about tsetse control and control tools was an important part of the process of empowerment. Some women explained that the training on the targets and the knowledge on ‘how to fix them [deploy them]’ made them feel empowered.

Being able to pass on the knowledge to others and to attain a new role in the community through their participation was also described as empowering. Women said they felt proud of their newly acquired skills and to be able to possess information about technical aspects of targets. Both groups realised that their ‘empowerment’ was based on sharing knowledge with other members of the community and on ‘telling other members of the communities confidently how to do the work with targets’. In Village 1, women took every opportunity to demonstrate their knowledge to others who were less informed about the programme.

Women also explained that being involved in the tsetse control intervention empowered them with a new sense of purpose and they felt that they had ‘some important work to do’. They talked openly about feeling satisfied to participate in the programme and that this form of participation gave them an important role in the community.

Box 5.4: Women feel empowered through the communication of knowledge and skills

“Give us training on the targets, that’s how we will feel empowered” (FGD 1b).

“We want to know...how to fix it [deploy targets] and where to fix it... That’s what we want to know to feel empowered” (FGD 1a).

“When I was passing, I met a woman who saw us walking around [with targets]. She asked: -what were you people doing there? I told her: - there is a group that brought us some nets [targets] which are used for preventing tsetse flies. Those ones [targets] we have deployed down the other river... So that is what I was telling her” (FGD 3a).

“Yesterday I met some lady and her husband; they have seen these small targets around, and they were asking me: what is the use of that? And how does it trap the tsetse fly? Then I was explaining saying: - No, those targets don’t trap flies... Tsetse flies come from the other end, they hit it and they go somewhere and die... After some minutes they go and die somewhere- that’s what I told them” (FGD 6a).

“One time, there was a man who asked me:- How does the target work? How does it work and how can it catch tsetse flies? I started telling that man that:- targets do not catch tsetse flies! The tsetse fly comes and sits on it; after it sits on it, it goes [flies away] and dies somewhere. Target doesn’t catch it there! You can’t see whether it [tsetse] was caught or not! But what you can just experience [as a result] is, you might experience reduction in the number of bites, you do not experience much bites [by tsetse] anymore-. That is what I told the man” (FGD 8a).

Perceptions of effectiveness and feasibility of intervention

During focus group discussions women were encouraged to talk about their perceptions on effectiveness and feasibility of intervention. Perceptions on tsetse reduction were confirmed using monitoring traps in intervention and control areas.

Perceived decrease in tsetse density after intervention (Box 5.5)

Three months after the intervention, we asked if the women had observed any changes. Women from both villages enthusiastically reported a lower abundance of tsetse and a decrease in tsetse bites. They mostly talked about making these observations while carrying out tasks at the river banks, such as drying cassava, washing clothes and bathing. Many of them started slapping their shoulders, to gesture how tsetse had ‘disturbed’ them before, but explained that ‘tsetse are not there anymore’. In both villages, some women also expressed their surprise, saying that ‘at first they thought it [targets deployment] was a joke’, but after observing some real changes they felt ‘happy and impressed’ with the impact of the operation.

Women also reported that a drop in tsetse numbers brought some concrete changes in their lives. Most of them said that they: a) were not feeling ‘scared’ anymore when they bathed at the river, b) were able to take their children with them without worrying that they will get bitten and c) were not distracted from their work at the river banks by tsetse.

Box 5.5: Perceived decrease in tsetse density after intervention

“There is a change, after deployment; that’s why we have come [for the meeting again]. When we used to go to spread cassava [at the river bank], we used to tap ourselves [due to tsetse attacks]. But now [after we placed targets], tsetse are not there” (FGD 9b).

“I am also experiencing that there is reduction of tsetse flies, because where I was washing clothing I don’t experience anything [any bites] anymore... Like before time [with targets], if I went there [to the river to wash], I started experiencing some bites. But these days, I don’t” (FGD 8a).

“At first I thought it was some joking stuff [I didn’t take targets seriously]. But now I realized it is a good idea for me to revenge sickness [this way]. And these days I don’t scratch myself [anymore due to bites]” (FGD 9b).

“I am impressed and happy because last time where we fixed nets [targets], I go there and wash [clothes] from there. But before you could just go to fix the clothing [to dry] and you experienced some bites and flies [disturbing you]; but these days you can even go there where you wash [at the river], you may even go with your child! Tsetse doesn’t bite a child [anymore]” (FGD 8a).

“If you go down to the river for bathing you are not so scared like you used to be. Tapping yourself, slapping everywhere [to keep tsetse away]. This time we are not doing that” (FGD 8a).

“We are finding it better now after deployment. Because before you could just bend down doing something, it [tsetse] would bite you. Then you find yourself raising yourself up, you take some time to go back [to work], so we are not experiencing it [these disturbances] now.” (FGD 8b).

Measuring relative tsetse density using monitoring traps, which was carried out nine months after targets were deployed, validated these perceived changes. Participants’ impression that tsetse numbers had declined was confirmed. Results from the monitoring traps showed a 10-fold difference in tsetse density in areas with and without targets¹⁹. Within the area of women-led tsetse control intervention, the mean daily catch of tsetse was 0.08 tsetse/trap/day²⁰, during a 3 day sampling period. In accordance with expectations, in the lower reaches of the Kochi river system (control site), 6 km from the intervention area (Figure 5.8), catches were 7.6 tsetse/trap/day during the same time period²¹.

¹⁹ This result is consistent with the data from the larger trial, which used teams of trained field technicians to deploy and monitor targets.

²⁰ A single fly was caught in 13 trap monitoring days.

²¹ In order to introduce tsetse tools to naïve participants, tsetse monitoring was not done in intervention areas managed by women before targets were deployed. A ‘control area’ on the same river system is therefore used to evaluate perceived changes in relative tsetse density.

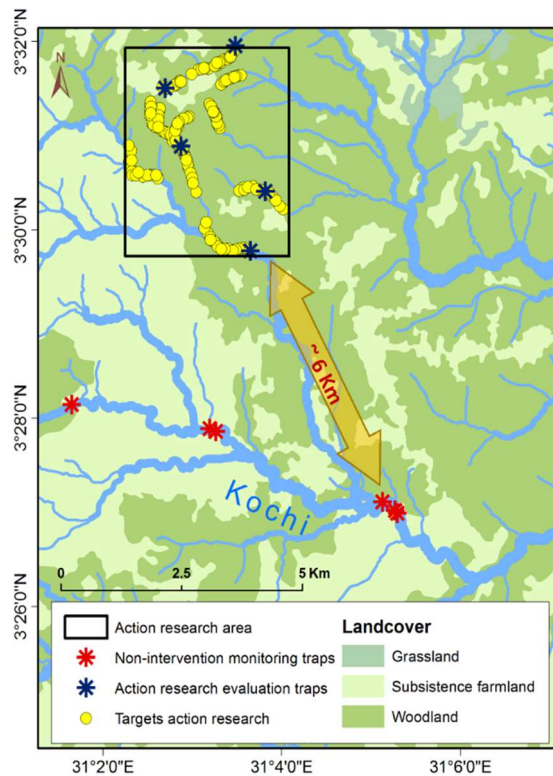


Figure 5.8: Position of the monitoring traps in intervention area and control area

Women regard their involvement in tsetse control as feasible despite some identified barriers (Box 5.6)

In focus group discussions in both villages during the period of ‘reflection’ after deployment, we explored women’s views of feasibility, particularly to what extent it was possible to carry out the tasks involved. Despite the fact that women eventually completed all the tasks and managed to mobilize resources needed (as already discussed earlier in this section), women in both villages reported experiencing challenges related to time management (only reported in Village 2 and 3), borrowing tools, lack of protective footwear and difficulties in accessing the intervention area.

Village 1 deployed their 42 targets within a week as agreed with the research team and they did not report any difficulties related to this timeframe. However, villages 2 and 3²² deployed about 80% (121) of their 152 targets over four weeks as planned but delayed the deployment of the final 31 targets for another four weeks. Women commented that when they suggested deployment time before actual deployment, they did not factor in unforeseen events. Delays were associated with the beginning of Ramadan and fasting, working in the fields, preventing monkeys from destroying crops, and funerals. During mentoring

²² Village 3, which joined the programme by their own initiative, was represented by a smaller number of participants (see section 3.5). Village 3 was therefore only included in evaluation of deployment and target maintenance and cost-effectiveness analysis.

meetings, the research team also observed that if the meetings were still in process at noon, women hastened the research team to finalize discussions. The reasons were related to approaching rains, drying cassava, prayers and domestic tasks.

Poor availability of tools to clear vegetation and protective footwear (like gum boots) were frequently mentioned as main challenges for deployment and target maintenance. Some women stated that the lack of protective footwear discouraged some of the other women from joining the target deployment team. Related to this, other women voiced reluctance to check targets regularly due to a 'fear of snakes' in the 'bushy' vegetation adjacent to where targets are deployed²³. Figure 5.9 shows that target deployment involved making passages through dense vegetation, for which vegetation cutting tools and protective footwear were essential. Whilst women managed to assemble tools to clear vegetation, by 'asking husbands' or 'other people', borrowing them seemed to be problematic as tools were not always readily available even with other people.

Despite these challenges, the women reported that their motivation was strong enough to complete the tasks willingly. Participants in both villages insisted that if provided with tools, protective footwear and some flexibility in deployment timeframe, tsetse control interventions could be managed by women in other communities as well. Participants were confident that they could initiate the programme 'teaching other women' what they have learned during the action research.

Box 5.6: Women regard their involvement in tsetse control as feasible despite some identified barriers

"The deployment was successful but the only problem was the place was too bushy; so we were being cut, cut by the grasses" (FGD 6a).

"We delayed deployment because we faced difficulties in fasting [Ramadan]; monkeys were also disturbing us and [extensive] field work we had... So it was hard, we couldn't handle all those" [activities together]" (FGD 8b).

"We were moving a lot up and down for the funerals that's why we didn't manage to fix the targets [finish deployment]. We had three funerals, in three different distant places (...). It was the same group of us, all the same people, going for [all] the burials, so this caused a delay" (FGD 8b).

"We accepted we will carry out the deployment, but others they said without footwear they can't move because they will get pricked by thorns. That's why they refused to join us" (FGD 8b).

"We are motivated and we did it [deployment] willingly because of the sickness (...). We wanted to know whether there is a change if we do that [deployment]. This is what motivated us more, to have a change and that's why we deployed all the targets immediately" (FGD 8a).

²³ The highly venomous forest cobra (*Naja melanoleuca*) is indeed present in this area.

“Yes, women can be involved in communities for planning, deploying, maintaining targets [in other communities too]” (FGD 8b).

“If we tell them [women from other communities], if we talk to them, they will accept [the idea], they will come [to learn and do deployment]” (FGD 7a).

“We think the women in other areas will be willing to do that [deploy targets]” (FGD 8a).



Figure 5.9: Target deployment involved making passages through dense vegetation

Men did not object to women’s participation (Box 5.7)

We also explored what domestic tasks women sacrificed in order to carry out their tsetse control responsibilities and what would be the long-term consequences if these tasks were not completed regularly. Women commonly mentioned ‘sweeping the compound’, preparing meals and working in the gardens, and explained that if these tasks were ignored, there would be severe consequences in terms of crop losses to rats and other animals, hunger in the family, and potential disease due to unhygienic conditions in the compound since no-one else performed domestic chores. However, women reported that despite their involvement with the programme they were able to perform these tasks, so these consequences were less likely to occur. Participants did not report any gender-related tensions from their male family members despite devoting their time to meetings, target deployment and maintenance. Involvement in disease prevention activities seemed to be an acceptable and desirable activity that was favoured within family settings.

After their experiences with the intervention, women were still of the opinion that they were more motivated and better positioned to carry out tsetse control operations compared to men. They explained that because participation was voluntary, and the control activities time-consuming, men would be reluctant to engage in the intervention; in addition male exposure to tsetse was perceived to be lower.

Box 5.7: Men did not object to women’s participation

“No, if only ladies are involved this could not bring any tensions [within the family], because it is for preventing diseases; we don’t think we could get into problems. If we deploy targets and say it is to protect one against some diseases no one would obviously do anything [to oppose this]” (FGD 8b).

“No, we didn’t have any problems at home while participating in this programme (...). If we would come here (...) and we would go back late for cooking when kids are there crying from hunger, that’s when the problem would come. They [men] may be like shouting at you or back at you because of the kids” (FGD 6a).

“Men of these days, what they think is just about the money. They don’t think of any other thing! Us women, we do everything for ourselves: like fetching water, washing clothes, we do that ourselves” (FGB 8a)!

“By now the men would have left. They would have left the work they would not [finish it like us]; they would not do that, because the [amount] of time we spend here [attending this programme] it would not work for them” (FGD 8b).

“The men... They could come back in the evening, just ask for water for bathing, while us we shall be bitten by tsetse flies [fetching it]. And the men they would be on the safer side, they would not be bitten (...). That is why their mind is so much focused on the money [if they needed to do this type of intervention]” (FGD 8a).

“We are happy because you involved us, women alone! We are happy because of that. Because most time it’s the women who do the work [that exposes them to tsetse]. Men don’t get chances to get exposed to tsetse flies. So when we go to the field, fetching, there we get experience [with tsetse] but for the men they don’t; so we are happy [to be able to protect ourselves], because we are the one suffering from that” (FGD 8a).

5.4 Operational evaluation

As described in the methods chapter (section 3.6), the impact of women’s participation on the overall tsetse control operation and its sustainability was assessed in three ways: i) through evaluation of target deployment, ii) assessment of target maintenance at three time points and iii) through calculation of its cost- effectiveness.

Quality of target deployment

A total of 194 targets were deployed by women across an area of 13.9 km² (Figure 5.10). The results show that there were some gaps in deployment on some sections along the river that occurred due to the difficulty in agreeing where the exact boundaries between the villages lay. The overall density of deployed targets however, was ~14 targets per km², which far exceeded the recommended level of 6 targets per km² [47] and this density was sufficient to control tsetse population in the intervention area.

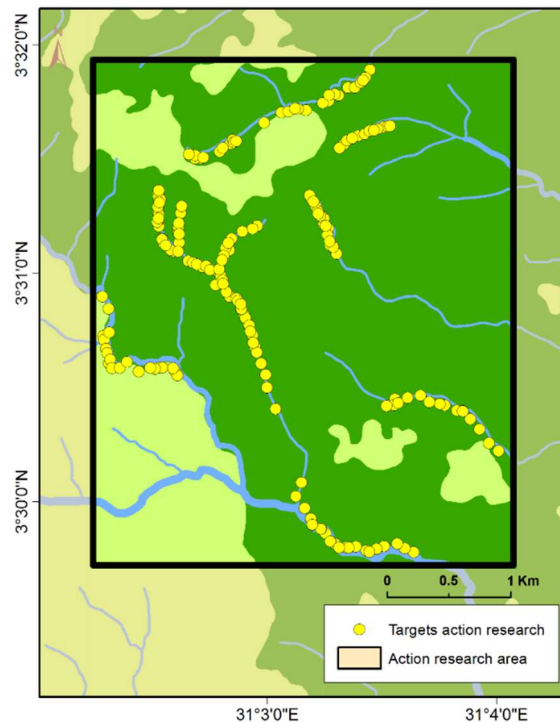


Figure 5.10: Deployment map

Target maintenance

Fully functional targets (with inserted wooden poles or hanging targets with attached ropes) were distributed to the women in the deployment phase (Village 1: 42 targets, Village 2: 108 targets, Village 3: 44 targets; Total: 194). Figure 5.11 and Figure 5.12 show the percentage of these fully functional targets and how they were maintained over 6 months intervention. Field assessment of deployment showed that targets were deployed in the recommended way – within 5 m of the river (ground targets) and less than 50 centimetres above water level (hanging targets). The area around each target was cleared of vegetation and 95% of the deployed targets were fully visible when assessed. Three months after deployment, 75% of targets were still fully functional and 65% of the sites were cleared of vegetation. The percentages declined to 51% and 38% respectively six months after deployment. This compares very

favourably with the nearby large-scale operation²⁴ where only 22% (107/475) of the targets were functional six months after deployment²⁵ (personal communication, Esterhuizen J., January, 2013).

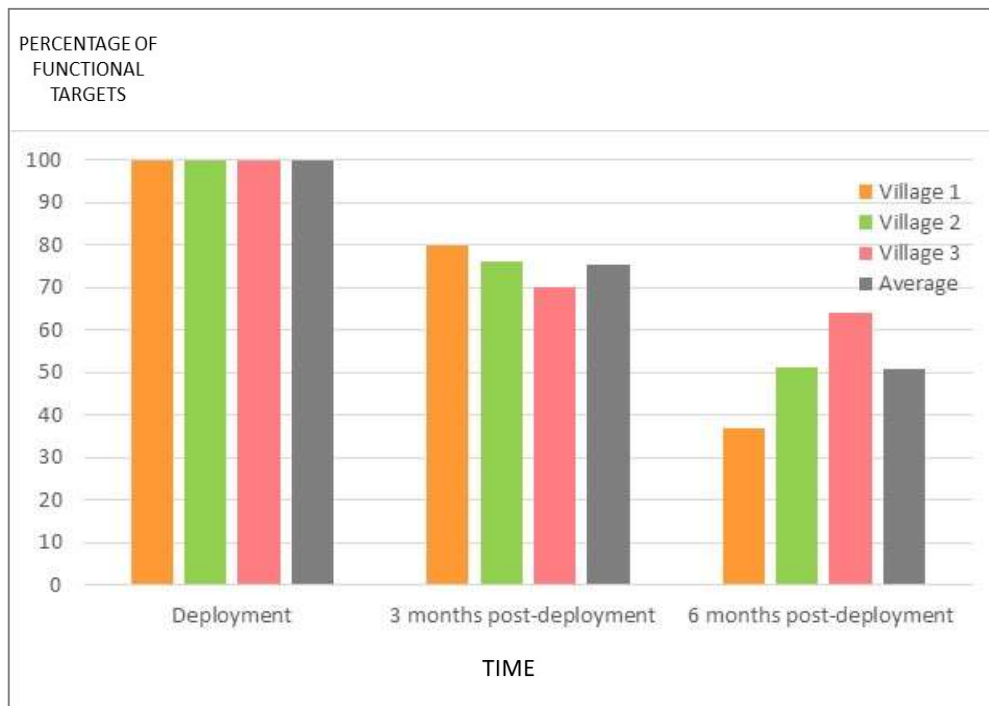


Figure 5.11: Graph showing the percentage of functional targets (6 months long intervention)

²⁴ External operation was implemented without community participation; communities in the trial area only received information on intervention and explanation on tsetse control tools.

²⁵ No data for target sites-condition is available from externally-led intervention.

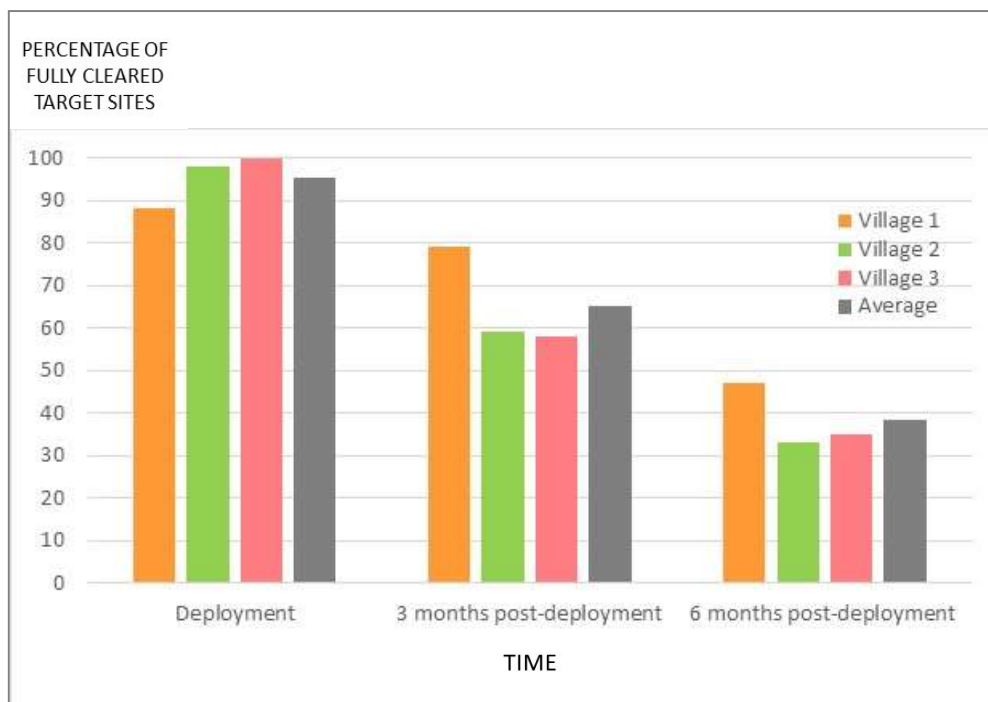


Figure 5.12: Graph showing the percentage of fully cleared target sites (6 months long intervention)

Cost-effectiveness

The cost of action research

The total cost of action research included all the elements related to preparation, intervention and evaluation and was calculated for the overall area of 13.9 km². Expenditure, travel and time inputs were recorded during the work and are summarised in the tables below converting USD to UGX as appropriate²⁶. The total external (research team) financial input was 9,612 USD (Table 5.1), the total internal (community) financial input was equivalent to USD 186 (Table 5.2). This gives a total research programme cost of: USD 9,798, or USD 3,266 per village (for 3 villages) or USD 705 per km² (for 13.9 km²), of which 78% was used by the research team for transport. Of the community inputs, 90% (or 1.7% of the total cost) was for participant time, calculated as an opportunity cost.

²⁶ Conversions from UGX to USD were done at the rate of UGX 2595 = USD 1, as explained in section 3.6/cost effectiveness. Figures for the USD conversions are rounded, so there may be some minor differences due to the calculations being undertaken using more decimal places than are given in the summary tables or text.

Table 5.1: Costs of full action research programme in 2013: external inputs

| Item and category | USD |
|--|-------------|
| Staff | |
| Researcher ²⁷ (2 months' salary at USD 597.36/month) | 1195 |
| Researcher daily field allowance (17 days at USD 5.78/day) | 98 |
| Driver and translator/facilitator (17 days' pay each at USD 11.56/day) | 393 |
| Transport | |
| Use of Toyota pick-up (5712 km at USD 1.17 per km) | 6683 |
| Fuel (635 litres at USD 1.464 per litre) | 930 |
| Equipment | |
| Targets (194 at USD 1.10) | 213 |
| Ropes for hanging targets (1 at USD 20.81) | 21 |
| Stationery (materials used at mentoring meeting) | 12 |
| Refreshments | |
| Samosas | 63 |
| Napkins and sugar | 4 |
| Total external | 9612 |

The researcher spent 44 days involved in work related to intervention and evaluation, which is equivalent to two months comprised of 17 days to prepare, 17 days in the field and 10 days data management. The monthly salary rate paid to the team leader was that for a local entomologist of USD 597 and a daily field allowance of just under USD 6 per day was added. Similarly, local salary rates for the driver and translator/facilitator were used. The research team spent 40 hours in meetings and 68 hours driving (17 meetings x 4 hours driving) resulting in a total of 108 hours. Transport involved 17 days travel in a Toyota land cruiser over a total of 5,712 (336 km per field trip). The running cost per km, including depreciation, were estimated over a year's use and came to USD 1.17 [49]. The targets cost USD 1 each plus an estimated USD 0.10 for transport by sea versus USD 0.13 to 0.40 for transport by air (ibid.). A total of 194 targets were deployed (approximately 10 per woman participating in the programme), giving an average density of 14.0 targets per km². Stationery consisted of two marker pens, a flip chart stand and a paper. For mentoring meetings, the research team provided refreshments consisting of locally made *samosas* and napkins and on one occasion a kilogram of sugar for the tea, which was provided by participants. The research team did not give any gifts to the community members.

²⁷ To make costing comparable to 'externally-led intervention', researcher salary and allowances were valued at Uganda government local rates for a senior entomologist. The objective of costing the action research was not to cost it as a research project, but rather to obtain a baseline for calculation of community based programme.

Table 5.2: Costs of full action research programme in 2013: internal inputs

| Item and category | USD |
|---|------------|
| Staff | |
| Opportunity cost of women’s time (USD 8.35 each, for 32.5 hours work, by 20 women) | 167 |
| Estimated depreciation on owned equipment used for project work | |
| Table, 3 chairs and sitting mat (total value USD 10.40) estimated life 6 months for furniture, 3 months for mat, so depreciation over 3 weeks would be USD 1.59) | 2 |
| Equipment for clearing vegetation: slashers and pangas (15 at USD 1.73), hoes (3 at USD 2.70), sickles (2 at USD 1.54), total value USD 37.19, estimated life 1 year’s full use, so depreciation over 3 weeks would be USD 2.30 | 2 |
| Gum boots (9 pairs at USD 7.71) estimated life 1 year ‘s full use, so depreciation over 3 weeks would be USD 4 | 4 |
| Refreshments | |
| Mangoes, roasted maize and tea | 5 |
| Gifts given to research team | |
| Avocados, mangoes and a necklace | 6 |
| Total internal | 186 |

The time invested by community members (20 women) was calculated at 32.5 hours each, valued at UGX 433,560. The significance of this and how its value was calculated is discussed below under ‘opportunity cost’. Although 20 women in total were involved in the implementation of all operational phases, a greater number participated in the meetings. There were no transport costs as participants walked to meetings or to undertake the various tasks entailed by the intervention. The time taken to walk to and from the meetings (~0.5 hour/person, total), however, is included in the ‘staff’ calculations. The equipment consisted of chairs, tables and mats, which were used for a fortnight. The mats cost 6,000 UGX and were estimated to have a useful life of 3 months. The tables cost UGX 3,000 and chairs UGX 18,000; with a useful life of 1 year. So 1/12 and 1/24 of their respective values was included in the cost of this project. The total market value for slashers, pangas, hoe, sickle and gum boots was depreciated over the 3 –week period during which tsetse control activities were carried out. For remaining equipment, refreshments and gifts given to the research team, costs are calculated at actual prices paid or the market value.

Opportunity cost of women’s time

In total, 20 women were actively involved in all phases of action research. During the programme, each woman dedicated, on average 32.5 hours over a period of six months (Table 5.3, Action research). Over two thirds of this time (21 hours) was spent walking to and attending mentoring meetings.

I carried out a calculation of the opportunity cost by calculating how much income participants potentially sacrificed by giving time to attend mentoring meetings and activities, time that would otherwise have been spent on income generating activities. Participants reported that the most common income generation activity in the research location is paid labour for working in a landowner's fields; this typically includes preparation for planting (re-digging the soil) or harvesting. According to participants, these paid activities are carried out by men and women and there is no gender differential in payment. For instance, workers typically receive UGX 30,000 (USD 11.56) for digging a quarter of a field (~ 0.1 Ha). The participants also reported that it takes on average three people, three days (working approximately five hours a day) to finish digging a quarter of a field. In short, each person receives UGX 667 (just over USD 0.25) per hour of work.

Using this calculation, a woman who regularly participated in our programme would have sacrificed a total of UGX 21,678 (or USD 8.35) of potential income. This amount, according to the socio-demographic questionnaire (section 4.3; Appendix C, Table C2) is equivalent to almost half of a household's monthly cash income, which was estimated to be UGX 38,000.

Cost of a community-based intervention over a three year period

The overall cost of action research included elements that were linked to the research processes rather than the tsetse control itself. A number of meetings with women were organized to evaluate how their perceptions of managing intervention changed over time. The likely costs of community-based intervention were accordingly adjusted by excluding the items that were purely for research.

The likely cost of a community managed intervention, if it ran for three years and with support of an expert Ugandan team (entomologist, driver and facilitator), was estimated over an area equivalent to action research area (~ 13.9 km²). We allowed for one deployment and one target maintenance (re-deployment) round every year. In this situation, sensitization was planned for only in year 1. It has been shown that once good knowledge and acceptance of tsetse control tools are achieved through the sensitisation of local people, the necessary level of community awareness is likely to be sustained for at least the three years, as assumed in the costings below [138]. Similarly, the measurement of the rivers to plan target deployment was assumed to be necessary only in the first year, as target positions remain unchanged for the entire duration of intervention.

For the internal inputs, the time inputs of village women were assumed to be reduced from the 32.5 hours required for the action research process to 19 hours in year 1, and then to 12.5 hours in year 2 and 3 (Table 5.3).

Table 5.3: Inputs of time by each woman participating in tsetse control

| Activity | Action research programme (as implemented over 6 months) | Estimated for 3-year control programme | | |
|--|--|--|-------------|-------------|
| | | Year 1 | Year 2 | Year 3 |
| Number of meetings | 7 | 3 | 2 | 2 |
| Time required for activities | | | | |
| Time walking to and from meeting (hours) ²⁸ | 0.5 | 0.5 | 0.5 | 0.5 |
| Time at meeting (hours) | 2.5 | 2 | 2 | 2 |
| Sub-total: time for meetings (hours) | 21 | 7.5 | 5 | 5 |
| Sensitising community members (hours) | 1 | 1 | 0 | 0 |
| Measuring river (hours) | 3 | 3 | 0 | 0 |
| Target deployment (once a year) | 3.5 | 3.5 | 3.5 | 3.5 |
| Target maintenance (once a year) | 4 | 4 | 4 | 4 |
| Total hours | 32.5 | 19 | 12.5 | 12.5 |

For the external contributions, the time inputs were estimated as follows. The external team leader (district entomologist) and driver would spend one third of the month working on the tsetse control intervention. The total field days estimated are five for the team leader²⁹ and seven³⁰ for driver and facilitator (Table 5.4). The calculation of transport is based on the use of a motorbike for seven days and 336 kilometres (Table 5.4) for each field trip. The distribution of targets was costed as being undertaken using a motorbike that would carry both the team leader and driver. This follows common practice in other current local operations in assuming that two people would share a motorbike, instead of requiring a 4x4 pick-up or similar vehicle for this activity. The number of targets deployed in the area was rounded up to 200 from the 194 actually issued during the action research programme, bringing the average density up to 14.4 per km². With an average life of 6 months, 1200 targets would be required for three years of deployment.

²⁸ 15 minutes was an average walking time to the meeting place.

²⁹ Five field days for the team leaders were estimated for: introduction and training on targets (2 days), planning (1 day), demonstration of deployment (1 day), post deployment debriefing (1 day).

³⁰ Two additional field days were added for delivery of the targets to the villages on deployment day and maintenance day 6 months later.

Table 5.4: Estimated cost of a three year implementation programme: external inputs

| Item and category | USD |
|--|-------------|
| Staff | |
| Team leader - entomologist (1/3 of a month, including 5 field days) – 1/3 of monthly salary of USD 597.36 | 199 |
| Entomologist's daily field allowance (5 days at USD 5.78) | 29 |
| Driver (1/3 of a month, all of it spent in the field) 1/3 of monthly salary of USD 135 | 45 |
| Driver's daily field allowance (7 days at USD 4.24) | 30 |
| Facilitator (locally recruited, 7 days at USD 11.56) | 81 |
| Transport | |
| Use of motorbike (336 km per field day for 7 days, making 2352 km at USD 0.33 per km) | 776 |
| Fuel (123 litres at USD 1.46 per litre) | 180 |
| Equipment | |
| Targets (1200 at USD 1.10) | 1320 |
| Ropes for hanging targets (6 at USD 20.81) | 125 |
| Stationery (UGX 20,000 per year) | 23 |
| Slashers/pangas (bought for villagers, 20 at USD 1.73, 3 year life, 10% of depreciation to project, total cost USD 3.47) | 4 |
| Gumboots (bought for villagers, 20 at USD 7.71, 10% of depreciation to project, total cost USD 15.41) | 15 |
| Refreshments | |
| Samosas, napkins, sugar (provided over 3 years) | 77 |
| Total external | 2904 |

Table 5.5: Estimated cost of a three year implementation programme: internal community inputs

| Item and category | USD |
|--|------------|
| Staff | |
| Opportunity cost of women's time (USD 11.31 each, for 44 hours work, by 20 women) | 226 |
| Equipment | |
| Table, 3 chairs and sitting mat (total value USD 10.40, estimated life 6 months, so depreciation over 2 x 3 weeks would be USD 2.60) | 3 |
| Refreshments | |
| Mangoes, roasted maize and tea (USD 3 per year) | 9 |
| Gifts given to team | |
| Fruit, etc. (USD 3 per year) | 9 |
| Total internal | 247 |

On the basis of the above, for a three year intervention, the external inputs totalled USD 2,904 and USD 968 per year (Table 5.4) and the internal inputs came to USD 247 in total and USD 82 per year (Table 5.5). The overall percentage breakdown of costs was 92% for the external inputs 8% for the internal inputs.

The overall cost of a three year community-based programme would total USD 3,151, USD 1,050 per year or USD 75.6 per km² per year, excluding all research components as well as the cost of monitoring tsetse populations.

In this cost analysis, not all the categories were comparable to the costing of the government-based delivery model that was costed through externally led interventions [49]. After adjustments were made for differences in transport and target densities (details in Appendix D2), the community scheme was USD 43.4 per km² as compared to USD 71.2 for the local government scheme (assuming the exclusion of tsetse monitoring and surveying).

5.6 Key findings

- In the action research process, women demonstrated competence in the planning, execution and evaluation of all operational phases. They were resourceful in providing information on areas where communities were more likely to be exposed to tsetse and developed practical solutions to overcome lack of technical equipment. Information spread about the programme within and between villages, resulting in good acceptance of tiny targets and the overall programme.
- Women were highly motivated to carry out control intervention, which they linked to observed or experienced suffering from sleeping sickness; motivation was maintained throughout the action research. The sense of ownership increased through the process as a result of sufficient information, experience in handling targets and assumed responsibility to organize and run the intervention. A sense of empowerment also increased among participants and was related to the sharing of technical knowledge and skills by the research team with participants and by participants with other members of community. As a result of this newly acquired knowledge and skill set, women were also able to re-negotiate their role in the community as active contributors to prevention of disease and well-being of the entire community. Women also demonstrated good leadership and organisational skills.
- The process was feasible in terms of organising and achieving all needed operational phases of tsetse control intervention. However, women reported challenges in terms of the pressure of time and of competing daily demands and tasks, physical difficulties in accessing target locations, by having to move through dense vegetation, with little access to appropriate footwear and vegetation-slashing tools. If given the necessary tools, protective clothing and flexibility in programme timeframe, women promoted this approach as being highly feasible.

- The community observed a reduction in tsetse densities after intervention, which served to increase faith in technology and commitment to the programme. The decrease in tsetse numbers within intervention areas was confirmed by tsetse monitoring traps.
- Participation of women did not cause any gender-related tensions and they felt better positioned to carry out tsetse control intervention compared to man, especially as this role entailed voluntary participation.
- Women deployed targets in sufficient density (14 targets per km²) and exceeded the density in externally-led operation (6 targets per km²). Targets were successfully maintained over a six month period³¹, achieving operational sustainability of intervention. 51% of the targets were still functional after six months, which is more than double the functional targets in externally-led operations.
- Cost analysis showed that action research was more expensive compared to a control operation that used expert field teams. However, in action research, those research components associated with assessment, largely contributed to this cost. Without this expense, community intervention (calculated over three years period) was actually cheaper for UDS 28 per sq km per year, compared to the externally led operation run by an expert team (see Appendix D2 for further details).

The next chapter will examine how community and other stakeholders perceived community-based tsetse control as a potential future HAT control strategy.

³¹ Six months is a duration of the active insecticide on the targets [47].

Chapter 6: STAKEHOLDERS' REFLECTIONS ON COMMUNITY INVOLVEMENT

6.1 Chapter overview

In the previous chapter, I used the data obtained to discuss how, given the necessary inputs, communities have the capacity, interest, willingness and motivation to manage tsetse control operations. In this chapter, I focus on their role as stakeholders in HAT control programmes and the perceptions and attitudes of decision-makers (village chiefs, Uganda district and national staff, WHO and African Union representatives) towards community- and women-based interventions.

The first part of the chapter reports findings from community role play and describes how the community perceives the decision-making processes and what lobbying arguments they find important. The second part reports the views of key decision-makers working at different levels on community participation. In particular, the following questions were posed: i) Is the community recognized as an important stakeholder? ii) What are decision-makers' attitudes towards community involvement? iii) What are current barriers and enabling factors for women and communities to participate and be part of tsetse control strategies? The chapter ends with the summary of the key findings in relation to these questions.

6.2 Communities as stakeholders in HAT control programmes

If community is to be considered as an important stakeholder in decisions about HAT control strategies, then it is important to evaluate, how they could lead a dialogue with other decision makers. Theatre techniques, particularly a role play, carried out with women in the action research villages, provided a platform for such evaluation (section 3.7). Participants acted out different roles of the 'community' and decision-makers at all levels of the decision-making chain, from village to international level. The emerging themes are described below, illustrated with quotes organized in a hierarchical structure, starting with the quotes from the community moving to those from donors. For further quotes and examples, see Boxes (6.1-6.4).

Women in both villages enthusiastically accepted the idea of the role play, although Village 1 was less engaged in acting; for instance, Village 1's dialogues between different personalities were shorter than

that of Village 2. In all cases, the role play and dialogues started with polite greetings and introduction of the role of the speaker and sometimes a description of the village, region or the country they represented.

Community negotiation skills

Provoking sympathy while lobbying for their own priorities (Box 6.1)

Participants commonly used sympathy as their negotiation tool. Emotionally-charged expressions, such as ‘people will be finished’ and ‘it’s a matter of life and death’, were frequently used by most of the participants to convey the importance of tackling HAT to policy-makers. Women playing roles of district and ministry decision-makers tended to aim to evoke compassionate reactions by describing the suffering of communities affected by HAT. They used emotive phrases such as villagers ‘crying for help’ and sleeping sickness having ‘tortured’ the villagers. One participant emphasised that the threat is not only on adults, but that the disease affects both ‘adults and children’.

After engaging co-participants in a sympathetic way, most participants in both villages clearly stated their priorities. Surprisingly, despite the fact that this research engaged participants in the management of tsetse control interventions, participants in both villages playing roles of community, village chief, sub-county, and ministry levels, openly and strongly argued for HAT testing and treatment as their first priority. Participants acting as village leaders, for instance, emphasized that ‘especially treatment, and access to treatment’ and ‘tests to understand if people have sicknesses’ were the most pressing requirements. Community level roles also made similar arguments, with some people stating that ‘it has been three years since the last testing for sleeping sickness’. Only a few participants playing roles of community and ministerial members mentioned tsetse control, that too only as a second option to testing and treatment. Although community participation in the management of tsetse control interventions did not emerge as a top priority, the role play demonstrated an understanding of negotiation dynamics, such as engaging the other side and informing them about the general community sentiment on disease control; it also showed that the community was able to state clearly defined aims during the negotiation process.

Box 6.1: Provoking sympathy while lobbying for their own priorities

(‘Village chief’ to the ‘Sub-county chief’): *“My boss, people from my village they are crying [for help]... The way sleeping sickness is spreading in the village has tortured them a lot”* (FGD 9a).

(‘Minister’ to the ‘WHO representative’): *“I have come to talk to you... In my districts and villages sleeping sickness has become more serious! It’s affecting the children, the adults and I am helpless in that”* (FGD 9a).

(‘Minister’ to the ‘WHO representative’): *“I have voice from the districts that sleeping sickness has finished [wiped out] people in their districts”* (FGD 9b).

(‘Minister’ to the ‘WHO representative’): *“If it’s possible try to forward the issue to higher levels, because people are really suffering”* (FGD 9a).

(‘Sub-county chief’ to the ‘District chief’): *“You should try to look for some ways to help them [people suffering] out; especially treatment, access to treatment [is needed]. And also some tests so that we will come to understanding whether our people do have the sickness by examining them”* (FGD 9b).

(‘Community’ to the ‘Village chief’): *“From your help you could [provide] access for us to examining tests, testing for sleeping sickness so that we will know whether we still have sleeping sickness in our bodies or not. To help us out! It has taken like three years now since we last tested for sleeping sickness! Is it possible to come and get test for us?”* (FGD 9a).

(‘Community’ to ‘Village chief’): *“We have tsetse flies around us which bite us. What is chief going to for us to stop tsetse flies from biting us?”* (FGD 9b).

Confidence of women in role play (Box 6.2)

Role plays were characterised by a strong self-confidence of the actors. During dialogues, participants generally used an assertive tone of voice when addressing ‘personalities’ in a higher hierarchical role. No sense of subordination was expressed through dialogues or performance. Their confidence was also reflected through strong and clearly defined statements, fluent dialogues and calm facial expressions. Participants acting out community roles were particularly firm. They used different rhetorical strategies to create pressure when lobbying for their requests for help. Some, for instance reminded the ‘village chief’ of her professional responsibility to them as they stated: ‘we elected you to help us with our problems’. One participant used a provocative tone and statements such as ‘why was the government brought to us in your representation’ to create further pressure. Suggestive statements, such as ‘if leaders are not bothered about it, sleeping sickness may become a bigger problem’ were also common, implying that that consequences of disease are directly linked to the lack of fulfilling professional responsibilities. This argument was used in even more extreme ways by participants acting as ministers, accusing leaders, who do not respond to the plea to address ‘suffering’ and ‘death’, and that they ‘should do something, for sure’. Directed questions, such as ‘in what ways are you going to help me?’ expressed by participants from ministerial level roles also demonstrate self-esteem through direct requests for immediate and unambiguous response.

Box 6.2: Confidence of women in role play

('Community' to the 'Village chief'): *"They [leaders] should come and help us! Assist us in preventing the disease. If they are not bothered about that, (...) this sickness might become a bigger problem"* (FGD 9a).

('Community' to the 'Village chief'): *"Chief, why have they brought us the government [in your representation]?"* (FGD 9b).

('Community' to the 'Village chief'): *"What I am doing [is communicating the problem] and that is for the village chief to extend my talks to government people so that they could come and help us"* (FGD 9b).

('Minister' to the 'WHO representative'): *"In what ways are you going to help me? How to solve that problem of sleeping sickness?"* (FGD 9a).

('Minister' to the 'WHO representative'): *"What are we supposed to do about that illness? We need your help! You should give your help to those people [suffering] there (...). It's matter of life and death! You should do something for sure, it's real bad"* (FGD 9b).

Critical insights in decision-making process

Using 'us versus them' rhetoric to express decision-makers' inaction (Box 6.3)

There were several examples in the role play dialogue of decision-makers refusing to offer assistance to communities in tackling sleeping sickness. In these circumstances, women frequently used the 'us and them' scenario to communicate this sense of injustice. When playing various roles, women used this sensibility to argue that decision-makers at higher levels were reluctant to help because they were not directly affected by the disease. In Village 2 particularly, the role play dialogue between 'community members' and the 'Village chief' made mention that the 'chief' refused to deal with sleeping sickness 'because it hasn't affected you...for now it has affected us only' and the assertion that the chief would only communicate to higher government levels when it 'first affects you... And that's when you will take it seriously'. Others acting in sub-county roles presenting arguments to the ministerial level that they were 'suffering down in the village' and that if the disease continues it would 'reach you as well'. One participant, acting as village chief, clearly separated herself from being one of the villagers, and responded to these 'accusations' by expressing frustration: she communicated that she had 'been harassed by people' when extending her request to the next level up the hierarchy and that she will be 'in trouble with people' (referring to the community members), if help is not provided, thus indicating her helplessness in her role as village chief and liaison between the community and local governance structures. One participant playing a minister role responded aggressively and used insult and blame to convey that the

uncivilized behaviour of 'them' (the community) is responsible for the spread of disease, also stating that 'people are not slashing vegetation and are eating from dirty places'.

Box 6.3: Using 'us versus them' rhetoric to express decision-makers' inaction

('Community' to the 'Village chief'): *"Chief you have refused to extend our message up there [to higher levels] because the sickness hasn't affected you! For now it has affected us [only]! Do you first wanted to affect you and that's when you will take it seriously, you will take it forward?"* (FGD 9b).

('Village chief' to the 'Sub-county chief'): *"People have become too harass [too persistent], they are harassing me! If I don't forward the issue, I will be in big trouble with the village members"* (FGD 9b).

('Sub-county chief' to the 'District chief'): *"Do you want us to die [that's why you are refusing the help]?"* (FGD 9a).

('District chief' to the 'Minister'): *"I have come to ask you for help because I am there suffering down in the village... Don't you think if it [HAT] continues, won't it reach you as well"* (FGD 9b)?

('Minister' to the 'District chief'): *"No, [I don't agree]. Many diseases come as a result of not slashing around [removing vegetation] and eating from dirty places. People are not taking good care of themselves, and now you have come to me [in search of help], what do you want me to do?"* (FGD 9b).

Acknowledgement that decision-makers are limited in their ability to act (Box 6.4)

The role play dialogues, particularly in Village 2, revealed that women clearly recognised that leaders face challenges and limitations in making decisions on health issues such as HAT. When responding to requests for 'help' in tackling sleeping sickness in communities, for instance, those acting in village or district chief roles mentioned feeling pressurised into making a quick decision and attempted to negotiate for more time, saying things like 'I need time to agree on that, I need some time'. Others playing the role of village chief argued that 'there is no money' for sleeping sickness, and 'there are so many issues I am to deal with'. That decision-makers deal with numerous competing priorities that prevent them from taking action was also acknowledged in the role play. For example, a woman in the role of a minister, in discussion with a district chief explained, 'there are so many sicknesses now...everyone is turning to me', and another in the role of WHO representative explained why she could not offer help, because 'there are so many people who are coming up to me [approaching me for help]... I might not be so able to give help'. One participant acting the role of community was also insightful on limitations of power and requested to be given more 'power' for communicating her demands. All participants eventually responded to the request by giving 'help' despite the constraints they faced, thereby communicating that

this is what is ultimately expected from decision-makers i.e. to provide community with testing, treatment and prevention of HAT.

Box 6.4: Acknowledgement that decision-makers are limited in their ability to act

(‘Village chief’ to the ‘Community’): *“I just want to see during this period, this year, I want to finalize this year to see if the sickness is serious or not”* (FGD 9b).

(‘Sub-county chief to the District chief’): *“There is no money for that work [sleeping sickness control] because there are so many issues that I am going to deal with; I don’t want that [sleeping sickness to be on my agenda]”* (FGD 9b).

(‘Minister’ to the ‘District chief’): *“There are so many sicknesses now. Each and every one [so many people are] is turning towards me [in request for help]! What am I supposed to do?”* (FGD 9b).

(‘WHO representative’ to the ‘Minister’): *“I can’t give any help per now, because there are so many people who are up to me, they need my help... Because of that [pressure] I might not be so ready to give help”* (FGD 9b).

(‘Community’ to ‘Village chief’): *“I came to talk to you, since I have little power, I have to extend power to other people [like you] above me to come and prevent the sickness”* (FGD 9a).

(‘WHO Representative’ to the ‘Minister’): *“I have agreed to give help and the help is in form of money”* (FGD 9b).

6.3 Decision-makers’ views on community involvement

Five main themes (Boxes 6.5-6.8) were identified from the analysis of the interviews with decision-makers (village chiefs, national programme planners and implementers and international policy-makers; section 3.7) regarding perceptions towards community- and women- based participation in HAT. Findings are organized in three main sections: i) engagement of decision-makers with HAT control; ii) views on involvement of women in implementation and decision-making roles; iii) stakeholders’ engagement with beneficiary communities.

Engagement of decision-makers with HAT control

Commitment for HAT control is currently reinforced by elimination plans (Box 6.5)

The majority of participants talked about elimination of HAT with obvious excitement. They described this goal as being ‘possible’ and ‘feasible’. HAT elimination seemed to be strongly bound up with the renewed focus and notion that this is the most critical time to be involved in HAT and trypanosomiasis control. One participant from WHO, for instance, explained this by saying that ‘the finisher [of HAT] is the winner’,

suggesting that there is a certain level of prestige to be gained for experts involved in the elimination process. A growing interest was also characterized by a competitive atmosphere, and people who were not previously interested in HAT, but who are now currently getting involved and acting as experts: ‘new experts appearing and teaching everyone’. To further illustrate current dynamics among stakeholders, already mentioned WHO participant also stated that ‘everybody wants to be near the host [experts already involved in HAT control]’.

The feasibility of HAT elimination was particularly strongly related to already available technical tools. Many participants, from both national and international levels, confidently talked about the ‘technology bag being full’ and new tools, such as ‘a new treatment, diagnostic tools and vector control tools being in the pipeline’. Some felt that HAT already has an available ‘solution’, compared to other diseases, such as malaria and HIV/AIDS which do not have ‘clear solutions’ and are therefore ‘ongoing’. Ugandan national-level participants were also convinced that as a country, they have enough expertise to achieve elimination and they only need ‘resources’, ‘logistics’ and ‘direction’.

Box 6.5: Commitment for HAT control is currently reinforced by elimination plans

“If you are thinking about elimination, yes it’s possible!” (DM 6, district).

“There are so many [new] specialists [appearing] now and teaching [everyone]! Because everybody wants to be involved in that [elimination]. The finisher is the winner! So everybody wants to be near the host [experts already involved in HAT]” (DM 13, WHO).

“I think it [HAT elimination] is feasible now; with [all] the things in the pipe line; this harbour: like new drugs, possible new diagnostic tools [which can facilitate diagnosis], vector control tools...” (DM 14, WHO level).

“There is enough solution to just do it! It’s not like other problems [such as] HIV, malaria, something on going... Those [diseases] do not have clear solutions. This problem [of trypanosomiasis] has a solution! We say that the technology bag is full” (DM 3, national).

“We can eliminate sleeping sickness! For us Ugandans the only things we need are the logistics and resources (...). Yah, experts exist in the country. We just mobilise them and then we do the work” (DM 4, national).

Motivation is related to personal, professional, and self-interests (Box 6.6)

A sense of genuine interest to contribute towards elimination of suffering from HAT and a strong feeling of responsibility was communicated by decision-makers when discussing personal and professional motivations. Participants talked passionately about their work and many took a compassionate approach when describing their personal experience with HAT patients, either as doctors managing hospitalized

patients or as witnesses of HAT victims in their neighbourhoods. A few mentioned that their careers were strongly influenced, even shaped, by the experience of 'losing people they were close to' due to HAT.

Some participants were motivated by the desire to use their professional experiences for a worthwhile purpose, for 'something useful and interesting'. In particular, Ugandan participants from national and district levels, commented with satisfaction that being involved in trypanosomiasis control opened many professional opportunities for them. They frequently mentioned opportunities to work in multi-sectoral and international environments as being related to their sense of professional satisfaction. Others were committed to their professional role out of a sense of responsibility and public trust. One participant, however, described religious reasons as the main reason for getting involved. Only one participant from the district level mentioned not being motivated and commented that his 'job takes away most of his time in life' and that 'the payments are not so comfortable'.

Senior level decision-makers (AU, national), however, discussed other motivations of actors involved in HAT control, more in the realm of self-interest, and which were not about the commitment to contribute towards disease control. The African Union participant seemed to criticize researchers for not sharing results with programme planners, and of acting like 'there will be a Nobel prize and a lot of money for it'. National decision-makers also complained about how their national colleagues carried out their programme implementation roles and about the wastage of resources, due to abuse of resources. The interpretation of an organization's mandate to serve their own 'human needs' was also frequently mentioned by national and AU participants as being one of the factors hindering implementation. The atmosphere of tension, rivalry and mistrust was generally described as a result of these dynamics.

Box 6.6: Motivation is related to personal, professional, and self-interests

"I was driven [in my career] by the passion that I needed to do something for the problem, because in the village where I come from, every homestead had a case of sleeping sickness (...). So surrounded by that problem, I lost very close people and I thought I needed to make a contribution" (DM 3, national).

"You can see strong men that lost dignity [due to sleeping sickness] acting like a baby, requesting help! Asking for your help" (DM 13, WHO).

"You think what you are doing is more or less useful and interesting... You know you have been working there [in this field]; you know the situation [from experience]. I was excited for the desire [to contribute towards HAT control]" (DM 14, WHO).

"The fact that I am entrusted with the planning and managing the entire health sector (...). And when you reflect it further and you realise the whole district health system has been entrusted into

your hand as a head of the unit [it is even more intimidating](...)! Because these are [our] offices, we hold in trust of the public” (DM6, district).

“In terms of academic career, I am self-actualised, very satisfied” (DM 3, national).

OPPOSING VIEWS:

“It takes away most of your life time, really (...). And in case you are not at job, somebody is already monitoring, supervising you, you always have to keep [in] the job! And payments are not so comfortable that’s why some people in civil service; they are not willing to do 100% work for the Government” (DM 5, district).

“I think you [as] scientists and sometimes when you are doing little research, you think it’s a secret for you to keep (...)! We [as scientists in this field] are not doing basic research, where we [could] say this one [method] will be patented, there will be noble prize [for it]; you will get a lot of money... It’s really not true (DM 1, AU).

“Really everyone has a role to play, but all of us have a specific mandate, but in order sometimes to confuse issues, we interpret that mandate as to fit our own human need” (DM 1, AU).

“The biggest problem we have in this country is that the disease of corruption has eaten up the country! It has eaten up some of the [core] elements! So as money moves through the chain, I think there is a bit of wastage” (DM 3, national).

Views on the involvement of women in implementation and decision-making roles

The policy environment is predominantly male who perceive tsetse control as their domain (Box 6.7)

With the exception of a single female participant, the views described below are expressed by male decision-makers. Most participants from both national and international levels expressed positive attitudes towards the participation of women in disease control programmes. Ugandan participants in particular cited their own positive experiences of involving women from beneficiary communities in the programmes. Women were frequently described as being easier to involve and their participation more effective compared to men. Some participants discussed that women were more reliable, more trustworthy, responsible, supportive, active, devoted, intelligent, and willing to contribute voluntarily. One participant also explained that women were a good source of knowledge when it came to tsetse control as they spend more time in tsetse affected areas compared to men. In comparison, some participants reflected that men were generally less motivated by community well-being and tend to have an ‘I don’t care’ attitude when it comes to contributing to anything that does not directly serve their own interests.

Despite positive attitudes regarding the involvement of women with other disease control programmes, when tsetse control was under discussion, many participants from district and national levels also

expressed their reservations about women's involvement. Most of them, particularly from the district and national levels, were convinced that tsetse control entails men's involvement-it 'is the kind of work for men'. Many admitted that this notion is driven by the motivation of men 'to preserve it [this area of work] so much'. They attempted to justify this by explaining that the nature of this work is associated with traditional male activities. Movements in areas with dense vegetation, necessary for tsetse control, was considered to be associated with hunting and 'you don't get women going for hunting'. Some believed that the work and working environment were 'too harsh' for women and that they would not be able to cope with this. One participant justified this by remembering old technologies, such as ground spraying and heavy pumps to be carried around, which was considered neither feasible nor appropriate for women. The notion that women are not well-positioned for tsetse control, however, was contradicted by the same participant who stated that 'technology used today [traps and tiny targets] is more 'gender sensitive'.

A few participants from the district felt that women in professional roles may find it unsuitable for themselves to be in implementation roles, as this meant that certain social taboos would have been broken. Women travelling alone in the bush was considered inappropriate and if they wore field outfits instead of traditional clothes 'society [would] look at women with bad feelings' – these were also mentioned as reasons for women not to get involved.

A few participants found social pressures from the local community and pressures from their husbands to be the main reason why women turned down professional positions in tsetse control. Men were described as real gatekeepers for female participation and one participant from the district stated that 'if men don't know what women are going to do, they cannot be supportive'. One village chief also agreed that men needed to give approval for women to be involved in non-domestic tasks, but he was convinced that leaders could break any resistance and encourage men to collaborate with women. One participant from national level mentioned five women who worked as district entomologists in Uganda. When one of them was interviewed she confirmed that her position was difficult and she is faced with many challenges 'because people expect this work to be done by men'. She was, however, extremely confident that she was capable of doing the job.

Box 6.7: The policy environment is predominantly male who perceive tsetse control as their domain

"Women group involvement is so good because when they are involved in a group, they get courage and they do the work that is entrusted to them much more than [if] men group is involved. This is known in other areas of poverty eradication programmes" (DM 5, male, district).

“Women are very easy people to mobilise. If you go to any meetings, even mass drug administration, they are the ones there [attending it] with their children. (...). Women are very [supportive]... If you talk to them they are likely... Not they are likely, they will take up what you are telling them and they will follow it up” (DM 4, male, national).

“It works well, involving women. I have had community meetings, where I meet men alone, I meet women alone and I meet both together. The most hopeless meeting is when you meet men alone! The most excellent is when you meet women alone! The normal meeting is when the two are mixed. So the intelligence of women dilutes the stupidity of men to blend it to average” (DM 12, male, district).

“Many times I get more comfortable working with women than men (...). You assign women responsibilities; I can assure you (...), when they say:- we are going to do this- they will do it. But when men will say:- we are going to do this- sometimes they may do it half way or sometimes they don’t [do it at all].” (DM 6, male, district).

OPPOSING VIEWS:

“First of all, entomological work is a work which if you take it, it is not an easy work. Most of the work is done in the jungle, in the bush (...). And you find that most of the work is harsh, it needs harsh environment where these insects live (...). And mostly people think that doing these things, these hard things in harsh environment, is actually kind of work for men and men persevere it so much” (DM 10, district).

“With our traditional norms, it is actually forbidden for women to move alone in the bush. That is an activity for men, particularly associated with hunting. You will not get women going for hunting but men are the ones who can manage those harsh environment” (DM 10, district).

“And then also the kind of attire that you wear; you know in our African setting particularly among the Lugbara and the tribes around, they even disgrace women wearing pair of trousers or overalls... So they need to wear women attire, these skirts. So because of that you find the traditional feeling towards wearing, the dressing code is actually [off putting]. When you are an entomologist, doing any entomological related work you have to dress in those overalls, you wear these gumboots, you wear these a pair of trousers for work... They [society] look at them [women, being dressed like this] with bad feeling. So women at times turn such kind of [professional] offers down” (DM 10, district).

“Yah, it’s challenging to be a female entomologist because people expect this work to be done by men (...).I am capable of doing it [as a female entomologist]” (DM 8, district).

Stakeholders engagement with beneficiary communities

Senior policy makers recognized involvement was important, but were unclear in their role to ensure this (Box 6.8)

Most participants viewed active community involvement as crucial for disease control programmes, including HAT. Some regarded this as obvious and said that ‘of course you can’t do [disease control programmes] without the community’. Community was described as the ‘key to success’ and most participants felt that community contributions in terms of knowledge and support of the programme are

invaluable, and strongly associated community participation with ownership and improved sustainability. In essence, HAT and tsetse elimination was viewed inseparable from community participation. A national level decision-maker explained this by saying that elimination can only be achieved 'by people who have the problem' and elimination cannot be achieved by anyone else 'who is not affected'. Some participants, for instance, used an example of successful guinea worm eradication in Uganda and attributed this success to strong community commitment. Community efforts in this eradication campaign were described as 'very, very tireless work', which resulted in the guinea worm becoming 'history'. Village chiefs confirmed that community interventions, including tsetse control, are possible and desirable from their perspective.

Despite recognition of the important role of communities, mixed messages were given when discussing how participation could be achieved and whose role it was to organize it. Senior level participants (AU, national) mostly pointed out that the people involved were not tackling the problem effectively; however, these participants said little about their own involvement and their provision of support to the community. An AU participant, for instance, said that 'we come from town and we are in hurry and we don't want to talk' so no effort is made to communicate, and 'we just come and put our trap and go'. Another participant from the national level criticized that programme implementers label and undermine beneficiaries because of their illiteracy so that 'people are assumed not to have a brain'.

There was also confusion when discussions took place on who was to be responsible to liaise between the community and senior policy makers in national and international positions. None of the participants perceived this to be their responsibility and different reasons were given to justify this. Many participants, for instance, frequently claimed lack of qualitative research skills for communication with beneficiary communities—so much so that—as a foreign researcher, I was perceived better positioned to engage with Ugandan villagers even compared to Ugandan programme staff, only because I was perceived as having the technical skills to engage with communities. A Ugandan participant from the national level declared, for instance, that one needs to be 'specialized' for creating a communication link with communities. Furthermore, both participants from WHO were convinced that their role was not in any way associated with beneficiary communities. They regarded the Ministry of Health as their only 'partner' and stated that 'community involvement for them is not a priority' and there are things they can do 'with the government structure', thus indicating their insights in WHO's institutional limitation to engage with beneficiary communities. The community was also perceived by one of the WHO participant as not being trustworthy as 'their priorities are different to ours' and working with them was seen as 'complicated' due to a variety of cultural differences in different countries.

Box 6.8: Senior policy people recognized involvement was important, but were unclear in their role to ensure this

"It is really possible [to organize tsetse control intervention with the community], because people really want to stop the sleeping sickness in their area" (DM9, village).

"I work in the field [and I know]: the knowledge the community has, the support the community has to give to the programme is invaluable" (DM 1, AU).

"The only people who can eliminate tsetse and trypanosomiasis are the people who have the problem" (DM 4, national).

"We need to go out there and talk to them [community]. Maybe you [as foreign researcher] are a specialist in that... I don't know the best way to talk there in the communities... But for you, you have stayed with them [for a long time], you can talk to them directly" (DM 4, national).

"But unfortunately we come from town, we are in hurry, we don't want to talk, we don't want to explain, we come and put our trap, [and] we go" (DM 1, AU)!

"But usually the assumption is that people we are dealing with [beneficiaries] are illiterate... I mean these are human beings, they have the brain! If you tell them I am going to give you these things [control tools], it's for your, it will protect you- they will guard it" (DM 4, national).

"But you know as WHO, we cannot work with communities... We can feel [sympathetic], we can understand, we can stress the line or the hard-line the importance of community, but our partner is the Ministry of Health" (DM 13, WHO).

"[Community involvement] is completely needed, but sometimes [our] priorities are not the same as [those] of the communities (...). It's complicated, but it's needed" (DM 14, WHO).

6.4 Key findings

- The role plays illustrated women's understanding of decision-making processes, including its limitations, and how they would approach lobbying of key government officials. Women demonstrated strong self-esteem, good negotiation skills, and capacity to define and push for their own priorities. These insights present a good starting point for community entrance into dialogues with other stakeholders.
- Through the role play, the gap between 'us', namely the community and 'others', namely programme planners and policy-makers was apparent, demonstrating community awareness of the disconnect between local realities and current policies and programmes, which do not reflect daily lives of the people in HAT affected areas. Hence, through role plays, the community demonstrated being an involved, critical and confident stakeholder.

- Analysis of the interviews with decision-makers showed that the current strong focus on HAT elimination generated a new energy and dedication for programme implementers, planners and policy-makers. This may facilitate commitment to future community participation especially since community contributions are perceived as essential for achieving elimination.
- Personal and professional motivation of the majority of interviewed stakeholders is strong, which may be an important launching point for introducing new approaches such as community participation, into current policies. Such approaches, however, may fail to materialize as a result of competition with other priorities, including personal interests.
- Involvement of women in disease control programmes is perceived as favourable by decision-makers. However, participation in tsetse control still seems to be regarded as unfeasible and inappropriate by male decision-makers. These perceptions are related to past and current interventions both of which are strongly male-dominated. Lack of female representation among higher levels of programme planners may present a barrier for introducing women-led tsetse control interventions.
- Despite decision-makers perceiving community involvement as important they had no clear direction on how to ensure that this is implemented and whose role this should be. If nobody assumes the role to connect the community with programme planners and policy-makers, communication links will remain tenuous, and community views and participation will never be incorporated into programme planning and implementation. Thus, despite decision-makers perceptions on the need to involve communities in disease control, and their confidence in community capacities, these views remain largely theoretical and rhetorical, for, integration of communities in current strategies is absent and there is a lack of a strong liaison to enable this communication and work process between communities and stakeholders.

Chapter 7: DISCUSSION AND CONCLUSIONS

7.1 Chapter overview

This chapter begins by examining the limitations of this study to take into account in interpreting the results. I then summarize the main findings against the research questions posed in Chapter 1. Finally, the operational and policy implications of the findings are discussed. Operational implications addresses: i) sustainability and scale up of women-led, community-based tsetse control, and ii) how this model could be replicated in other settings. Policy implications addresses: current factors facilitating and barriers to community-based approaches in strategies to eliminate HAT. The chapter describes the potential for implementation of findings in the broader context of disease control and the need for further research and ends by stating the main conclusions.

7.2 Reflection on research constraints and limitations

Critical interpretation of research results needs to take into account the limitations of the study and how those limitations were managed. Here this falls into three categories: i) sampling methods, ii) data collection methods and iii) interactions with participants.

Limitations of sampling methods

Some limitations occurred in relation to the sampling methods used. In the study related to human exposure to tsetse (Chapter 4) children were excluded, who are, by my observation, involved in daily water collection, thereby exposing them to tsetse. Furthermore, in the randomisation process for selection of participants to carry a GPS tracker, individuals carrying out occupational activities at the rivers banks, such as sand collectors may have been missed. A larger sample could potentially have captured more occupational risk groups.

The sampling for action research (Chapter 5) was initially done by the village chief who informed women about the first meeting, and later by the participants themselves, who invited other women. This sampling strategy was prone to some selection bias in favour of participation of individuals who were already exposed to HAT through their own experience, either as patients or care-givers of sick family members. Personally affected by these experiences, these participants were likely to be more motivated to participate in the tsetse control operations. This may have resulted in expression of overly positive views

and higher acceptance of tsetse control technology and of the operation itself. It may also have reduced the likelihood of any negative perceptions about the intervention. To minimize this bias I attempted to: i) enquire and use more probing questions with participants on any observed behaviour or when they expressed how other community members may think or feel, ii) perform an external evaluation of the condition of targets to check if any vandalism occurred in the process³², and iii) interview village chiefs at the end of the action research to ensure that we had some external views on the processes. Through this additional collection of information, I checked for any overly positive framing of research results. However, more interviews with those members of community not engaged in the intervention, would have provided a better representation of a wider range of opinions.

Limitations in data collection

In the assessment of the impact of women-led intervention on tsetse density, no baseline assessment on tsetse density was carried out before women deployed targets. This decision was taken to ensure participants did not have prior knowledge of the control tools. While this ensured that the community was 'naïve' it prevented measurement of the apparent density of the tsetse population before the deployment of targets. The relative density of tsetse was assessed within and outside the intervention area to verify perception of women on effectiveness of intervention. The trend was in accordance with expectation with tsetse numbers being lower in areas where targets were deployed. Nonetheless, it is conceivable that the difference existed before targets were deployed.

Some limitations also occurred in collection of qualitative data. Elders' memories may have been affected due to age, so recall bias may have occurred when discussing their memories. Only elders who had the ability to articulate their thoughts were interviewed which means that less articulate individuals who may have nonetheless had relevant different thoughts and memories were not included in the study.

The use of technical equipment for collecting data could have resulted in bias. For example, a number of limitations are recognised in the use of GPS trackers for monitoring daily human movements. Despite participants being instructed to carry on with their usual daily routine, the novelty of being in possession of a GPS trackers is likely to have influenced or changed their behaviour. Some participants openly shared that carrying the GPS tracker strongly influenced their movements—these were then excluded from the study. One female and two male participants were excluded because they were either a) moving with the tracking device to record boundaries of their land, or b) walked to the meet friends to show them the

³² If targets were vandalized by members of the community this would indicate that acceptance of the women-led programme, including tsetse control tools, is low.

devices. However, it is possible that some participants did not openly admit to altering their normal behaviour and so may have influenced the study results. Furthermore sand extraction is a common activity among women and in some of the villages about half of the women reported being engaged in this activity. Sand extraction activity however was not recorded in my sample. Participants also expected that GPS loggers would be collected at sunset and this may have influenced (or curtailed) longer-distance movements.

The occasional use of video camera during action research may have brought additional enthusiasm among participants. This could have caused overly motivated behaviour and more enthusiastic expression of opinions. A careful assessment of the impact of this technology on potential bias was done beforehand. All villages involved in action research do not have regular supply of electricity. In one of the villages, however, the village chief installed a generator and satellite TV for villagers to view the football World Cup. At the local markets, televisions are common for communal viewing of the news, football matches and films. Hence participants are not unexposed to media and technology, which are part of their daily lives. Careful planning was done before any video recording: recording was conducted by a single female Ugandan journalist, who joined the group discussions and only occasionally switched on the camera and no scenes were repeated specifically for video recording. Furthermore, most of the deployment and maintenance of targets was carried out by women in the absence of the research team or the journalist, therefore these results could not have been biased.

During the role play, participants acting roles of decision-makers that are not known to them from their daily life, such as 'minister', 'donor', 'WHO representative' roles may lack complete understanding of the exact nature of these positions and people. All efforts were made to explain related details. Also, being involved in a tsetse control intervention prior to the role play and focusing on discussions related to sleeping sickness control may have created bias towards over-presenting priorities related to this disease and this bias may have played out in the role plays.

Interactions with participants

The critical self-evaluation of myself in the role of a researcher and the impact of this role on the research process and its outcomes, is referred to in the social sciences as 'reflexivity' [208, 224]. Such reflection allows one to identify the potential for personal characteristics to have influenced data collection, analysis or interpretation. Flanagan [225] proposes that both processes, enquiry related to the research and self-enquiry, can only be analysed and described separately.

Before boarding on a PhD I obtained a degree in medical anthropology (MPhil), during which I conducted a study of health-seeking behaviour of HAT patients in West Nile. My own experience witnessing HAT patients and interviewing their care-takers three years before the start of this research left a strong emotional impact and ultimately spurred me to conduct this research. Some authors refer to this as 'studying the familiar' [224] and in the context of this research I felt better able to engage with participants and understand their struggles and challenges related to HAT. For instance, I understood participants' expressions of difficulty related to the distances and problems of accessing HAT treatment facilities because I had previously observed how hard it was for family members to travel with patients in late stage HAT with a bicycle as the only means of transport.

My personal background, particularly my upbringing in a rural area in a socialist state contributed strongly to my value systems which are centred on community cohesion and voluntarism. These have served to shape my enduring belief that community collaborative action is feasible and beneficial. This belief was perhaps translated into practice through action research, and my interactions with the study participants. Action research, however, allows for both: action and research to occur simultaneously as a transformative process with the boundaries between researcher and participants becoming blurred. Being aware of these dynamics also helped me to develop a reflective approach to my research. For instance, I engaged with the community aiming to record their views but not proceed with an intervention if they did not express a wish to do so. Prolonged engagement with participants, triangulation of research methods and debriefing sessions with the research team also helped to keep on my own influence on the research process [224].

During the action research, and despite the research team maintaining a neutral stance and letting participants make their own decisions, the presence of the research team is likely to have affected group dynamics. As Rifkin suggests [226], the process of participation inevitably involves power dynamics and to address clearly who has power and who does not is an important reflection. Provision of targets by the research team as the only way for participants to access these tools inevitably placed the research team in a position of power. The community, however, will not be completely autonomous in delivery of tsetse control and will depend on external suppliers of tiny targets in the future. These dynamics therefore were realistic and allowed me to assess how the community negotiates its way through such power dynamics. It became obvious through the role play for instance, that the community, regardless of its involvement with tsetse control programme facilitated by my research team, still promoted testing and treatment of HAT as their first priority. This indicates that power dynamics, between community and programmes, implementing disease control are likely to exist, but that the party holding power will be challenged and

have to adapt during the process of interaction with the host community.

The community's perception of me as a white foreign woman is important to consider. The behavioural norms and relationships that community members often develop with other foreigners, such as missionaries or NGO workers (before my arrival), could also have caused some reluctance on their part to express their views openly and critically. I was based in West Nile for over four years (between 2011 and 2015) and intensive interaction with the villagers throughout this period created many opportunities for informal observations which helped me to gain a certain level of understanding of the cultural norms and ways of communication. I obtained a basic knowledge (some greetings and expressions of politeness) of the Lugbara language to facilitate my interaction with participants, which helped to break inter-personal barriers.

The decision-makers interviewed were aware of my links with the Liverpool School of Tropical Medicine (LSTM) and the schools' work in tsetse control in West Nile. My research with local communities and women was also known to most of them. This may have caused them to express uncritical and positive attitudes towards community and women- focused tsetse control interventions. Senior levels of decision-makers were also likely to be influenced by their political role and therefore conscious when expressing their opinions to agree with institutional and political views of their organizations. An entirely neutral interviewer could perhaps have collected opinions that were nearer the truth.

Lastly, I was employed by LSTM as research assistant concurrently as I conducted my PhD research. In capacity of research assistant I was responsible for organization of sensitization campaigns to inform local communities in the trial area about the purpose and functionality of the targets. I was also in charge of liaisons with the district authorities to keep them updated on the progress of the Gates' funded project. My working obligations however were completely independent to my research objectives. Where my study villages overlapped with the Gates' project data collection was completed prior to any sensitization activities took place. I am therefore confident that this 'double role' as a researcher and research assistant did not influence the data collection process.

7.3 Operational implications

Question 1: Could involvement of local communities, and particularly women, improve sustainability of tsetse control using tiny targets?

Policy makers often assume lack of sustainability of community-based interventions in tsetse control, but this remains unverified due to lack of such interventions (Chapter 2). My thesis has helped to narrow this gap in verified intervention. I discuss my research findings in the context of three requirements for sustainability:

- i) Long-term commitment of the community and involvement of women
- ii) Maintenance of logistic support and coordination
- iii) Financial sustainability achieved by external and community contributions.

All these requirements are inter-connected and I provide some examples of the factors that are likely to impact them (Box 7.1).

Long-term community commitment and involvement of women

I discuss some mechanisms and potential threats to sustained community-based intervention, namely i) maintaining community motivation; ii) scale up of village based interventions; and iii) gender dynamics that may either facilitate or hamper participation of women. Some empirical examples, which illustrate how these barriers may be overcome are provided and originate from my research or other field evaluations, particularly those involving women.

Maintaining community motivation

Some caution is needed when promoting the need for long-term community commitment. Communities that experience the impact of disease may initially have high motivation and strong commitment to tsetse control, as was observed during the action research reported here and supported by other studies [52]. However, maintaining participation may become difficult once no more HAT cases are reported and the older generation, which still remembers drastic consequences of HAT epidemics (reported in Chapter 4), is not able to share their memories anymore.

Other, non-disease related benefits may therefore become crucial for sustaining motivation. In the case of this study, participation was largely driven by women's aspirations to improve their knowledge and skills and their desire to take control of HAT prevention. Other studies involving women's groups have also recorded an increased sense of empowerment, self-confidence, ownership and sense of pride following participation [152, 159, 227]. This suggests that women, who may perceive these outcomes as beneficial in other areas of their lives, are likely to appreciate and remain motivated on the programme. Some programmes involving women's groups and maintaining participation over several years provide

some evidence to support this hypothesis. One such example is a women's groups intervention to improve neonatal health in which 95% of the women groups remained active over a three-year trial period without any financial motivation [157]. Several other interventions involving women report similar findings in achieving long-term participation of women [152, 158].

Ostrom [185], who examined the impact of 'free riding' on collective action, noted that collaboration in different settings is largely varied. He proposed some principles that seem to be consistent across settings characterized by high collaboration. For instance, when users enforce their own rules on shared resources, rather than these rules being externally imposed on them, resources are managed in a more sustainable manner. Such internally negotiated rules already include monitoring mechanisms and sanctions against 'free riding'. Following this principle, he argues that externally imposed rules, which do not consider these internal dynamics, work against collective action (ibid.). A practical example of the local social collective action among female farmers in Kenya and Uganda [227] demonstrated benefits of such internal group management. Authors argue that risk sharing, shared labour and resources, preventive activities, experimentation and resource conservation characterize group relationships, which results in improved livelihood sustainability. Hence, this examples show that many mechanisms for sustainable collaboration already exist and are self-driven in organization of collective action in Africa and elsewhere.

How long is long is long enough?

To break HAT transmission, a reduction of more than 70% in the density of tsetse is required [47, 228]; and this needs to be sustained for over three years, the period that trypanosomes can persist in humans [228, 229]. In this case, it becomes important to judge whether a community-based programme could be sustained over several years. The women-led intervention presented in this thesis was planned for six months³³ (a timeframe determined by research team based on longevity of tiny targets [47]). The results of this study do not allow us to conclude that a three-year long participation by women could have been achieved.

My research team, however, received some indications from the community that prolonging this intervention was possible and desirable. At the end of the intervention, the women requested replacement targets and these were supplied by the research team. Thereafter, the women deployed the targets as previously and without any inputs from the research team. Some of the early community-based interventions in Congo (Brazzaville) [125], Ivory Coast [126] and South Sudan [132], which ran for several

³³ This includes only the period that the research team interacted with participants during intervention; the entire period, including evaluation after intervention was 9 months.

years also indicate that long-term interventions are possible. In Ivory Coast, for instance, 95% of the farmers wanted to continue the intervention at the end of the planned period [126]. In other places, communities managed to extend tsetse control interventions beyond the project timeframe [52, 127, 128, 130, 230]. Thus, these examples suggest that sustainability in terms of longer time-frames are not necessarily jeopardised by participating communities, but rather by the time-frames defined by projects (and funding agencies). Therefore, such operations could be potentially prolonged, once initial investment of time and training is provided, and delivery of targets is maintained.

Scaling-up village level interventions

Scaling up of health interventions depends on multiple factors. The large scale implementation is more likely to be successful if intervention is technically simple and has a widespread consensus on its value [231]. Other predictors of success include strong leadership, engagement of multiple, including non-state actors, and strong local ownership (ibid). Scale up usually requires institution building process, which is time consuming and needs to be strategized from the beginning of the intervention [232].

To control vectors of HAT, it is necessary to cover relatively large (>50 km²) areas of riverine tsetse habitats with targets to obviate the effects of tsetse re-invading from uncontrolled neighbouring areas. In other words, in the context of West Nile at least 10 participating villages would be needed. Women-managed operation in this research was implemented in three villages (13.9 km²) but my results showed that there is a potential for organic spread from community to community to achieve coverage of a larger operational area. Similar observation was reported by Okoth et al. [131], who noted that villages neighbouring the intervention area in southern Uganda, took an interest in tsetse control.

Some other interventions delivered by women's group demonstrate that extensive scale-up is feasible. In Malawi for instance, 207 groups were established to promote maternal and child health outcomes. The groups were supported by 72 female volunteers, 24 cluster facilitators who were trained women from the community, and 4 supervisors over an area of 48 village clusters [158]. Scale-up, however, would require additional coordination effort and expert support to maintain sufficient coverage of targets over several villages or sub-counties. Hence, scaling up entails multiple processes: geographical expansion of intervention, strengthening the technical capacity of the community and building links between the community and other stakeholders, such as government agencies and NGOs involved in HAT control.

Scaling-up village based interventions largely rely on recruiting and maintaining sufficient number of committed participants. This process depends on the enthusiasm and trust shared between all the parties

involved. The research team in this study was received with excitement and a constructive relationship with participants evolved over time. An atmosphere of transparent and open dialogue was established, which was critical in facilitating relationships between participants and the research team. If participants feel that they are listened to and that their opinion is valued, then they are more likely to trust those introducing an intervention. This may sound obvious, but these issues are frequently over-looked. The recent Ebola crisis in West Africa is a reminder of the importance of trust in disease control programmes. Negative perceptions of the emergency response programme and people implementing it created a strong resistance on part of the local communities to the outbreak control measures, resulting in exacerbation of the epidemic instead of its control [233, 234]. Hence, certain 'soft' skills, more related to day-to-day human interactions and communications, rather than the so-called technical skills, are essential to planning and implementing community-based programmes.

The importance of gender relations in participation of women

This research has shown that participation of women depends on various factors. Women's participation was supported by the broader social environment and no resistance from male members, including local leaders (village chiefs, sub-county and district officers), was observed during the study. However, this is not to say that the situation will be the same in other contexts; in fact there could be potential for creation of harm in some countries. The WHO recommendation on community mobilisation via women's groups reports the potential risk for women involved in maternal and child health interventions, namely gender-based violence or conflict with other community members or health providers [194]. As women become more knowledgeable and more empowered through an intervention this may change relationship dynamics within the households and the wider community leading to shifts in power and conflict. This issue is illustrated by the project from rural India that aimed to empower women through direct interventions in health care, education and economic activities [235]. Using this example, Raju argues that women, after being empowered through the programmes still have to position themselves in relation to men. This repositioning may not result in desired changes and attempts to empower, may lead instead to disempowerment of women. Furthermore he discusses that women empowerment projects charge women with the unrealistic task of achieving a greater social change. To mitigate this risk, there is a pressing need to understand the power dynamics of social and gender relations (ibid.), particularly in context where community based interventions rely on women participation.

Against this examples other studies suggest that empowerment through access to financial resources improves women's decision-making at household level, their independence and access to other financial opportunities [236]. A study on women's entrepreneurship in Uganda [237] showed no correlation

between women's empowerment and gender-based violence. Other studies concerned with health demonstrate the potential for strongly collaborative relationships among households' members. In Nigeria for instance, a shortage of insecticide-treated nets for all family members was compensated by adult males giving their nets to women and children [151]. Furthermore, supportive husbands and other men are recognized as key enablers of women's participation in programmes to improve perinatal care [152].

Thus, long term community commitment is needed to achieve required duration and scale of tsetse control needed for reduction of HAT transmission. Results of this research, supported by the evidence from other women-group interventions, indicate that involvement of women has a beneficial potential for sustainable tsetse control interventions at required scale. Empowerment of women through participation in tsetse control, as in other programmes, however, carries risks and opportunities. A careful assessment of gender dynamics is necessary to determine the appropriateness and level of female participation in different settings. As already proposed elsewhere, recruitment of local female facilitators who are aware of gender-related dynamics, to train women groups in delivery of tsetse control, could be one way of enabling female participation [238].

Supporting hard-to- reach communities

Community-based interventions cannot be sustained without the long-term support of other external stakeholders, institutions and resources [194]. This comprises of coordinated support of local, national and international systems involved in organization and delivery of tsetse control, which also includes monitoring and evaluation. Sustained technical expertise and maintained access to tsetse control tools, is particularly critical in hard-to-reach HAT foci.

Overcoming barriers to reach communities in HAT foci

The remoteness of some foci and weak health systems, has been argued to slow down progress of control of NTDs [239, 240]. Remoteness, however, often defined by the poor road accessibility, is a dynamic concept. In the last decade intensified infrastructural development occurred across Africa, resulting in newly constructed road connections between peripheral areas and urban centres³⁴. In case of HAT, the notion of 'remoteness' has already been challenged by practical examples. Delivery of the current diagnostic tools and treatment, for instance, has already been established and these tools are currently despatched from WHO to all the main HAT treatment centres across Africa [22]. In addition, recently

³⁴ This development was observed over four years when this research was conducted in West Nile.

developed, new diagnostic tools, which do not require cold-chain anymore, have been delivered to health centres in the most distant and isolated health centres located in HAT areas [241].

Another aspect worth exploring is delivery of control tools with assistance of locally available transport means. Local communities living in these 'remote' places use other means of transport, such as motorbikes, bicycles and boats to move in the areas where roads are not built for use of larger vehicles. The small size of tiny targets is well adopted for such transport as it does not require large vehicles for their distribution [49]. If community members are provided with tiny targets and included in intervention the use of their means of transportation would facilitate distribution of these tools where they are most needed--in isolated areas, where local communities enter into the habitats of tsetse.

Hence, the notion of 'remoteness' is dynamic and requires frequent re-conceptualization to capture the intense development of the rural Africa, including HAT endemic areas. Examples of delivery of medical tools to all main HAT foci provide an evidence that HAT affected communities can be reached. Tiny targets, characterized by small size, are technologically adapted for areas with difficult access. What would facilitate their distribution is the use of the locally available transport means, already adjusted to overcome mobility challenges.

Linking communities and external organisations

An organizational link between communities and other national and international structures is required to ensure coordinated efforts and sustained supply of materials and tools. Village representatives are vital in this process and they will need to be formally integrated into organizational structure. Local leaders are the first entry point into the community and the most obvious contact persons. Their early engagement is essential and their interest needs to be maintained throughout the life of the programme to make community-based approach sustainable.

The tsetse control intervention documented in Chapter 5 was perceived as important by village chiefs and administrative sub-county and district leaders. This is not always the case. A study of community participation and empowerment in an HIV/AIDS programme [242] showed that a single leader can make the difference between programme success and failure. In this HIV/AIDS initiative, the village chief's beliefs about community values and traditional roles of women completely de-stabilized the programme, and as a result, the programme objectives were not achieved. However, fostering support of local leaders makes it easier to ascribe them an active role in the intervention and thereby maintain their interest and support. Beneficial impact of such constructive relationship between local leadership and disease control

programmes have been already documented [243-246]. In the context of the intervention reported in this thesis, the enthusiasm of the local leaders could have been channelled into coordinating efforts between neighbouring villages and reporting on activities and progress to other governmental organisations.

Once village based contact is established, an uninterrupted link to supply of tools and materials needs to be maintained from international to the village level. In some of the earlier tsetse control interventions, traps were produced by the community which gave them a certain independence in accessing and using these tools [132]. Tiny targets, however, are currently produced by a commercial company (Vestergaard-Frandsen) in Vietnam and their production is likely to remain outside Africa in the near future, due to quality assurance issues. A sustainable procurement chain from producer to the end user is vital in logistical planning. Organization of transport to the target countries, such as Guinea, Chad and Uganda, has been so far organized by Vestergaard-Frandsen, importation documentation and storage has been organized by the national HAT control programmes, and dispatching and implementation at the field locations by implementation teams. These, already established supply chains could be linked with community representatives to ensure continuous supply of needed tools.

Monitoring and evaluation of community-based interventions

Routine monitoring and review of progress will be required if the community is responsible for implementation to ensure that community and other experts supporting them are: a) aware of the impact of the intervention and b) get alerted and respond to emerging risks threatening success.

One potential challenge could occur in ensuring that targets are deployed regularly across the intended geographical area. As reported in Chapter 5, some gaps in target deployment occurred due to uncertainties about village boundaries. These gaps were however smaller than 3 kilometres, which based on simulation model [247] has no impact on effectiveness of tsetse control³⁵. To ensure sufficient coverage of tiny targets and avoid larger gaps in deployment, village representatives could be supplied with GPS units and trained in their use. The GPS units could be shared between villages and provide an objective means of monitoring deployment by a regional monitoring team. This team could provide feedback to communities on any gaps in deployment which would then require follow up. The regional team might be in charge of compiling information and passing it onto the national coordination level.

³⁵ The exact impact of deployment gaps would, however, need to be tested with riverine tsetse in this ecological setting.

Hence, for effective monitoring and evaluation to occur from village through regional and national- to international coordinating bodies, several processes need to be established and maintained. This includes clearly defined roles, operational guidelines, open communication channels and mechanisms to evaluate and follow-up risks.

Financial sustainability

Supply of tiny targets and the support of external organisations to local communities will only be possible if national or international financial commitment is sustained. To this end, the experience of the action research and the cost calculations presented in Chapter 5 demonstrate that a women-led approach is not only feasible but also cost-effective. Compared to the use of other control methods, such as standard trap-based methods, an 80% reduction in costs has been achieved by the use of tiny targets [47]. If the operation is carried out by local communities and implemented over a three-year period, it would further reduce the cost by USD 28 per km² compared to an intervention implemented by the government services.

To achieve community- based tsetse control over an area of 500 km² would cost USD 21,700 a year. In comparison organizing a single round of active screening to reach 80% population coverage in the same area (estimated cost USD 433,333) is almost 20-times more expensive [47]. Medical interventions cannot be replaced by vector control alone to control HAT, but financial resources could be more economically used if some funding is channelled to community based vector control to protect human populations at risk versus detecting and treating already infected individuals later.

The relatively low cost of community-based tsetse control may make vector control more appealing to the government, non-government, donor and philanthropic institutions which support efforts against HAT. Indeed the development of a relatively cheap and easy method of tsetse control that can be implemented by local communities provides a new opportunity for government-implemented interventions which will be less dependent on the uncertainties of external funding and changes in donor priorities. Long-term financial commitment will require continuous lobbying to ensure that HAT remains on national and international agenda.

Cost savings through contributions of community labour and resources may be attractive to donors and programme planners. However, the constraints faced by communities must be considered. The calculation undertaken in this costing evaluation indicates that the value of the women's time expended on the project accounts for 7% of project costs. Competing demands for their time led to delays in target deployment. Some tasks undertaken by women (e.g., protecting crops from pests) were seasonal. Other

time constraints were related to religious obligations. These predictable demands could be factored into plans (e.g., fasting during Ramadan, Christmas holidays). Other demands are less predictable (e.g., funerals, weddings) and these will inevitably impact on operations if planning is not realistically carried out. The impact of seasonal farming demands on community participation were in line with observations by Kamuanga et al. [137] who reported that the willingness of farmers to contribute either money or labour to tsetse control in Burkina Faso depended on the household availability of time or cash when contributions were requested. After the harvesting period, for instance, when farmers had more time, they were more willing to contribute labour than money. The fasting season during Ramadan and households' domestic commitments were recognized to pose barriers in female participation in other health related studies [238, 248]. Hence, if the community perceives the cost of their involvement to be higher than perceived benefits, this is likely to hamper their participation. To be sustainable, a community-led project would need to ensure that critical tsetse control activities (e.g., deployment of targets during the dry season) should avoid predictable conflicts and maintain sufficient flexibility to allow for unpredictable events.

When community-based tsetse control is planned, expectations of the numbers of targets deployed needs to be agreed so as not to overburden the participants. Provision of protective clothing, footwear and tools, is absolutely essential for implementation of tasks related to deployment and maintenance of targets, and this was already calculated as part of the 'external cost' of community delivery schemes in Chapter 5. These items should be considered as a part of the delivery package and provided along with targets.

| Box 7.1: FACTORS RELATED TO IMPROVED SUSTAINABILITY | | |
|--|--|--|
| Main factors | Examples | What is needed |
| Community long term commitment | <p>Participating community expresses wish to continue extend the programme.</p> <p>Community decides on their own rules for participation and managing common resources.</p> <p>Evidence from women group interventions [152, 157, 158] which lasted for several years.</p> <p>Evidence from community-based tsetse control [125, 126, 132] interventions which continued for several years.</p> | <p>Flexible planning that allows extension of the programme.</p> <p>Communication with the community members on terms of participation; opened dialogue how they manage common resources.</p> <p>Involvement of women groups, where this is feasible; preliminary assessment of the likely role of women.</p> <p>Building up trust with the community through strong programme leadership and transparent communication practices.</p> |

| | | |
|--|--|---|
| Maintained logistic support and coordination | <p>Linkage between communities and external technical inputs (information, skills, tools).</p> <p>Monitoring and evaluation of target deployment and maintenance.</p> | <p>Using already established supply chains or alternative systems.</p> <p>Keeping local leadership engaged.</p> <p>Engagement of community into planning and programme evaluation using available technology to document and monitor the progress.</p> |
| Financial sustainability | <p>National and international commitment to financial allocation for HAT control.</p> <p>Using community-based approaches as cost-effective option but with consideration of facilitating factors and potential constraints.</p> | <p>Lobbying donors and national programme makers about the benefits of community-based approaches to tsetse control.</p> <p>Provision of tools ('slashers', protective footwear and clothing) to the community.</p> <p>Flexibility in expected timeframe of the intervention and adequate consideration of other demands and responsibilities of the community.</p> |

Finally, the sustainability of community-based tsetse control interventions will depend on specific local factors. The type and level of participation can only be decided in collaboration with the beneficiary communities and generic guidelines, while helpful, can never be universally applicable. An open, flexible and respectful attitude, including a readiness to receive community criticism and suggestions is essential for community participation processes to be set in motion.

7.4 Policy implications

Question II: How could community-based approaches become part of the HAT control policy and implementation?

Current HAT strategies aim to eliminate HAT as a 'public health problem' by 2020 [5, 249], but community participation is virtually absent [50], indicating that this approach is not a current priority. My research has shown that a number of benefits could arise from active community involvement in tsetse control, and particularly with involvement of women.

I synthesized the findings from all research phases to document the potential for community-based approaches to improve current policy and practice. In Chapter 1 and 3 I explored the assumption that communities can move from no participation to active participation in tsetse control, but that there will

be forces driving this change as well as resisting it. My thesis started with a theoretical approach, that of ‘force field analysis’ [176, 177] as used in organizational management; in this section, I revisit this theoretical framework to illustrate various factors working for and against community participation, from the perspective of the community and other stakeholders, derived from my research.

Figure 7.1 (adapted from [177]) illustrates the main driving and resisting forces occurring at the village (orange) or national and international level of stakeholders³⁶ (blue). Strong engagement at the village level and global and national initiatives to eliminate HAT generating new energy and a sense of commitment were some of the key driving forces. No resisting forces originated at village level providing there is flexibility in the timing of interventions and provision of equipment to perform tasks (as already discussed in section 7.3). The main resisting forces were lack of engagement of policy stakeholders with HAT-affected communities and their lack of understanding of community-based approaches.

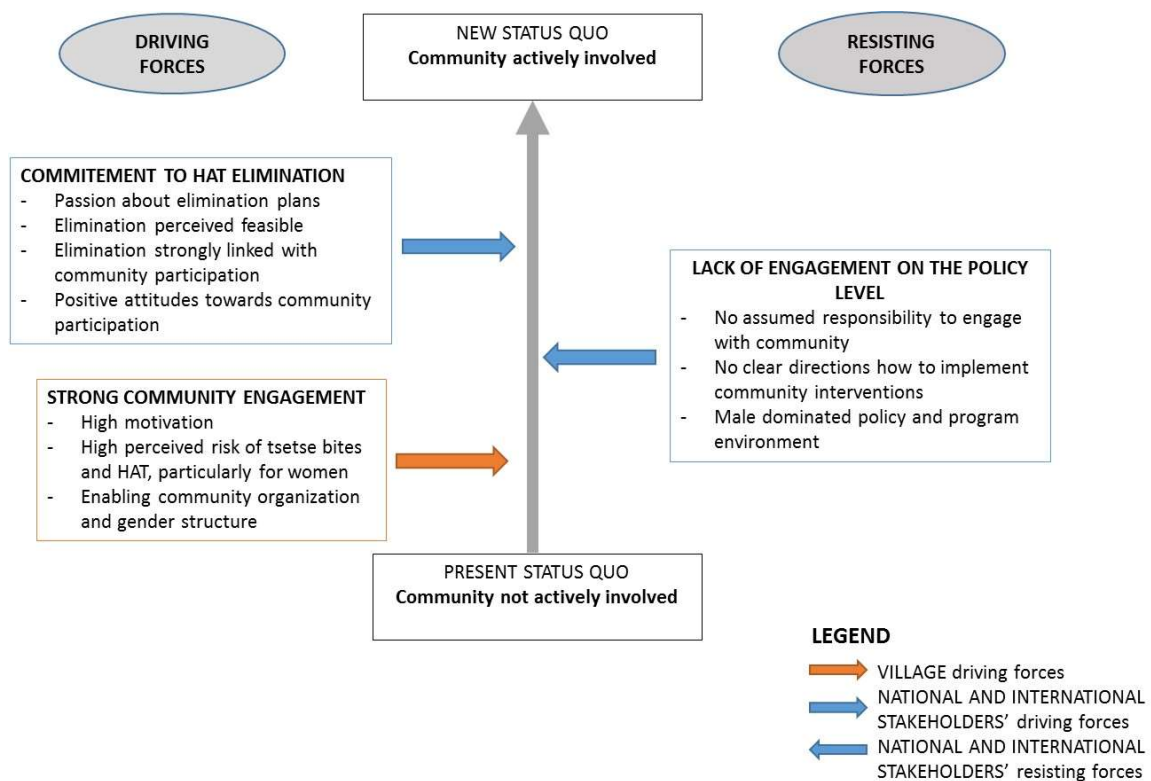


Figure 7.1: Driving and resisting forces in the implementation of community participation

³⁶ Interviewed national and international stakeholders shared the same perceptions on illustrated areas and are therefore joined under the same colour scheme in Figure 7.1.

Lewin [176] argues that change can be implemented by either adding forces that are pushing into desired direction, or reducing the resisting forces. In both cases the change will be achieved, but the secondary impact will be different. For instance, when forces are added into desired direction, this will result in increase of tension and higher emotional response in people affected by the change. On the contrary, when force is applied in reducing resisting forces, less tension will be triggered as a secondary effect (ibid.). Applying this theoretical approach, I discuss potential ways in which 'driving and resisting forces' could be managed in relation to future HAT strategies, based on community and women participation.

Reinforcing driving forces

Commitment to eliminate HAT is an opportunity

While decision-makers interviewed in this study showed positive attitudes towards community participation, the process of integrating this approach into policy and practice is not straightforward. Positive impacts of community-participation, for instance, have been previously documented [125, 126, 130, 132, 250], but this has not resulted in integration of this approach into HAT control strategies. Elimination plans provide a new opportunity for this change to occur.

In the context of the factors that facilitate translation of the research evidence into policy and practice, several findings, recorded in my research could potentially foster this process. Gilson et al. [166] for instance propose that research findings have to be shaped around implementation. My pilot study, which showed cost-cutting benefits and demonstrated feasibility of women-led intervention, is an example of that. Furthermore, personal networks among researchers, policy-makers and programme planners, which were suggested as a vital element for strengthening research influence [165], already exist in HAT control arena. Favourable timing, characterized by defined goal to eliminate HAT and stakeholders' perception that this goal is unachievable without community support, further assists in lobbying for this approach. More frequent and better targeted contact with key institutions and individuals could occur during public meetings such as annual PATTEC (Pan-African Tsetse and Trypanosomiasis Eradication Campaign) meetings, WHO stakeholders meetings and international conferences focusing on tropical health.

Engaging communities as advocates

Another strong argument for adoption of this approach is that the community living under the threat of HAT is willing, motivated and skilled to be involved in efforts against this disease. This argument is stronger, potentially, if members of the community make these statements and advocate for change. Women demonstrated good negotiation skills and confidence through the role play, as well as insights

into the decision making process, which makes them excellent candidates to act as ambassadors for their communities and demand for programmes to help them to fulfil their health needs. UNICEF, acknowledges that providing the opportunities for beneficiary community to demand their rights, serves both ways: 'right holders' (community), receive adequate support defined by their rights and 'duty bearers' (health delivery programmes) are able to fulfil their duty towards 'right-holders'. This process, as an example of effective advocacy, was described as leading towards change in policies, attitudes and action [163].

An absence of community representatives at the stakeholders' meetings [5] clearly shows that community views have not yet been taken into consideration. To adopt a community approach the culture of decision-making process and decision-makers must change. The community would need to be provided with the opportunity for their voice to be heard. This could have been achieved through the personal contact between community representatives and policy makers or through videos recording their views (an example in Appendix D1) and distributed to the relevant audience.

Reducing resisting forces

Building up knowledge and skills on community-based approaches

Following the framework of the 'force field analysis' [176] efforts to reduce resisting forces are more important than reinforcement of driving forces since this results in less tensions. The main resisting forces recorded in my analysis were associated with the lack of policy engagement with beneficiary communities. Discussions with stakeholders on this topic revealed that this is partly related to a widespread lack of skills and knowledge on how to plan and implement community-based interventions. Accordingly, there is a pressing need for more social scientists working in this arena to provide decision-makers and policy-planners with the requisite awareness, skills and capacities.

The reservation about involving women, expressed by some programme planners and implementers, was related to tsetse control being considered as male domain. As women in West Nile demonstrated, the use of tiny targets and management of control operation was seen as feasible by perspective of women. The conceptual shift is therefore needed among leaders in tsetse control to acknowledge that responsibilities related with planning and implementation of tsetse control could be shared with women. Lobbying could focus on raising awareness on gender imbalance at more senior positions and the barriers that this imbalance creates for promotion and implementation of women-led interventions.

Engagement with the communities driven by donors' priorities

One way of improving trust in community-based approaches is to promote interactions of all the stakeholders with the beneficiary community and discuss related concerns directly with them. If donors are committed to community-based approaches, then there is a greater likelihood of this approach being accepted by all stakeholders. One example, where this level of commitment exists, is a dengue elimination programme [251]. A group of dedicated social scientists were involved and everyone, including senior project staff, interacted with the community in a collaborative manner. As a result the programme achieved support from the host community and other local and state officials also engaged in the process (ibid.). Similar examples of collaboration and integration of all stakeholders, providing a mutual learning experience, are needed in tsetse control.

This prioritization, set by donors is also likely to ensure that engagement with communities is not overridden by other professional or non-personal priorities. Results in Chapter 6, for instance, showed that community-based approaches partially but not wholly coincide with senior decision-maker's objectives. Scoones [172], who interviewed stakeholders with power and influence over research agenda, policy and funding in HAT, also found that motivation was driven, in part, by personal goals. He attributed researchers' lack of willingness to hand over tsetse control operations to local communities to the former's attempts to protect their power and prestige. This indicates that some effort will be required to push community-based approaches to overcome such personal and political priorities, but donors could influence and drive this change.

I have argued that HAT programme planners and decision-makers has partly already been in favour for community-based approaches. An enthusiasm to promote such approaches combined with a period when HAT elimination efforts are high on national and global stakeholders' agenda, provide a historical opportunity which should not be missed. These research results feed into practical guidelines for such changes to occur.

7.5 Implications for further research

This research signals into three general areas for future research work as follows: i) consulting elders to engage communities into disease control programmes; ii) operational research to test participation of women and other perceived risk groups in other settings and on a larger scale; iii) additional research to expand on gender related risk to tsetse.

Consulting elders to engage communities into disease control programmes

The study of the elders' memories (Chapter 4) of past HAT interventions showed that despite the community's recollection of some past interventions as being coercive, this did not prejudice community perceptions towards current tsetse control interventions. Consulting elders was a useful framework for capturing collective memories about experiences with past control programmes and it reflected current community attitudes towards participation. This framework could be used to study other disease contexts before community-based interventions are introduced. In addition, this approach could be useful in the contexts where community trauma is likely to have occurred in the past, such as in early HIV/AIDS interventions or in the recent (2014-15) Ebola crisis in West Africa. This assessment could be conducted by the following steps: i) exploring memories and/or perceptions of past control interventions, ii) acknowledgement, if any, of collective trauma having occurred and iii) discussion with elders, how to engage community into disease control programmes, since prior experience and trauma could affect their willingness and uptake of programmes.

Operational research of participation of women and other risk groups in different settings and on a larger scale

It is unclear if in other countries, where the status and position of women is different, women-based tsetse control intervention could be implemented with the same outcomes. More research and on a larger scale is needed to test this approach in various settings. To make this research comparable, the same evaluation categories, such as leadership, ownership, motivation, empowerment, resources allocation, quality of deployment, sustainable maintenance of tiny targets, and cost-effectiveness should be applied. Having more case studies of women-based interventions from different HAT-endemic countries, would indicate how widely applicable this approach may be and to what extent different socio-cultural settings influence its success.

Additional operational research evaluating the impact of involvement of other risk groups would help expanding the knowledge on community-based approaches. In northern Uganda women were perceived as a high risk group, but in Chad and Guinea, for instance, fisherman are commonly recognized as being the most exposed to tsetse and of being at risk of contracting HAT [110]. Such research could evaluate exposure of such groups to tsetse and their motivation for participating in interventions against tsetse. Comparative studies could also explore the involvement of groups frequently exposed to tsetse in areas where HAT is already largely under control such as in Ivory Coast. Lessons learned from these studies could help design interventions that would maintain long-term community participation in settings where

case incidence is approaching the elimination status and HAT cases are extremely rare (i.e., 1 case per 10,000 people).

Research of gender related risk to tsetse and HAT

Additional studies on gender-related risk to tsetse and HAT could guide the choice of participants. At the moment, it is unclear if such differences in risks exist and if so, in which HAT endemic settings they do. Gender-based analyses of patients' cohorts and anthropological studies of human activities in tsetse risk areas would assist in defining whether there are gender-related heterogeneities in disease risk and incidence. More generally, our knowledge of the behavioural interactions between tsetse and humans, and how this impacts on disease incidence is limited. Quantitative studies of the feeding behaviour of tsetse combined with anthropological studies of human activities in tsetse habitats would provide much-needed information on if and why some population groups are bitten more than others.

7.6 Broader implications for HAT and other disease control programmes

The present work on community-based interventions against tsetse has three general implications for HAT and other disease programmes. First, there is a need for integrated approaches against vector-borne diseases. In Uganda, medical and tsetse control interventions related to the alleviation of HAT are currently organized separately; medical screening and treatment is implemented by the Ministry of Health and vector control by the Ministry of Agriculture. Communities however perceive prevention (i.e. vector control) and treatment of HAT as having the same goal. Links between government organizations and affected communities would be strengthened if both services were presented and delivered under the same organizational package. One example of such integration, could be joined transport of medical and tsetse control tools from central points to the peripheral end-user, which would facilitate logistics and reduce the cost. Furthermore, community sensitization efforts could be used more efficiently. Communities could receive information on disease, testing and treatment as well as be empowered with the knowledge, skills and tools for tsetse control during the same sensitization campaign.

Second, women-based tsetse control was successfully piloted in the context of Uganda. This implementation is the most cost-effective example of the use of tiny targets so far. Furthermore, women in Uganda already have a certain level of independence related to decision making and authority. It is not unusual, for instance, for women to act as village leaders, community health workers or district administrators. Women-based control interventions in other endemic districts of Uganda are likely to be feasible and effectively implemented. Targeted dissemination of these research results to a wider

community of experts working in the area of NTDs could create opportunities for a multi-disease control approach managed by women.

Finally, this research showed that communities are receptive to technological innovations. Despite having no previous contact with tiny targets, the community quickly accepted, used and took ownership of these tools. This shows that there are opportunities for other health-related technological innovations to be introduced. New communication technologies, devices to purify water, new easy-to-use diagnostic tools and other vector control tools are likely to be successfully accepted and used by the community. Their acceptance and successful use is however contingent on being introduced in accordance with community perceptions and needs, with provision of adequate information on their purpose and use, through community participation methods.

7.7 Conclusions

- **The use of tiny targets is a simple and effective tsetse control method which can be used by communities living in HAT foci.** In three endemic villages in Uganda, community members, particularly women, clearly demonstrated and communicated that they are motivated, skilled and organized in the use of tiny targets to protect themselves against tsetse. From their perspective, the implementation of tiny targets was feasible and desirable.
- **Women-based delivery of tiny targets demonstrated the potential to improve sustainability of such programmes.** The research showed the implementation was cost-effective and prolonged the longevity of tiny targets. This approach provides an alternative option to current programmes delivered by external technical teams, and needs testing in other countries.
- **National and international decision-makers were positive about involving communities, but were less clear about how to operationalize this.** This research provides an example of how to achieve this in practice with the principle of recognizing communities as equal partners in HAT elimination efforts.

APPENDIX A

CONSENT FORM CONFIDENTIAL

Title of Project: **Effect of Community Involvement on Sustainability and Cost-effectiveness of HAT (Human African Trypanosomiasis) Control Interventions**

Consent given for the Study (researcher ticks as appropriate):

1.1 Elders memories of HAT interventions

1.2 Community risk analysis (human vector contact)

2.1 Participatory Action Research

3.1 Stakeholders' reflections

Participant Identification Number for this Study: _____

1. I confirm I have read and understood the information sheet dated..... (Version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that participation in this study is voluntary and I am free to withdraw consent at any time, without giving a reason, without any penalties.
3. I understand that data collected during the study, may be looked at by individuals from LSTM and from regulatory authorities. I give permission for these individuals to have access to my records.
4. I hereby declare that I have not been subjected to any form of coercion in giving this consent
5. I agree / do NOT agree for any visual materials with my image (photos, video-clips) collected during this study to being stored and used for public disclosure (written publications, conferences, raising awareness meetings)
6. I agree to take part in this study.

Signing this declaration does not affect your right to decline to take part in any future study.

Name of participant
or

Date

Signature

Name of illiterate participant
and

Date

Signature

Name of literate witness

Date

Signature

Name of person taking
Consent

Date

Signature

When complete: 1 copy for participant; 1 copy (original) for research file.

CONSENT FORM-Lugbara

E'yo zizaru ovule erekokoruri

E'yo Dri: E'yo ojataru enyati yini ecole esule, aje kokoru , ti ecita ezuru HAT (Human African Trypanosomiasis-azo mongotoni) ma atrita aliari.

Kalafe fele 'ba onita diri ma aliari dri ri: _____

- 1. Ma ai ra kini, ala karatasi i ecipi onita 'diri ma driari ra, o'du.....si, azini e'yo 'diri fi ma dria kililiru. Ma esu vini ndra drileba e'yo diyi ma dria e'yo egazura, zita yi zizu, azini omvita drifupira/ma trapira 'diyi esuzura.
- 2. Ma ovu vatabe kini e'yo ti ecizu onita 'diri ma driari, ovu feza ceni dinileri i, azini ma ovu vini drilebe mbo, efuzu e'yo 'diri ma aliari si ra, etu/odu ci mani lelerisi, asisile mani fekokoru, vini e'yo azini ma yekokoru.
- 3. Ma ovu vatabe kini e'yo okule etu/odu onita 'diri driri, eco ovu ndrezaru 'ba LSMT (Liverpool School of Tropical Medicine) / 'ba engapi Liverpool ma pari onita fepi ecetaru aro ma dria 'diyi dri ra, e'yo 'di engazu 'ba azita drileru 'diyi vu. E'yo disi, afe di driwala 'ba 'diyi dri ecozu osisia mani kaniku ma dria 'diyi esuzura.
- 4. A 'yo di doa adada kini, e'yo diri nzeria/eceria , 'ba omini ma geriko azinisi aluaniku.
- 5. Ma ai ra / ai niku /gasi, afa ndrezaru mani ekile e'daru, o'dule onita 'dirisi 'diyi ma ta mbazu ci azini 'bani ecozu yi ayuzu e'yo o'bini 'dinile 'diyi alia, osisia si, kaniku embata 'bani o'bi yi oruzu dinile 'diyi ma alia.
- 6. Ma ai ti ecizu onita di ma alia ra.

_____ Ru

_____ Mba o'du

_____ Dri tita

_____ Ru 'ba onita kokori ni

_____ Mba o'du

_____ Dri tita

_____ Ru sadini onitaberi ni

_____ Mba o'du

_____ Dri tita

_____ Ru 'ba e'yo 'di aipiri ni

_____ Mba o'du

_____ Dri tita

Ka di ovu ngonde: Esile alu 'ba ti ezipiri dri; esile alu (okori/e'dozuri) ero e'yo eti ondazurini.

Effect of community involvement on sustainability and cost-effectiveness of HAT (Human African Trypanosomiasis) control interventions

Dear Sir or Madam,

A research group from Liverpool School of Tropical Medicine in the UK is conducting a study and you are invited to participate.

Purpose of the study: As you probably know there are people who are affected by sleeping sickness in your area. Sleeping sickness is transmitted by the bite of infected tsetse fly. One of the methods to prevent this disease spreading is to kill a good number of tsetse flies. Part of the research is testing new techniques to kill tsetse flies. You will soon see small targets (blue and black in colour) being distributed along the rivers in the area where you live.

If these targets are effective enough in killing tsetse flies, we would like to recommend them for use in the areas with sleeping sickness, such as your area. We would also like to introduce this technology to the communities affected and try to involve them in tsetse fly control in the future.

Selection of participants:

For the study we are recruiting members of community who live in sleeping sickness area, or sleeping sickness patients or women who are willing to participate in tsetse fly control interventions.

Research procedures:

If you agree to participate, this will involve answering questions individually or in a group for example about:

- your attitudes and perceptions of sleeping sickness and tsetse fly control today or in the past
- your daily activities which will be recorded by a special device that you will be asked to carry around for the day
- your life after falling sick and being diagnosed with sleeping sickness (if you are currently ill and on treatment for sleeping sickness)

You may be asked to get actively involved in tsetse fly intervention and share your views and opinions in designing and implementing targets deployment.

Reasons and advantages of taking part in this study:

Your participation will help us understand any potential difficulties community experiences while dealing with the problem of sleeping sickness and tsetse flies. This may bring us closer to recommending you how to protect yourself and distribute targets that kill tsetse flies more effectively.

Your involvement in tsetse control intervention is very important. It will demonstrate how your community could organize yourself for such intervention in the future; it will also help developing strategies that are acceptable for you and will help us to present your views and opinions to decision makers.

Eventually your participation could help to prevent sleeping sickness spreading in your community and will potentially contribute towards protecting future generations.

Risk and costs:

The risk resulting from your participation in this survey is very limited. Discussing any potential traumatic events, that occurred to you or your family member while being sick, diagnosed or treated for sleeping sickness may result in emotional distress. In this case we will terminate the interview. We are also aware of absolute necessity to respect your confidentiality. Your participation in the study will not cost anything to you and your family and will not in any way affect your usual access to health care or treatment for sleeping sickness.

Your rights during this survey and confidentiality

- Your participation in this research is completely voluntary. You might refuse to participate without any consequence and you may withdraw from the study at any time.
- All the information you will give us will remain anonymous and strictly confidential. Only the staff involved in the study will have access to the information you will give us. We will not record your name in the study forms or any report resulting from the study. At the beginning of the study we will give you a study identification number and this number will be used on the forms. Only members of the research team will have access to information linking your name with your study number.
- No visual materials, collected during the study (such as pictures or video clips), will be shown publically without your permission.

If you have problems or questions about this study, you can contact any of the survey personnel including: *Vanja Kovacic, anthropologist, carrying out this study in West Nile (my phone: 07-77-961-725).*

E'yo/afa ongulumuni eco esu, amuti omvele HAT (Human African Trypanosomiasis) ma efita azo di atrita ma alia geriko yeta ndu ndu edri aza kozu kanikuni ageiteza, vini aje kililiru si diyi.

KARATASI E'YO ECETANI, TI ECITA CENI E'YO AIZURIBE.

Ata-anzi / Ata-ezo,

'Dori Amuti e'yo 'eti ovaa`pi/onda`pi 'diyi i, engazu Liverpool sukulu ovule Tropical Medicine niria; 'dari eri Liverpool ma pari onitaa fepi ecetaru, aro madriari ma alia. 'Diri engazu nyaku kalati omvele Olayaa ria, 'ka 'dini, ai di emi ti ecizu tualu yi be eyo 'diri ma dria.

Asisile onitaa 'diri vileri: Kile mini eco nira 'rile, ba azini yi dri ci azo 'mongoto' nisi angu emivile diria. Azo mongoto niri, eri i ere trei geriko onyukunyu omvele 'evii, ovupi o'bu mongotoni, 'berini 'ba cilerisi. Geriko azini alu 'bani ecozu azo 'diri ma eretaa atrizuri eri treyi bani ecozu evi 'diyi ma kalafe angiri 'diyi odizu/ofuzu te. Eyo eti ondaza 'diri ma esele aziniri, eri geriko odiruri 'obizu evi kaniku onyukunyu 'diyi odizu/ofuzu te. Mbeleru, emi 'ye otita were 'bani lele yima 'yeyira 'diyi ndre, wure blue ru azini 'eni ru, bani 'yeria e'yi awaria angu emini ovuzuria, ogogo yi ma tia,.

Otita kaniku geriko ayule 'diyi ka eco evi/onyukunyu diyi odi /ofu onyiru/kililiru tu, ama nga le geriko 'diyi ma ayuta atii/ai pari azo mongotoni ovuzu alenia ci 'diyi alia, ekile pari emini ovuzu alenia dirile. Dika, ama vini nga'le geriko ayule kililiru 'diyi e'da ongulumu pari azinia, tro tro dri cipi azo disi diyi dri, azini obizu e'yi ofizu yeta yini ecozu evi/onyukunyu diyi atrizu ewu drilerisi.

Opeta 'ba azi 'diri ngapi diyiniri:

Onitaa 'di 'yezu, ama 'ba opee engazu ongulumu ovupi angu azo mongotoni beri ma alia, kaniku, ba ovupi rua azo mongotoni 'be 'diyi, kaniku, oku ovupi ava azi ngazu atrita evi/onyukunyu mongoto erepiri atrizuri be diyi ma alia.

Geriko ayule e'yo eti ondaza azo 'diri driari:

Emi ka ai 'dinile ti ecizu azi 'di ngazu ra, e'yo nde nga i eci zitaa' omviza adule, kaniku, ongulumururibe; eki ecetaru e'yo andreleru 'diyi ma dria:

- Mi egata, azini va'taa azo mongotoni ma dria, azini onyukunyu eviiru diyi atrita andru, kaniku ewu agapi bori/driyo ri ma dria.
- E'yo mini 'yele o'du alu aluvusi, ovupi osizaru nyafe ma dria, e'yo ngapi mi aipi, yi 'yezu o'du alu aluvusi 'diyi.
- Edri mini azo mongotoni, mi 'bapi okpo kokori ma vutiari; azini esuzu kini mi rua azo mongotoni ribe ri (azo mongotoniri ka ovu mi rua curu'do ci, azini mi ka curu'do aro mongotoniri esu).

Mi eco ovu aizaru, ti ecizu avabe, efizu azi azakoza fezu onyukunyu omvele eviiru 'diyi atrita ma e'yo 'yezu. Azin mini mi egata azini eyo mi asia/omia ri ayuzu tualu amuti/ongulumu be, geriko afa edezu azini e'yo kililiru diyi o'yezu/sizu 'yeke yima paria.

E'yo 'bani onitaa 'diyi onizuri, azini e'yo muke onitaa dirini ecole fele 'ba e'yo nde yepi 'diyi dri 'diyi.

Mi ma ti ecita e'yo 'di 'yezuri ni nga ama azako, 'okpoako ci ongulumu yini esule 'adi'diza e'yo-azo ewaru mungotoni, azini onyukunyu eviiru diyi atrita pie diyi vazuu. E'yo 'diri eco 'di nga ama eji enyia, emi dri geriko fezu, 'mgbo, emini ecozu emima ta mbazu/ageitezu, azini afa 'bani lele ayule, ecozu onyukunyu eviiru diyi odizu/ofuzu, kaniku drijazuu 'te 'diyi awazu.

Mi ma ti ecita azini 'yeta, e'yo onyukunyu eviiru 'diyi atrizuri, eri e'yo azini amburu tu dinileri i. 'Diri nga ovu ecetaru, 'yozu ongulumu mivile 'diyi, eco nga yi otuu, e'yo tro-tro dilerisi, ewu drilerisi ngoni yari; eri vini nga azakoza fe 'bani geriko/e'yo drifupira diyi ezozu/sizu emi dri, azini eri nga ama azako e'yo emini egale emisi kililiru drifupira, 'diyi ecezu 'ba e'yo ma yeta 'bapi i ma paria diyi dri.

Yeta 'diyi ma vutia dria, mi ma ti ecita e'yo 'diri ma aliari, eco azakoza fe azo mungotoni ri ma eretaa atrizu, ongulumu mivileria, azini eri di nga 'okpo fe anzi ewu drile 'diyi ma agaei tezu/tambazu.

E'yo ecopi ori' fepi azini oya lepi 'diyi:

E'yo ecopi ori' fepi mi dri engazu mi ma ti ecita e'yo diri ma alia 'diyi, ovu tutuni atrizaru. E'yo ale nyazu, e'yo ci andra i yepi mibe, kaniku oriba mivile akuaribe, mini/erini ovuria azoruriari madria; okpo-ako fepi, azini fepi mi/eri ma asi ma oti tutu 'diyi, esuzu azo mungotoniri mirua ci, vini, mini aro azo mungotoniri ayuzu 'diyi eco fe omi, kaniku egatani ecazu acozaru/azazaru. E'yo 'dinile 'diyi ma alia, ama ngani mu drile e'yo oziza/zita zizu mi tia drile ku. Ama ovu vini egataa be e'yo adasi, e'yo mivile/rua kaniku mini nzele 'diyi ta mbazu ama asia inzitasi, ecozu fezu e'yo 'dinileri erekokoru. Mi ma atita azi onita 'diri alia ri ngani mivu azini mivile akurivu afa azini ai/oja kaniku eza ku.

Mima driwala odu e'yo eti ondaza di dririsi 'diyi azini e'yo miniru adulesi 'diyi

- Mi ma ti ecita e'yo eti ondaza diri madriari ovu dria e'yo mini lele mi i, avasi oya kokoru dinileri i. Mi eco vini gasi, ti ecizu azi di ngaza alia ra, e'yo azini ecozu vini mi yezu aluaniku, azini mi eco efu onita e'yo eti ondaza 'di ma aliarisi etu/odu ciria kile mini lelerile.
- Azita 'okporusi, e'yo dria amani ngale esule mivu 'diyi nga ovu lu ama eselia mibe, 'ba azini ngani e'yo 'di nze amve kaniku mi ru omve kalaa aluaniku; Pelu 'ba azi di ma drileru kaniku otita di ma alia engazu amuti e'yo di ejipi 'diyi nga e'yo mini nzele 'diyi esuni. Ama ngani mi ma ru si vaa karatasi e'yo 'diyi onizu 'diyi madria ku, kaniku e'yo efule onita di ma dria 'diyi ma alia ku. Onitaa di ni edoria, ama nga mi dri onita di ma karatasi fe dria kalafe mini edezu ribe, 'di esele coza edazu 'ba azini azi di ma alia ku 'diyi be; azini ama nga kalafe mivile dari ayu karatasi azi 'diyi ngazuri ma dria i. Pelu, 'ba ovupi amuti azi e'yo eti ondazu diri ma alia 'diyi nga geriko esu e'yo mini nzeleri ecizu onita di ma kalafe fele midri ribe.
- Afa drezaru, ekile edaru, kaniku senemaru, 'bani tra'le onita 'di ma alia 'diyi ngani e'da o'bi ma drilia mima aita kaniku atita kokoru ku.

E'yo mini esule ewaru/'dri-osizaru onita 'di ma dria ni, kaniku, zita ziza pile 'diyi ka ovu ci, mi eco 'ba ovupi ci, amuti diri ma dri'ceta, kaniku, amuti diri ma e'yo otita 'diyi be e'yo nze ra, 'ba ekile:

Vanja Kovacic, anthropologist('ba oduko nzepi/'dapi afa pamvu ndrezasiri), eri onita 'di oni pari omvele –West Nile (Ma nyofe o'yzuri ma kalafe-simu namba:0777-961-725).

Effect of community involvement on sustainability and cost-effectiveness of HAT (human African trypanosomiasis) control interventions

Dear Sir or Madam,

A research group from Liverpool School of Tropical Medicine in the UK is conducting a study and you are invited to participate.

Purpose of the study:

This study is linked to a trial, where smaller and cheaper targets, designed to kill tsetse flies are tested in a large scale trial. Community was involved to assist with designing and implementing deployment of targets and its monitoring. In the process of piloting community involvement and in collaboration with the community their views and recommendations were captured. One of the objectives of our study is to share these experiences with policy makers and explore their views on sustainability of future HAT control programs.

Selection of participants:

For the study we are recruiting key persons involved in HAT control on local (West Nile), national (Uganda) and international level.

Research procedures:

If you agree to participate, this will involve answering questions individually for example about:

- your views towards sustainability of tsetse control interventions in Uganda and other HAT affected countries
- your views on community involvement in such interventions and your reflexion on community views
- potential facilitators or barriers for implementation of tsetse control strategies in the future

Reasons and advantages of taking part in this study:

Since our research focus is community based your participation will help us understand the process of decision making on others, policy-based levels. This will be crucial for the critical approach to the collected data and will provide an opportunity for more holistic approach. In addition, your participation may help to shed some light on potential solutions for more sustainable future HAT control.

Risk and costs:

The risk resulting from your participation in this survey is very limited. We are aware that your views represent an institution you work for and your personal views, if stated so. We are aware of absolute necessity to respect your confidentiality.

Your rights during this survey and confidentiality

- Your participation in this research is completely voluntary. You might refuse to participate without any consequence and you may withdraw from the study at any time.
- All the information you will give us will remain anonymous and strictly confidential. Only the staff involved in the study will have access to the information you will give us. We will not record your name in the study forms or any report resulting from the study. At the beginning of the study we will give you a study identification number and this number will be used on the forms. Only members of the research team will have access to information linking your name with your study number.
- No visual materials, collected during the study (such as pictures or video clips), will be shown publically without your permission.

If you have problems or questions about this study, you can contact any of the survey personnel including: *Vanja Kovacic, anthropologist, carrying out this study in West Nile (my phone: 0777-96-17-25).*

LIVERPOOL SCHOOL OF TROPICAL MEDICINE

RESEARCH ETHICS COMMITTEE

| | | | |
|----------------------------|--------------------|-----------------|-------------------|
| FOR OFFICE USE ONLY | Date of submission | Date considered | Approval granted? |
| Application Number | | | Yes/No |
| Signatures | Reviewed by | Copy to | (Chair) |

Please complete this form in typescript. Select Yes/Not Applicable options as appropriate. It is essential that this form is completed fully and the relevant enclosures are received if the study is to receive proper scrutiny by the Research Ethics Committee.

Applicant contact details

| | |
|--------------------------------------|--------------------|
| Name: | Vanja Kovačič |
| Email address: | vkovacic@liv.ac.uk |
| Postal Address (if not LSTM): | LSTM |
| Telephone number: | +44 79-34-70-70-41 |

Administration Charges:

An administration charge of £250 for awards of over £10,000 and £50 for those below will be made for ethical approval on successful grant applications. Please make cheques payable to 'Liverpool School of Tropical Medicine'

| | | | |
|---|---|-----------------------------|------------------------------|
| Is the proposed work already funded? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> | n/a <input type="checkbox"/> |
| Total budget of proposal £ £7600 | Payment by Invoice <input type="checkbox"/> Internal School Transfer <input checked="" type="checkbox"/> | | |
| To whom should the administration charge be sent? | To Prof. Mike Lehane | | |

Check List:

The following **Check List** must be completed. Please indicate if the following have been enclosed by selecting Yes/No/Not applicable option below.

| | Yes | Not Applicable |
|---|-------------------------------------|-------------------------------------|
| 8 Copies of the completed Application Form | <input checked="" type="checkbox"/> | |
| 8 Copies of the Research Protocol | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| Copy of Questionnaire/case record form | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| Copy of Consent Form | <input checked="" type="checkbox"/> | <input type="checkbox"/> |

| | | |
|--|--|----------------------------|
| Copy of Patient Information Sheet | <input type="checkbox"/> X Participants' Information Sheet | X <input type="checkbox"/> |
| Copy of Translator Agreement | <input type="checkbox"/> X | <input type="checkbox"/> |
| Please indicate if the questionnaire is not yet finalised | <input type="checkbox"/> X | <input type="checkbox"/> |
| Is this a clinical trial application? | <input type="checkbox"/> | NO |
| Copy of Clinical Professional Indemnity Insurance for PI (clinical trial only) | <input type="checkbox"/> | X <input type="checkbox"/> |
| Draft interview/FGD or observation/Check list enclosed (if used) | <input type="checkbox"/> X | <input type="checkbox"/> |

The completed form should be sent to: Vicky Cowley, Secretary, Research Ethics Committee, Liverpool School of Tropical Medicine, Pembroke Place, Liverpool L3 5QA e-mail: Vicky.Cowley@liv.ac.uk

LSTM Research Ethics Committee

APPLICATION FORM FOR ETHICAL APPROVAL

(Revised November 2010)

Please refer closely to the Guidance Notes when completing this form.

All questions must be answered. Any form with sections left blank will be returned. This form must contain all information necessary for the Research Ethics Committee to make a decision on Ethical Approval


| | |
|---|----------------------------------|
| APPLICANT FULLNAME (including title) | Ms Vanja Kovačič, BA, MSc, MPhil |
|---|----------------------------------|

| | |
|-----------------------|---|
| PROPOSAL TITLE | Effect of Community involvement on Sustainability and Cost-effectiveness of HAT (Human African Trypanosomiasis) Control Interventions |
|-----------------------|---|

| | | |
|---|-------------------------------------|------------------------------------|
| Have you submitted this proposal to the LSTM Research Ethics Committee before? | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| If 'YES', please give date of previous review: | | |
| To which other ethical committees has/will this protocol be submitted? (please list) | | |
| The Ugandan National Council of Science and Technology | | |

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|---|
| APPROVALS |
| List LSTM research team and <u>all</u> collaborators. (Please include all overseas collaborators and give their affiliations, qualifications and role in the study). |

| |
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| |
| Vanja Kovačič, LSTM, Principal investigator |
| Dr. Helen Smith, LSTM, PhD Supervisor |
| Prof. Mike Lehane, LSTM, PhD Co-Supervisor, Project Senior Manager |

| | |
|--|---|
| If proposal is for work relating to a MPhil/PhD, please state the name and Research Group of Supervisor/Tutor | |
| Supervisor | Dr. Helen Smith |
| Research Group | International Health Group |
| Signature: |  |

SECTION A

STUDY OUTLINE

| | |
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| A.1 | TITLE OF PROJECT: |
| Effect of community involvement on sustainability and cost-effectiveness of HAT (Human African Trypanosomiasis) control interventions | |
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| A.2 | LAY SUMMARY: <i>(max 300 words)</i> |
| <p>HAT (Human African Trypanosomiasis) or sleeping sickness is a parasitic disease, caused by <i>Trypanosoma</i> parasite and transmitted by the bite of infected tsetse fly (<i>Glossina</i>). Disease distribution is limited to the African continent and still threatens 30 million people. The most affected are rural communities, living in remote areas.</p> <p>Treatment of HAT is extremely toxic and causes severe side effects and reduced contact to tsetse fly bites remains the only preventive method known today.</p> <p>Tsetse fly control is therefore crucial for preventing communities living in a tsetse belt to contract HAT. Targets and traps, impregnated with insecticide, are designed to attract tsetse flies and are distributed along the rivers and in areas with dense vegetation, which are preferable <i>Glossina</i> habitats.</p> <p>Up to date, and despite this technology being effective in reducing number of tsetse flies, targets and traps have not been used in large scale interventions. This was based on the argument that technology is too expensive and not sustainable enough.</p> <p>With the new technical solution to the problem-development of smaller and cheaper targets- there is a new opportunity for large scale interventions and effective sustainable tsetse control in the future.</p> <p>The study we are proposing is part of a larger Gates-funded project on tsetse control, to trial the use of new smaller targets, being conducted in Uganda and Guinea. This study will be conducted in field sites in Uganda, and will pilot test an innovative approach to involving target communities in HAT control. We will examine feasibility and effectiveness of a community-led intervention using action research with local women's groups, and asses its effects on the sustainability and cost effectiveness of tsetse control. This data will help us to address policy and contribute towards the future of HAT control.</p> | |

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| A.3 | IMPORTANCE OF THE RESEARCH: |
| <p>Local communities, affected by sleeping sickness are the first witnesses of the disease outbreak. However they lack tools to take an initiative in responding to these outbreaks. Their dependency on NGOs, whose involvement can be short-term, and a small group of local professionals specialised to use tsetse control strategies is unnecessary, since new targets are small and simple to implement. Our research will bring some insights into these areas, and eventually give communities a voice to address key decision makers who are setting HAT control policies. The final outcome is therefore improved health of the communities living in HAT endemic areas and sustainable prevention of HAT outbreaks.</p> <p>Our research approach, participatory action research, takes into consideration the social, economic and cultural environment we are working in. Community is not only an object of the research, but is a collaborative partner, who is contributing towards development of the research processes. With this approach we want to ensure that results are both, acceptable and applicable for the potential beneficiaries.</p> | |

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| A.4 | LINKS WITH NATIONAL/INTERNATIONAL RESEARCH PRIORITIES: |
| <p>HAT has a patchy distribution, related to specific micro environments which enable existence of tsetse fly habitats. Disease therefore, only occurs in certain regions and even there in only certain pockets of the region (certain villages are heavily affected, others not). Therefore HAT control on both national and international level competes with other, more widely distributed diseases and budget priorities.</p> <p>This resulted in sleeping sickness being a neglected disease and despite its devastating effects, has not been a high priority in either international or national research arena.</p> <p>Furthermore, it mostly affects communities in remote, isolated areas, commonly affected by political unrest, which contributes to the considerable challenges for field based research.</p> <p>All these factors resulted in big gap in published research in the specific areas we are proposing in this study.</p> | |

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| A.5 | DUPLICATION OF RESEARCH: |
| <p>Community involvement in tsetse control interventions using targets and traps is widely unexplored by the published research. A search of LSTM databases, including Scopus and Reference databases was performed. General terms: "tsetse" OR tsetse OR "Glossina" AND "control" AND "targets" OR "traps" resulted in 1951 results (between 1961 and 2011). These references were screened for articles concerned with community involvement (using "community" AND participation OR involvement OR action which resulted in 78 eligible publications. As a comparison the same combination of community-terms combined with "malaria" resulted in 14,862 results.</p> <p>Despite very limited number of interventions that attempted to involve local communities in tsetse trapping in the 80s and 90s (Ivory Coast, Democratic Republic of Congo, Uganda), authors report</p> | |

successful community participation. However for the past 10 years no active involvement of community was reported; research has mostly focused on case detection and treatment. However, recent research recognizes the importance of the community acceptance of- and collaboration with-tsetse control programs; community willingness to participate in interventions is seldom evaluated in this papers.

Our research will therefore break a long gap in existing publication concerned with the mentioned focus. Furthermore, to the best of our knowledge, specifically involving women’s group in tsetse control interventions has never been used before, hence this is a novel approach.

| A.6 OBJECTIVES AND EXPECTED OUTCOMES (please limit to three) | | |
|---|--|--|
| Objective | Expected Outcome | Target Population |
| To evaluate actual and perceived risk of HAT burden in the community | Insights into motivation factors for community participation in tsetse control | Rural communities in sleeping sickness foci of West Nile region (Arua, Maracha, Koboko Districts) |
| To examine effects of women’s involvement on cost reduction, sustainability and community acceptance of the new tsetse control strategy | Piloted community based control intervention | Women in sleeping sickness foci of West Nile region (Arua, Maracha, Koboko Districts) |
| To explore barriers and facilitators for future community-based tsetse control interventions on a national and international levels | Established dialogue between HAT affected communities and decision makers | Local key figures (District officers), national key figures (Ministries), international key figures (NGO representatives, WHO representatives) |

| A.7 METHODOLOGY | |
|--|--|
| <p><u>Phase 1 (Objective 1): EXPLORING PERCEIVED AND ACTUAL RISK OF HAT BURDEN IN THE COMMUNITY</u></p> <p>Study population: Local communities living in HAT endemic foci</p> <p>Selection: entry point through village chiefs</p> <p>METHODS:</p> <p>i.) Community perception of the risk of HAT and effectiveness of tsetse fly control will be explored using</p> | |

Focus group discussions (2 FGD per village in 4 villages with low and high HAT prevalence) (checklist draft sheet enclosed).

- ii.) Risk to exposure to tsetse flies measured by combination of **GPS technology** and interviewing techniques. Small I-gotu (I-Gotu, GT 120, Mobile Action, UK) georeferencing devices will be handed to participants (30 men and 30 women) for a day (10 hours). Participants will be shown how devices work and will be instructed to place them on their arms and to continue with their daily activities without any interruption (devices are waterproof). Map results (Google map) will be shared with participants and they will be **interviewed** in-depth about their main daily activities (see interview guide and socio-economic questionnaire enclosed) and reasons to performing them in that particular time and place. Results will be compared with tsetse distribution map (provided by Gate's tsetse trial research group LSTM/NRI, UK) to assess which activities are mostly related to tsetse fly exposure.
- iii.) How HAT burden and HAT control changed from the past until today will be explored with **in-depth interviews** with community elders (interview guide enclosed)
- iv.) Actual social, economic and emotional burden of disease will be determined with **in-depth interviews** conducted with willing HAT patients and/or their families or carers. Households with a family member diagnosed with HAT will be identified by the survey carried out in the risk study (see socio-economic questionnaire), described above (draft enclosed)

Phase 2 (Objective 2) WOMEN'S INVOLVEMENT IN TSETSE CONTROL INTERVENTION

Study population: women living in HAT endemic foci in West Nile, Uganda

The main principle of action research is a collaborative process between the researcher and the community in a non-hierarchical way with shared decision making. This approach has been recommended to be used with disempowered groups and therefore it is suitable for our field situation and attempt to initiate active community involvement into new vector control strategy.

MAIN METHOD: Participatory Action Research (PAR)

Selection of the communities/participants

Participatory communities will be defined as inhabitants of two villages with similar HAT prevalence (data from MSF Spain active screening report). Both villages are going to be selected based on the following criteria:

- i.) there was no organized tsetse control activity carried out for at least 5 years
- ii.) Communities live in the area with high tsetse density (data obtained from tsetse simulation, Gates research group)
- iii.) Only women will be selected as participatory body

Action research cycle and data collection

Community health workers, who will carry out routine door-to-door sensitization of the tsetse control methods (as part of the Gate's project), will be trained for the PAR approaches. They will introduce

Participatory Action Research to the community and invite women to participate. Willing women from two intervention villages will be invited to the initial meeting when principles of the project will be discussed in detail but in an appropriate format.

1. Step: Identifying local needs and constraints, develop priorities

The first meeting will be used as an opportunity to carry out 4 focus group discussions (2 with men and two with women) and collect baseline information on experiences and attitudes towards tsetse control programs to date and female and male views of women's potential involvement. To what extent tsetse control is considered a priority compared to other needs will also be explored.

2. Step: Sharing information and planning

The second meeting will consist of sharing information about intervention (principles of tsetse targets, deployment criteria) by the researcher. Participants will be encouraged to develop an implementation plan to deploy and maintain the targets based on a combination of their knowledge of where tsetse flies predominantly exist and on data collected in Phase 1.

3. Step: Action: target deployment and reflexion

Women will be supported by the researcher to deploy targets in specific locations. This will be followed by a group discussion to explore problems encountered and potential improvements.

4. Step: Action: target deployment and reflection

Target deployment will be carried out again, following the participant-developed deployment plan, but with incorporated changes suggested by the previous meeting. Group discussion will follow to reflect on previous achievements, progress and constraints experienced.

5. Step: Reflection on sustainability

The fifth meeting will consist of discussion with the women participants on how to make target deployment sustainable at the community level.

6. Step: Influencing policy

An exercise of role playing will be conducted (roles of global policy maker, minister of health, district health officer, community member, etc.). Each character will be in charge of decision making towards budget allocation and implementation of tsetse fly control in the context of competing other priorities. Audience will get a chance to offer solution during play intervals. This exercise will be concluded with the group discussion and proposed plan how to share action research results with policy makers.

7. Step: Dialogue with policy makers

Local key figures (district entomologist, production coordinator, district veterinary officer, district health officer) will be invited to a meeting in the participating communities. Dialogue with representatives of the community will be encouraged. The

meeting will be concluded with a plan for sharing research results with national and international policy makers and wider research audience.

Measured outcomes

The impact of PAR is going to be measured by the following criteria:

For tsetse control:

- i.) Effectiveness of intervention (change in tsetse fly density)
- ii.) Sustainability (condition of traps (nu. of damaged, disappeared, maintenance of clearance around the traps)
- iii.) Cost of the community-led intervention (compared to standard target deployment)

For community-led tsetse control:

- i.) Perception of skills obtained
- ii.) Confidence to carry out intervention independently
- iii.) Feeling of empowerment to change HAT related control policies
- iv.) Acceptability of women's groups and their involvement

In addition, a careful observational study collecting data on the process of mobilisation for the project, discussions (disagreements, constraints, motivating factors, etc.), community self-organization (who is taking active role, who is leading the group, how many women participate, what timing do they choose for deployment, etc.), implementation problems encountered and solutions obtained, will be recorded. Observations are going to be reported as a potential practical model of community involvement into tsetse control activities.

Parts of the discussions, target deployment, and role playing exercise will be video recorded. Video clips will be selected in collaboration of participatory women for final product (short movie) which may be used in Phase 3 for probing discussions with key gate keepers.

The tsetse control outcomes of the PAR project will be compared with the same outcomes from standard control under trial conditions (tsetse trial villages carried out by paid trained labour and supervised by the vector scientists) and standard usual control (villages that are under current government management in terms of tsetse control activities). Detailed cost-effectiveness analysis will be carried out comparing all three scenarios.

The PAR methodology is participatory, therefore study tools and protocols are NOT supposed to be pre designed, but rather developed in collaboration with participants throughout the research process allowing necessary flexibility of the process (therefore no protocols enclosed).

Phase 3 (Objective 3): ADDRESSING POLICY

Study population: Representatives of the key decision making bodies

Key informants (during group meetings or individually) will be asked to comment on issues concerning future community-involvement and sustainability of tsetse fly control. Videos produced in Phase 2 may be shown to probe discussions.

In-depth interviews will be conducted with the key gate keepers:

- a district level (district health officer, district veterinary officer, district production officer, district entomologist)
- national level (Minister of Health, Minister of Agriculture, COCTU Director)
- international level (representatives of NGOs currently involved in HAT control: MSF, Merlin, etc.; WHO director for neglected tropical diseases, in charge of global HAT control).

Issues around sustainability and community involvement in vector control (barriers, potential solutions, vision for the future) will be explored.

Interview questions will be closely related to the Phase 2 findings; therefore question guides will be developed later when incorporation of essential information is possible.

| | | | | | |
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| A.8 | PARTICIPANTS: | | | | |
| A.8.1 | Age / Sex: | | | | |
| | Neonates (<28 days) | Infants (1-11 months) | Young children (1-9 years) | Adolescents (10-19 years) | Adults (>19 years) |
| Males | 0 | 0 | 0 | Estimates:10 | Estimates:10 |
| Females | 0 | 0 | 0 | Estimates:130 | Estimates:140 |
| <p><i>If you are unable to give precise figures, state estimates and give an explanatory sentence in the space below:</i></p> <p>Figures are only crude estimates, since sample size will vary depending on the willingness for participation (which is particularly part of the Participatory Action Research).</p> <p>Adolescents only older than 16 years will be included. This is justified by the observation that their activities do not differ greatly from the rest of the adult population (e.g. working on fields, washing clothes at the river banks, etc.). This age group, therefore, represents a high risk group for HAT infection and excluding them from the research could result in the sampling bias.</p> | | | | | |
| A.8.2 | Describe how, where and by whom the participants are to be recruited | | | | |

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| <p>Participants will be members of rural communities in Arua, Maracha and Koboko Districts (Uganda).</p> <p>Phase 1: Potential participants will be approached in their villages by researcher in charge (with previous notification of village authorities-chiefs) and interpreter who will explain the purpose of the study and procedures involved.</p> <p>On some occasions (Phase 2) villagers will be approached by the volunteer health workers who will be carrying out routine sensitization related to the Gates tsetse control trail and asked if they are willing to participate.</p> <p>In Phase 3 Key informants will be invited for the interview by researcher in charge.</p> <p>Children and teenagers younger than 16 years will be excluded. HAT patients with mental symptoms will be excluded as well and care takers will be invited for the interview instead.</p> | | |
| A.8.3 | <i>Please justify your choice of sample size (as described in A.7)</i> | |
| <p>The sample sizes proposed are estimates; throughout the research we will follow the principle of saturation (no further participants are included when information collected starts to become repetitive and no new findings emerge). However, the estimates are based on the researcher's previous experience conducting qualitative data collection in Arua district, Uganda.</p> <p>In order to assure appropriate sample sizes and trustworthiness of data collected, the research proposal and study tools will be shared and discussed with other social scientists and tsetse fly control specialists at LSTM (Dr. Helen Smith, Dr. Luise Kelly-Hope, Dr. Imelda Bates, Prof. Mike Lehane) and Natural Resources Institute, U.K. (Prof. Steve Torr and Prof. John Morton).</p> | | |
| A.8.4 | <i>What specific measures are in place to take into account recruitment of participants from vulnerable groups?</i> | |
| <p>Recruitment of any specific vulnerable groups is not planned, however pregnant women may be recruited to participate. There is no particular procedure involved that would potentially harm their pregnancy.</p> | | |
| A.9 | PROCEDURES | |
| A.9.1 | <i>What procedures or methods will be employed in the collection of data?</i> | |
| <i>Procedure</i> | <i>To be carried out by:</i> | <i>Who is the person employed by?:</i> |
| 1. Focus group discussions | Local social scientist, trained interpreter, and principal investigator (medical anthropologist) | Principal investigator |

| | | |
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| 2. In-depth interviews/socio-economic questionnaires | Local social scientist or trained interpreter, and principal investigator | Principal investigator |
| 3. Geographical information system survey | Principal investigator and trained interpreter | Principal investigator |
| 4. Patients' interviews | Local social scientist or trained interpreter, and principal investigator | Principal investigator |
| 5. Key informant's interviews | Principal investigator | N/A |
| A.9.2 | | <i>State the extent to which the procedures to be used are a part of standard patient care (if appropriate).</i> |
| N/A | | |
| A.9.3 | | <i>Please indicate the basis on which the persons identified in A.9.1 are thought to be competent to carry out these procedures. List any training of staff which may be required prior to commencement of the study.</i> |
| Staff Member | Experience/competencies | Training Required |
| Local Social Scientist | Masters in Sociology, experience conducting research on health or illness using similar methods | Not required |
| Trained translator | Experience working with Medical NGO (MSF-Eng. Doctors Without Borders) | Two day training (carried out by principle investigator and social scientist) with exercises on direct translation methods |

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| A.10 | MAJOR METHODS OF ANALYSIS: |
| <p>Objective 1: All interviews and focus group discussions will be recorded using digital voice recorder (Olympus LS-11). Communication will be carried out in local languages and in case of interviews, simultaneously translated to English by trained interpreter. Recorded data will be transferred to the computer as digital files using Olympus software. The same software will be used during the transcription process. Transcripts will be translated (for FGD) and data will be managed using MAXQDA 10 Software; a coding frame will be established, transcripts will be coded, and coded data searched and managed in the software. Content analysis approach will be used for further analysis.</p> | |

Geographic positioning files will be saved in gpx form and mapping will be performed using Google (Google Inc., Ca, USA).

Descriptive statistics (SPSS, PASW Statistics 18) using proximity of water bodies and location of nearest water pump as variants is going to be carried out determining if any of these factors have a significant impact on the daily activities carried out by the communities.

Objective 2 and 3: The same methods will be used for qualitative data analysis

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| A.11 | QUALITY ASSURANCE OF DATA |
| <p>All the data collection tools will be pre tested prior to implementation in the field. Where tools will be used in local languages, questions will be back translated to ensure that the meaning has not changed in the process of translation. Interpreter will be trained in principles of direct translation and numerous translation exercises will be carried out in order to obtain high quality translations. Transcripts in English and native language will be proof-read by a second person for quality control purposes.</p> | |

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| A.12 | DISSEMINATION OF RESULTS |
| <p>According to the principles of participatory action research, the findings will not only be communicated to the community, but the community will also be actively involved in deciding to who, which results (messages) and how the data will be presented at local, national and international level.</p> <p>Objective 3 is primarily concerned with communication of the findings to all three different levels: local, national and international.</p> | |

SECTION B

CONSEQUENCES FOR THE LOCAL COMMUNITY / ENVIRONMENT AND PARTICIPANTS

| | |
|-------------------------------------|---|
| B.1 | POTENTIAL ADVERSE EFFECTS, DISCOMFORT OR RISKS |
| B.1.1 <i>Participants</i> | <p>The proposed study is observational and it is not based on invasive methodology. Majority of our methodology is mostly based on purposive sampling of the community members and does not target any specific patient group. Therefore we estimate that participation only involves a limited risk. According to our previous observations, sleeping sickness is not stigmatized within the local communities in West Nile.</p> <p>More precaution will be taken when patient's interviews are carried out. Emotional distress may arise when discussing any potential traumatizing</p> |

| | |
|---|---|
| | <p>situations experienced during disease or treatment. Occasionally sleeping sickness results in irreversible mental symptoms, which is emotionally draining not only for the patient, but also for other family members.</p> <p>Studies involving geo-reference tracking of individual have potential discomfort of invading privacy.</p> |
| <p>B.1.2</p> <p><i>Investigators</i></p> | <p>Potential adverse effects, discomforts or risks are very limited in this study.</p> <p>However, discussing traumatic events and witnessing suffering certainly affects both parties: the person discussing it and the listener.</p> <p>Potential risk of the snake bites during fieldwork.</p> <p>Potential risk of tsetse fly bites.</p> <p>Potential political unrest.</p> |
| <p>B.1.3</p> <p><i>Members of the public</i></p> | <p>N/A</p> |

| | |
|--|---|
| B.2 | MINIMISING ADVERSE EFFECTS, DISCOMFORT AND RISKS |
| <p>B.2.1</p> <p><i>For participants</i></p> | <p>Village chiefs will be visited prior to the implementation of the study and asked to inform community about the purpose of the study and potential home visits in advance.</p> <p>Each participant selected for participation will be informed about the objectives of the study, methodology, risks involved and their rights concerning participation or withdrawal from the study.</p> <p>Participation in the study will be entirely voluntary.</p> <p>Any information regarding HAT transmission, testing and treatment opportunities will be provided if requested.</p> <p>During patient interviews if any cause for distress arises, the interview will be terminated. De-briefing with informants will be offered, concerning potential distress experienced during and after the interview.</p> <p>Participants involved in geo-reference tracking will be shown examples of the data that geo-reference devices collect (maps) prior to the tracking. We will make sure that they understand that by the end of the study-day their daily</p> |

| | |
|--|--|
| | <p>movements will result in this kind of map. Geo-reference tracking will be followed up by the interview, where we will explore if results of the study have any discomforting effect. We will share individual map with participants and reassure them that all the results are entirely confidential.</p> |
| <p>B.2.2 <i>For investigators</i></p> | <p>My experiences during the similar, and much more sensitive studies (with HIV positive patients in rural Kenya, for instance) gave me necessary tools to approach sensitive issues with great caution and care, not only in relation to my participants, but also in the way I deal with my potential emotional distress.</p> <p>Enough communication and support will be provided to both field assistants (social scientist and interpreter) to be aware what to expect and have a good preparation for any emotional distress resulting from our work.</p> <p>Precautions against snake bites will be taken and all the investigators will be equipped with rubber boots.</p> <p>There is no known repellent that would effectively work against tsetse flies. Wearing blue and black coloured clothes (that attract tsetse flies) will be avoided during fieldwork. Exposed parts of the body will be covered with long sleeve-shirt. If exposed to tsetse fly bits, testing at Omugo treatment centre will be carried out.</p> <p>Information on security situation will be sought regularly from MSF (Médecins Sans Frontières) operating in the West Nile region. Security back-up plan will be discussed in event of any political tensions.</p> |
| <p>B.2.3 <i>For members of the public</i></p> | <p>N/A</p> |

| | |
|--------------|--|
| B.3 | CONSEQUENCES FOR LOCAL HEALTH SERVICES/LOCAL COMMUNITY |
| B.3.1 | <i>What demands will this research place on local health services?</i> |

| | |
|--|--|
| N/A | |
| Only volunteer community health workers will be involved in pre-study sensitisation and recruitment of participants. Community health workers are not part of the formal health service; however their assistance with the research may take them away from their usual working obligations. | |
| B.3.2 | <i>Detail how the design of the research project takes into account the demands described in B.3.1.</i> |
| When planning field activities communication with community health workers will be established and discussions concerning their duties will be carried out. Flexibility will be provided in meeting their needs. | |

| | |
|--------------|---|
| B.4 | CONFIDENTIALITY, PRIVACY, DATA AND SAMPLE STORAGE |
| B.4.1 | <i>What steps will be taken to ensure privacy and confidentiality for participants?</i> |
| | <ul style="list-style-type: none"> • All the members of the team involved in this research will be aware of the absolute necessity to respect confidentiality. • All the personal information collected during this study will remain anonymous and strictly confidential. • We will not record any names on participant's study forms or any report resulting from the study. At the beginning of the study we will give each participant an identification number and this number will be used on the forms. • A written consent will be obtained prior to disclosure any visual materials that could potentially identify the participant, such as pictures or video clips, to the public. |
| B.4.2 | <i>How will confidentiality and privacy be maintained for collected data?</i> |
| | <ul style="list-style-type: none"> • All the personal data will be password protected and only members of the study committee will have access to information linking the name of the participant with the study number. • All the hard copies of forms will be organized in a folder and only accessible by the principle investigator. • All the digital recordings will be computerized and password protected (only accessible to the study committee: principal investigator and social scientist during transcription process) • All the computerized files and paper copies will be kept locked for back-up on hard drive for whole duration of the project. |
| B.4.3 | <i>What biomedical samples will be collected? Where and for how long will they be stored? What arrangements will be made for their disposal?</i> |
| N/A | |

| | |
|--------------|--|
| B.5 | INFORMED CONSENT |
| B.5.1 | <i>Information given to participants:</i> |

Consent form and Participants information sheets enclosed

This notice will be translated to the local languages and back translated to English

| | |
|--|--|
| B.5.2 | <i>How will this information be delivered?</i> |
| <p>This information will be delivered by interpreter, social scientist or community health worker.</p> <p>All participants will be informed about the objectives of the study, methodology, risks involved and hers/his rights concerning participation or withdrawal from the study. This information will be given to the participants in oral and in written form as applicable and they will be given enough time to comprehend the information and ask questions to clarify any aspect.</p> <p>In order to ensure the meaning is not altered, all the forms and information sheets will be translated into local languages and back translated by a second person.</p> | |
| B.5.3 | <i>Please indicate how consent will be obtained, giving reference to local circumstances.</i> |
| <p>After the details of the study are explained, the person will be invited to participate. If they agree to participate, the individual consent form will be signed by the participant(s) and the member of research team. The investigator will retain one copy, and another copy will be given to the participant (s).</p> <p>Occasionally consent will be given by minors (16 years-18 years old). Since in local context this is an age when potential participants are treated as adults (married, live independently from their parents), additional guardian consent will not be sought. A special caution will be taken, however, to ensure that participants of this age group understand that they are treated as “adults”.</p> | |
| B.5.4 | <i>Outline any potential constraints to consent.</i> |
| <p>For participants who are illiterate, oral consent will be obtained.</p> | |
| B.5.5. | <i>Indicate how you will reduce the impact of these constraints to consent.</i> |
| <p>If participant is not able to provide a signature, a thumbprint will be taken instead in the presence of a literate witness, who will also sign the written form to confirm that this is the information, given to the participant.</p> | |
| B.5.6 | <i>Please outline any assistance (financial or otherwise) that will be offered to potential participants or individuals in return for their participation in this research.</i> |

Community health workers collaborate with the formal health system on a voluntary basis (without any financial support). Taking into consideration that they will dedicate their time (away from their normal duties), lunch allowances will be provided for them on a daily basis. 3000 UGS (approximately 2 \$) has been suggested to us to be an appropriate amount, since this is a standard amount used by NGOs who collaborate with community health workers in West Nile region.

Transport fee will be reimbursed to participants who will need to travel to reach meeting location (for FGD for instance).

Refreshments will be provided for community meetings and FGDs.

| | |
|--------------|--|
| B.6. | MAJOR ETHICAL ISSUES |
| B.6.1 | <i>Outline what you consider to be the major ethical issues involved in this research.</i> |
| | <p>We estimate that there are no major ethical issues involved with this study.</p> <p>Causing potential emotional distress to the interview participants who may have experienced trauma in relation to HAT illness or treatment is what we consider the most probable ethically controversial issue.</p> |
| B.6.2 | <i>Indicate how you plan to deal with these ethical issues.</i> |
| | <p>We will take enough time with each participant discussing traumatic events making sure that:</p> <ul style="list-style-type: none"> -they communicate to us if they experience emotional distress -that we stop the interview if there are signs of emotional distress -and that that they feel absolutely confident that they can return to us for any additional support any time after the interview |

| | |
|------------|---|
| B.7 | VULNERABILITY OF PARTICIPANT GROUPS |
| | <p>N/A</p> <p>FGDs will be configured separately for men and women in order to collect different gender based opinions and to avoid any potential power dynamics.</p> <p>Participatory action research will be carried out by women participants only, however in the local context this is a usual practice (existing organized women income generating groups, for instance). With this reason we do not expect any critical issues related to power dynamics concerning free given consents.</p> |

SECTION C

(Clinical Trials only)

| | |
|------------|---|
| C.1 | Who will monitor the safety of trial participants? |
| N/A | |

| | |
|------------|---|
| C.2 | HOW WILL THE COMMITTEE BE INFORMED OF SERIOUS UNEXPECTED ADVERSE EVENTS? |
| N/A | |

| | |
|------------|--|
| C.3 | HOW WILL THE TRIAL PROCEDURES BE MONITORED? |
| N/A | |

| | |
|------------|--|
| C.4 | WHAT STEPS HAVE INVESTIGATORS TAKEN TO MAKE THE BEST INTERVENTION OR TREATMENT AVAILABLE TO ALL TRIAL PARTICIPANTS AT THE END OF THE TRIAL? |
| N/A | |

SECTION D

RESPONSIBILITY

| | |
|---------------------------|---|
| D.1 | LITIGATION |
| D.1.1 | <i>In respect of any litigation which may result from this research, who is responsible for providing financial compensation to trial participants?</i> |
| LSTM Insurance | |
| D.1.2 | <i>In the context of any litigations which may result from this research, what insurance arrangements have been made by the applicant and his/her delegated assistants?</i> |
| Covered by LSTM insurance | |

| | |
|--|--|
| DECLARATION: TO BE SIGNED BY MAIN APPLICANT | |
| i) | I confirm that the details of this proposal are a true representation of the research to be undertaken. |
| ii) | I will ensure that the research does not deviate from the protocol described. |
| iii) | If significant protocol amendments are required as the research progresses, I will submit these to the Liverpool School of Tropical Medicine Research Ethics Committee for approval. |
| iv) | Where an appropriate mechanism exists, I undertake to seek additional <u>local</u> Ethical Approval in the country(ies) where the research is to be carried out. |
| v) | I agree to abide by the ethical principles underlying the Declaration of Helsinki and all relevant LSTM Standard Operating Procedures (SOP) relating to research conduct (available on LSTM intranet at http://pcwww.liv.ac.uk/lstmintranet/research_management/governance_polices_codes.htm or by contacting the Research Office). |
| vi) | I understand that all conditions apply to any co-applicants, researchers and other staff involved in the study, and that it is my responsibility to ensure that they abide by them. |
| I expect the project to commence on (Date): | 7 th July 2011 |
| and be completed by (Date): | 7 th July 2014 |

To be signed by applicant

| | | | |
|----------------|---------------------------------|-------------|------------|
| Signed: | Vanja Kovačič <i>v. Kovačič</i> | Date | 25/05/2011 |
|----------------|---------------------------------|-------------|------------|

THE REPUBLIC OF UGANDA

UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

APPLICATION FOR PERMISSION TO CONDUCT RESEARCH

(N.B. Read instructions and guide in Annexes I and II before completing this form)

FOR OFFICIAL USE

APPLICATION No.

FIELD OF RESEARCH

PROJECT No.

SECTION A:

PARTICULARS OF APPLICANT

1. Full NameVanja Kovačič
(Underline Surname)
2. Male Female (Please tick (3))
3. Date and Place of Birth .09 May, 1977; Ljubljana, Slovenia
4. Marital StatusSingle.....
5. NationalitySlovenian.....
6. (i) Permanent AddressMuljava 8A, 1295 Ivančna gorica, Slovenia
Telephone: +386 1 7876-311
E-mail: vanjakovacic@yahoo.com
(ii) Address of Institution of affiliation in Uganda

Prof. John C. K. Enyaru
 Makarere University, Department of Biochemistry,
 P.O. Box 7062 Kampala

Fax. Telephone: +256- 414- 530- 555

E-mail: jenyaru@gmail.com

7. Current Immigration Status:* tourist

(if already in Uganda)

*Refers only to foreign applicants.

8. Present Occupation Status:

(i) PhD Student / Contracted Research Assistant (temporary contract)

(ii) Institution: Liverpool School of Tropical Medicine

(iii) If on contract, date of expiration: May, 2014

9. Education

| (i) University | Qualification | Class | Year | Field of Specialization |
|--|---------------------|------------|------|-------------------------|
| Uni. Of Ljubljana, Slovenia | BA, Biology | completed | 2002 | Ecology, Conservation |
| London School of Hygiene and Tropical Medicine, U.K. | MSc, Vector Control | completed | 2004 | Vector Control |
| Oxford University, U.K. | MPhil | completed | 2009 | Medical Anthropology |
| Liverpool School of Tropical Medicine, U.K. | PhD | First year | 2011 | International Health |

(ii) Postgraduate research experience, with list of publications, if any (use additional paper if necessary).

enclosed CV with information required

(iii) Names, qualifications and status of personnel involved in the research:-

| Name | Qualifications | Status* |
|-----------------|--|-----------------|
| To be recruited | Educated to degree level in an appropriate subject | Translator |
| To be recruited | Educated to a degree level or studying for a Masters level in Social Science or a related discipline | Field assistant |

*STATUS with regard to the project

SECTION B: MAIN FEATURES OF RESEARCH PROJECT

10. Title of research project:

“The effect of community involvement on sustainability and cost-effectiveness of HAT (Human African Trypanosomiasis) control interventions”.

11. Main objective of research

AIM: To contribute towards development of more effective and sustainable tsetse control strategy in Uganda

OBJECTIVES:

- To evaluate actual and perceived risk of HAT burden in the community
- To examine effects of women’s involvement on cost reduction, sustainability and community acceptance of the new tsetse control strategy
- To explore barriers and facilitators for future community-based tsetse control interventions on a national and international levels

12. Brief outline of research methodology (more details on methodology in Proposal enclosed)

The nature of this research is qualitative.

The main procedures of data collection are:

- Focus group discussions (Participants: members of community)
- In-depth interviews/socio-economic questionnaires (Participants: members of community)
- Geographical information system survey (Participants: members of community)
- Patients’ interviews (Participants: sleeping sickness patients diagnosed less than 3 years from research and their family members)
- Participatory action research (active community involvement in tsetse control intervention and its evaluation (Participants: women from community)

- Key informant's interviews (Participants: local, national, international authorities involved in sleeping sickness control)

Data analysis and management:

All interviews and focus group discussions will be recorded using digital voice recorder (Olympus LS-11). Communication will be carried out in local languages and in case of interviews, simultaneously translated to English by trained interpreter. Recorded data will be transferred to the computer as digital files using Olympus software. The same software will be used during the transcription process. Transcripts will be translated (for FGD) and data will be managed using MAXQDA 10 Software; a coding frame will be established, transcripts will be coded, and coded data searched and managed in the software. Content analysis approach will be used for further analysis.

Geographic positioning files will be saved in gpx form and mapping will be performed using Google (Google Inc., Ca, USA).

Descriptive statistics (SPSS, PASW Statistics 18) using proximity of water bodies and location of nearest water pump as variants is going to be carried out determining if any of these factors have a significant impact on the daily activities carried out by the communities.

13. Research type (Please tick (3)):

Degree Award

Non-degree Award

(If Degree Award, state type of degree e.g BA, MSc or Ph.D etc, and the institution awarding it)

PhD at Liverpool School of Tropical Medicine (LSTM), U.K.

14. Districts of Uganda in which research will be carried out

Arua, Koboko, Maracha, Yumbe

15. (i) Estimated cost of research ...15,000\$

(ii) Source of funds

This project works in collaboration with a controlled trial on tsetse fly control, already funded by the Bill & Melinda Gates Foundation, led by LSTM.

(iii) Duration3 years.

16. BREAKDOWN OF EXPENDITURE:

(This table must be filled by all applicants)

| | | | | |
|--|--|--|--|-------|
| | | | | Total |
|--|--|--|--|-------|

| ITEM | Year 1 (US\$) | Year 2 (US \$) | Year 3 (US\$) | (US\$) |
|-----------------------|------------------|-------------------|------------------|--------|
| Personnel | 2500 | 2500 | 2500 | 7500 |
| Travel* | 1200 | 1200 | 1200 | 3600 |
| Materials & Supplies | 350 | 350 | 200 | 900 |
| Administration | 150 | 150 | 150 | 300 |
| Results dissemination | 250 | 250 | 350 | 850 |
| Other | 250 | 250 | 250 | 750 |
| Contingency | 300 | 300 | 300 | 900 |

*Both local and international.

SECTION C

17. Names and addresses of two referees:

- Dr. Helen Smith, Liverpool School of Tropical Medicine, Pembroke Place, Liverpool, L3 5QA, U.K.
- Prof. Mike Lehane, , Liverpool School of Tropical Medicine, Pembroke Place, Liverpool, L3 5QA, U.K.

18. (a) I undertake to submit:

- (i) Six monthly progress reports of my project
- X (ii) Final results on completion of the project
- X (iii) Copies of any published paper/article arising from the project

(b) I hereby certify that to the best of my knowledge and belief, the particulars given in this form are true and complete in all respects.

Date 01 June 2011..... **Signature of Applicant** *v. Kovačič*

SECTION D

TO BE FILLED IN BY HEAD OF DEPARTMENT, INSTITUTION AND/OR SUPERVISOR

19. Comments by Head of Institution/Department/Supervisor

I am a Lecturer in Social Science & International Health at LSTM and I am Vanja's primary supervisor. Vanja's project will explore approaches to community involvement in tsetse control in Uganda, set within the context of a large and well funded trial of new vector control tools for HAT. Her project will use a highly innovative approach to engaging communities in deploying and maintaining targets in the field and she will evaluate the sustainability of this approach as well as cost-effectiveness. Vanja has carefully developed the research proposal and methods and given her previous experience in tsetse control in Uganda, I am confident she will carry out this work to a very high standard. I expect the results will be of significant benefit to policy and programme level staff involved in HAT control in Uganda; dialogue with policy makers is a key component of this project.

NameDr Helen Smith.....

Signature 

Date23rd May 2011.....

20. Ethical clearance (especially for health research involving human subjects).

Submitted to Liverpool School of Tropical Medicine, Ethics committee

Letter enclosed

RS. 6

PRESIDENT'S OFFICE

RESEARCH SECRETARIAT

P.O BOX 7168

KAMPALA, UGANDA

APPLICATION FORM FOR RESEARCHERS WISHING TO CARRY OUT RESEARCH IN UGANDA AND TO USE GOVERNMENT ARCHIVES

(Please complete three (3) copies of this form and attach four (4) recent passport-sizes photographs)

SECTION A

1. Surname: Kovacic

2. Other Names: Vanja

3. Date and Place of birth: 09 May 1977

4. Nationality: Slovenian

5. Country of residence: Slovenia

6. Passport Number, Date and Place of Issue: Number: POO307099; Date of issue: 03/04/2002; Grosuplje, Slovenia

7. Permanent address (including P.O. Box Number, Telephone, Street/Plot Number,

City/Town

Muljava 8A, 1295 Ivancna gorica, Slovenia; Tel.: +386 1 7876 311

8. Address of Institution of affiliation in Uganda (including P.O. Box Number, Telephone, Street/Plot , Number, City/Town

Prof. John C. K. Enyaru,

Department of Biochemistry

P.o. Box 7062 Kampala

Tel.: +256- 414- 530- 555

9. Have you been sentenced or bound over by a civil court, or has a charge against you been dismissed by a civil court? If so, give dates and circumstances.

NO

10. Marital status:

- (a) Married or X single (Tick as appropriate)
- (b) If married, give names of spouse at birth.....N/A
- (c) Number and ages of children.....0 (N/A)

11. Details of father:

- (a) Name and nationality at birth: Stanislav Kovacic; nationality: Slovenian
- (b) Present nationality: Slovenian

12. Details of mother:

- (a) Name and nationality at birth: Jozica Zupancic; nationality: Slovenian
- (b) Present nationality: Slovenian

SECTION B

13. Details of Educational standard:

- (a) Names of schools and collages attended with dates and qualifications obtained
 - Primary School Sticna, 1986-1996, Certificate
 - Gimnasium, Ivancna gorica, 1992-1996, Certificate
- (b) Names of universities attended with dates and qualifications obtained
 - University of Ljubljana, Biotechnical Faculty, 1992-2002, BA Biology
- (c) Postgraduate courses taken
 - London School of Hygiene and Tropical Medicine, 2003-2004, MSc Vector Control
 - Oxford University, 2007-2009, MPhil Medical Anthropology
 - Liverpool School of Tropical Medicine, currently (enrolled in 2011), candidate for PhD in International Health
- (d) What language(s) do you speak?

Slovenia, Croatian, English, Spanish, Portuguese (fluent)

German, French (basic)

SECTION C

14. Employment since leaving school or college, with dates

- **Field Coordinator/Research Assistant**, *University of Warwick, U.K. and Instituto Evandro Chagas, Brazil*, November 2004 – June 2006; Based in Brazil
Project: *“Community Based Intervention Trial for Visceral Leishmaniasis Control in Brazil”*

- **Consultant for HIV/AIDS program**, *MSF (Medecins Sans Frontieres)*, France; March-December 2010; Based in Homa bay, Kenya
Project: *HIV/AIDS and TB control program*
- **Consultant, tsetse control program**, *Liverpool School of Tropical Medicine*; February-March 2011; Based in West Nile, Uganda.
Project: Preliminary research field visit

15. Countries you have visited

Africa: Uganda, Kenya, Tanzania, Ethiopia, Morocco

Asia: India

Latin America: Mexico, Guatemala, Colombia, Brazil, Argentina

North America: USA

Europe: Most countries in Europe

16. Title of research project

“Effect of community involvement on sustainability and cost-effectiveness of HAT (Human African Trypanosomiasis) control interventions”

17. Brief description of how research will be conducted including methodology of project

The nature of this research is qualitative (more details on methodology in Proposal enclosed).

The main procedures of data collection are:

- Focus group discussions (Participants: members of community)
- In-depth interviews/socio-economic questionnaires (Participants: members of community)
- Geographical information system survey (Participants: members of community)
- Patients’ interviews (Participants: sleeping sickness patients diagnosed less than 3 years from research and their family members)
- Participatory action research (active community involvement in tsetse control intervention and its evaluation (Participants: women from community)
- Key informant’s interviews (Participants: local, national, international authorities involved in sleeping sickness control)

Data analysis and management:

All interviews and focus group discussions will be recorded using digital voice recorder (Olympus LS-11). Communication will be carried out in local languages and in case of interviews, simultaneously translated to English by trained interpreter. Recorded data will be transferred to the computer as digital files using Olympus software. The same software will be used during the transcription process. Transcripts will be translated (for FGD) and data will be managed using MAXQDA 10 Software; a coding frame will be established, transcripts will be coded, and coded data searched and managed in the software. Content analysis approach will be used for further analysis.

Geographic positioning files will be saved in gpx form and mapping will be performed using Google (Google Inc., Ca, USA).

Descriptive statistics (SPSS, PASW Statistics 18) using proximity of water bodies and location of nearest water pump as variants will be carried out determining if any of these factors have a significant impact on the daily activities carried out by the communities.

18. Areas of Uganda in which research will be carried out:

| District | County/ Municipality | Sub County/ Town Council | Parish | Duration |
|----------|-------------------------|-----------------------------|---------|--------------------------------|
| Arua | various | various | various | Occasionally in for 3 years |
| Maracha | various | various | various | Occasionally in for 3 years |
| Yumbe | various | various | various | Occasionally in for 3 years |
| Koboko | various | various | various | Occasionally in for 3 years |

19. Name and address of organization recommending/sponsoring the candidate (P.O. Box
Number, Telephone Numbers, street/Plot number, city/town

Liverpool School of Tropical Medicine

Pembroke Place

Liverpool

L3 5QA, U.K.

Tel: +44 (0)151-705-31-00

Fax: +44 (0) 151-705-33-70

20. Project duration

3 years

Signature of Researcher *V. Kovačič*

Date 01 June 2011

Vanja Kovacic
Liverpool School of Tropical Medicine
Pembroke Place
Liverpool
L3 5QA

Friday, 03 June 2011

Dear Vanja Kovacic

Re: Research Protocol (11.73) Effect of Community involvement on Sustainability and Cost-effectiveness of HAT (Human African Trypanosomiasis) Control Interventions

Thank you for your letter dated 03 June 2011 responding to the points raised by the Research Ethics Committee. The protocol now has formal ethical approval from the Chair of LSTM Research Ethics Committee.

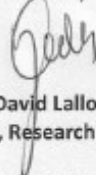
The approval is for a fixed period of three years, renewable annually thereafter. The committee may suspend or withdraw ethical approval at any time if appropriate.

Approval is conditional upon:

- Submission of ethical approval from other ethics committees.
- Notification of all amendments to the protocol for approval before implementation.
- Notification of when the project actually starts.
- Provision of an annual update to the Committee. Failure to do so could result in suspension of the study without further notice.
- Reporting of all severe unexpected Adverse Events to the Committee
- Reporting of new information relevant to patient safety to the Committee
- Provision of Data Monitoring Committee reports (if applicable) to the Committee

Failure to comply with these requirements will result in withdrawal of approval. The Committee would also like to receive copies of the final report once the study is completed.

Yours sincerely



Prof David Laloo
Chair, Research Ethics Committee

cc: Helen Smith and Mike Lehane

Vanja Kovacic
Liverpool School of Tropical Medicine
Pembroke Place
Liverpool
L3 5QA

Friday, 21 June 2013

Dear Vanja,

Re. Research Protocol (17.73) Effect of community involvement on sustainability and cost-effectiveness of HAT (Human African Trypanosomiasis) control interventions

Thank you for your email of 27th May and 14th June 2013 providing the committee with the latest updates for phase 2 of the above study.

The updates and additional documentation relating to confidentiality for the journalist associated with this project has been reviewed by the Chair and noted and accepted on behalf of the committee.

Yours sincerely,



Dr Anglea Obasi
Chair, Research Ethics Committee



Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS 2561

July 15, 2011

Ms. Vanja Kovacic
c/o Prof. John C. Enyaru
Makerere University
Department of Biochemistry
P.O Box 7062
KAMPALA

Dear Ms. Kovacic,

RE: PROVISIONAL APPROVAL FOR RESEARCH PROJECT, "THE EFFECT OF COMMUNITY INVOLVEMENT ON SUSTAINABILITY AND COST-EFFECTIVENESS OF HAT (HUMAN AFRICAN TRYPANOSOMIASIS) CONTROL INTERVENTIONS"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **June 16, 2011** and granted provisional approval to enable you start preliminary research activities. Please note that final approval letter for the research project will be granted after clearance from the Research Secretariat, Office of the President. The process of securing approval from Office of the President is in progress and you will be notified as soon as clearance has been secured.

Yours sincerely,

Jimic Nabhuto

for: Executive Secretary

UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION/CORRESPONDENCE

Plot 6 Kimera Road, Ninda
P. O. Box 6884
KAMPALA, UGANDA

COMMUNICATION

TEL: (256) 414 705500
FAX: (256) 414-234579
EMAIL: info@uncst.go.ug
WEBSITE: <http://www.uncst.go.ug>

The notification of clearance from the Research Secretariat, Office of the President was received on the 16th August, 2011 (archived in UNCST office, Plot 6, Kimera Road, P.O. Box 6884, Kampala).

APPENDIX B

Justification of methodology

The research was guided by different methodological approaches, including: i) grounded theory approaches, ii) ethnographic approaches, and iii) phenomenological approaches [208].

Grounded theory

The grounded theory was established by Glaser and Strauss [252]. The formation of this theory is exactly the opposite of the hypothesis testing process. In grounded theory, data are collected and used to conceptualise and develop a theory which can be tested in another setting. This is essentially different from a pre-established theoretical framework within which the hypothesis is tested using quantitative methodological approaches. This is well-illustrated by Patton et al: "Grounded theory focuses on the processes of generating theory rather than a particular theoretical content" ([208]:125).

In this research, I used a grounded theory approach in the data collection and data analysis processes in all three research phases. Each of the study phases had a broad general research question, which was refined and re-conceptualized as required, during the data collection process. The grounded theory approach was also used throughout my data analysis process through the use of coding, thematic classification and conceptualization of data.

The principle of "saturation point" [252] embedded in grounded theory guided my sample sizes in baseline phase. Saturation point is reached when newly collected and analysed data does not add any new conceptual value towards an understanding already obtained, and therefore does not contribute towards theory development (ibid.). Therefore, when the information collected became repetitive, the data collection process was concluded.

Ethnography

Ethnography is a classical method within the anthropological tradition. It is based on the technique of participant observation, conducted by the researcher who is immersed in the new culture under study during a long period of fieldwork. Early ethnographers studying the cultures of remote isolated

communities to which they often referred as “uncivilized” and “primitive” were criticized for imposing western colonialism to their research enquiry [208]. Participant observation, however, became one of the core methods in anthropological research and was later refined to develop more techniques for field assessments, such as Participatory Rural Appraisal and Rapid Rural Appraisal (RRA) (PRA) [195]. In this research, nearly four years of fieldwork provided enough opportunities for participant observation through different levels of engagement with participants. Simultaneous observation and participation, typical of participant observation techniques, was particularly characterized the entire action research process in intervention and evaluation phase.

Phenomenology

Phenomenology is applied to several theoretical frameworks which share a common focus on phenomena and how it relates to human experience, individually or collectively. Van Manen describes this process as: “Phenomenology asks for the very nature of a phenomenon, for that which makes a some-‘thing’ what it is-and without which it could not be what it is” ([253]:10). The importance of the “lived experience” is a major focus in this theoretical approach and generation of research data is centred around people who have directly lived through the phenomena and their retrospective reflection [208].

The methodological application of this approach in my research is relevant to all three phases. The lived experiences of my participants were reflected in the way they related to and reported about phenomena under research. Furthermore, I was influenced by the notion that “The only way for us to really know what another person experiences is to experience the phenomenon as directly as possible by ourselves” ([208]:106). This led to the choice of various participatory methods developed in close collaboration with participants. Throughout the action research process, for instance, participants and the researcher gained a “lived experience” of learning, implementing and reflecting which comprised an essential part of my data collection processes.

Justification of methods

Table A1 lists the methods used, the research phases in which they were applied and provides justification for the choice of method.

Table B1: Justification of the methods

| DATA COLLECTION METHOD USED | RESEARCH PHASE | JUSTIFICATION OF THE METHOD |
|--|-----------------------|--|
| In-depth interviews | 1, 3 | Combination of structure and flexibility; face-to-face interaction offered a relaxing, intimate and informal context to allow a constructive working relation to develop between respondent and researcher [197]. |
| Seasonal calendars | 1 | Participatory methods in which participants discuss and draw different seasons of the year and link them to crops, labour, sickness, amongst other things [195]. This method allows for the measurement of time relevant to indigenous communities which often differs from Western understanding and the Gregorian calendar [254]. |
| Participatory mapping | 1 | This method encourages participants to map their geographical (natural resources, water bodies, transport connections,) or social (demographic, health) environment using paper or suitable surface [195]. Through this method participants demonstrate their own understanding of the geographical and social landscape and capture dynamic use of natural resources. |
| GPS tracking of human movements | 1 | Cheap, commercially available, easy-to-wear GPS loggers (I-GotU GT-120, Mobile Action U.K.) have become a feasible tool for tracking human movements and are already used for risk assessments of different diseases [255, 256]. Previous studies [257] have also found that GPS loggers are well accepted by participants. |
| Socio-economic questionnaire | 1 | This method offers little room for variation since questions are generally pre-established and the participant is presented with pre-defined options for answers. Compared to in-depth interviews the engagement between respondent and researcher is less intense hence the interviewer has relatively minor impact on the quality of responses. Similarly emotional dimensions are not explored as focus is placed on explicit responses [258]. |
| Focus Groups Discussions (FGDs) | 1,2 | In the process of FGDs the data is generated by participants' spontaneous interactions with each other; one opinion triggers the next, and individual contributions eventually refine and deepen in the progress of discussion. The researcher's role is more diffused compared to the interviews and participants themselves take over some of the interviewing roles. FGDs provide an opportunity to explore a difference in views, but compared to interviews they are more prone to generate opinions generally accepted as norms in a given social context [197]. FGDs also gives a safe environment to share ideas and opinions among participants of the same social, economic, cultural and gender background [258]. |
| Participatory Action Research (PAR) | 2 | PAR is a dynamic process and captures empowerment, ownership and participation [198]. It is not a pre-designed process, the main principle is the flexible, adjustable nature of this method [198]. Repetitive cycles of action and reflection are key aspects of PAR which occur as a collective and collaborative process between researchers and participants [202]. |

| DATA COLLECTION METHOD USED | RESEARCH PHASE | JUSTIFICATION OF THE METHOD |
|------------------------------|----------------|---|
| Participatory scoring | 2 | Participatory scoring is a method used for classification and ranking of different objects or phenomena [195]. The technique consists of different number of scores with participants voting for each pre-defined category being evaluated. I used this in the context of action research to measure how participants' self-perception of managing tsetse control operation has changed over time. Pre-defined categories in this case were definitions of empowerment, motivation and ownership based on which participants evaluated their self-assessment. This method is suggested to prompt self-reflection [259]. |
| Cost-effectiveness | 2 | Most recent economic analyses related to tsetse control have focused on either the economic benefits of tsetse and trypanosomiasis control and/or eradication [144, 260] or have compared the costs- of different methods of tsetse control [261, 262]. In my research the cost of tiny targets based intervention delivered by the local communities was used. |
| Role play | 3 | Using role-play allows participants to explore complex issues in the environment where mistakes are tolerated and not attributed to the individual. Assuming a new social role and playing it out changes individual behaviour and provides an opportunity to observe how roles are interpreted by actors [263]. Acting is the central concept of this method and through participants' performance social concepts and interactions are explored [208]. Theatre techniques have been developed as empowerment tool [264-266]. |

APPENDIX C

Table C1: Participant's' social and demographic profiles (breakdown by percentage)

| GENDER | NUMBER OF PARTICIPANTS | PROPORTION OF PARTICIPANTS | AVERAGE AGE |
|------------------------------|------------------------|----------------------------|-------------|
| F | 28 | 48% | 33 |
| M | 30 | 52% | 39 |
| GRAND TOTAL | 58 | 100% | 36 |
| RELIGIOUS ORIENTATION | | | |
| ROMAN CATHOLIC | | 71% | |
| PROTESTANT | | 26% | |
| MUSLIM | | 3% | |
| MARITAL STATUS | | | |
| SINGLE | | 7% | |
| MARRIED-MONOGAMOUS | | 47% | |
| MARRIED-POLYGAMOUS | | 34% | |
| SEPARATED | | 2% | |
| DIVORCED | | 3% | |
| WIDOWED | | 7% | |
| COMPLETED EDUCATION | | | |
| NONE | | 10% | |
| PRIMARY 1-4 | | 36% | |
| PRIMARY 5-8 | | 34% | |
| SECONDARY 1-2 | | 9% | |
| SECONDARY 3-4 | | 0% | |
| COLLEGE | | 2% | |
| OCCUPATION | | | |
| FARMER | | 93% | |
| CASUAL LABOURER | | 2% | |
| MARKET VENDOR | | 3% | |
| STUDENT | | 2% | |

Table C2: Socio-economic information on participants' households

| AVERAGE FAMILY STRUCTURE PER HOUSEHOLD | NUMBER |
|---|---------------------------------|
| ADULTS (ABOVE 16 YEARS) | 4 |
| CHILDREN (5-16 YEARS) | 3 |
| BABIES (0-5 YEARS) | 2 |
| TOTAL AVERAGE PER HOUSEHOLD | 9 |
| AVERAGE DOMESTIC ANIMALS PER HOUSEHOLD | NUMBER |
| COWS | 1 |
| GOATS | 4 |
| SHEEP | 1 |
| NUMBER OF OWNED VEHICLES | PROPORTION OF HOUSEHOLDS |
| BICYCLES | |
| 0 | 40% |
| 1 | 48% |
| 2 | 7% |
| 3 | 5% |
| MOTORBIKES | |
| 0 | 95% |
| 1 | 5% |
| CARS | |
| 0 | 97% |
| 1 | 3% |
| ROOFING MATERIAL | PROPORTION OF HOUSEHOLDS |
| GRASS | 93% |
| IRON SHEETS | 7% |
| AVERAGE MONTHLY CASH INCOME | PER HOUSEHOLD |
| | 38.000 UGS (~ 14 \$) |

APPENDIX D

Appendix D1: DVD *'Controlling sleeping sickness together'*

Also available at:

<https://www.youtube.com/watch?v=-PYz1MA5MhY>

Appendix D2: Comparison of delivery methods

Some categories of the women-led intervention were not directly comparable to the cost of delivering tsetse control using tiny targets by local government [49]. In the community-based calculation tsetse monitoring was excluded³⁷ and some differences occurred in costing of different transport options therefore adjustments were made (see explanation below) to make all categories comparable. Both interventions included the following operational phases: community sensitization, one round of deployment and one round of target maintenance. The results are summarised in Table C2.

The cost per km² for the government scheme was USD 85.4. However, this included USD 5.1 of preliminary tsetse surveys and USD 9.0 for tsetse monitoring. For comparison with the community scheme therefore we excluded these components in Table C2, arriving at a cost of USD 71.2 per year, as compared to 75.6 for the women-led scheme.

Two other categories need to be adjusted to make these two figures further comparable. First, the transport costs given in Table C2 require several adjustments. The transport costs appear very similar at USD 22.9 for the community scheme and USD 22.4 per km² for the government scheme. However, different means of transport were used for calculation of transport cost in the two schemes. For the community scheme, the transport cost was based on a motorbike (Table 5.4) whereas for the government scheme, a mix of motorbikes, bicycles, pick-up truck and hired transport were used, with the truck accounting for about 20% of the mileage [49]. For the community scheme, if all the travel were done using the Toyota pick-up, the cost of transport would increase from USD 22.9 per km² to USD 75.2. If 20% were done using the pick-up and 80% using motorbikes, the cost for transport for the community would increase by USD 10.5 to be USD 33.4 per km².

Another difference was that the community scheme was located further away from Arua, with daily travel averaging at 336 km, as against 102 for similar work undertaken and costed under the government scheme [49]. Adjusting the community-based transport cost to allow for 70% reduction in mileage³⁸ which would reduce the transport cost of USD 33.4 estimated above to USD 10.1 per km². This is a likely travel scenario if the district entomologist were managing intervention within the area of the district

³⁷ In action research, on which community-based operation was based, traps were not used systematically for tsetse surveys and monitoring by women. This element was therefore excluded from costing analysis.

³⁸ If the community scheme were supported by the district entomologist it would be more realistic for the distance travelled to the field location to be about 100 km.

boundaries. Thus, adjusting for these two differences would mean that the cost of the community scheme would fall by USD 12.8 from USD 22.9 to USD 10.1 per km².

Second, in the community scheme of 13.9 km², the target density of 14.4 targets per km² exceeded that of the government scheme of 6.2 targets per km² over an area of 250 km². Both areas were measured as polygons [47], so as to include the riverine areas and the area around them. To make the target density comparable, only 174 targets per year (one round of deployment and redeployment) would be needed in the community-based programme to achieve the same target density and this would reduce the overall cost of equipment for from USD 35.7 per km² to 16.3, a reduction of USD 19.4 per km².

Conversely, if tsetse monitoring were added to a community scheme the following assumptions are considered. The tsetse monitoring during deployment in the local government scheme was undertaken at an intensive level required to accomplish research objectives. On the assumption that a tsetse control operation without a research focus would require a reduced frequency of trap deployment and fewer traps this figure could be reduced by 50 – 60% without compromising the objective of monitoring the intervention's effectiveness (personal communication, Tirados I., October 2014). On this basis, for a three year community-based operation, the additional cost for tsetse surveys and monitoring implemented by professional entomologists from local government services could be estimated at USD 1.5 – 2 per year for the initial survey (USD 5.1 spread over three years) and a further USD 4 – 5 per year for monitoring during target deployment. This would add between USD 5.5 and 7.0 to the cost per km². The cost of monitoring by local government would apply in the same way to both women-led and local government managed schemes, so the price differential per km² would be maintained.

Combining the per km² cost reductions of USD 12.8 for transport and USD 19.4 for target density would imply that the cost of the community scheme could be as low as USD 43.4 per km² as compared to USD 71.2 for the local government scheme, if monitoring and surveys are excluded from both. This implies that the cost differential could be as much as USD 28 per km².

Table D2: Cost comparison of delivery modes for tsetse control using tiny targets (excluding costs of tsetse survey and monitoring)

| | Action research | | Community-based control | | Local government control | |
|---------------------------|-----------------------|--------------|-------------------------|--------------|--------------------------|--------------|
| | USD / km ² | % | USD / km ² | % | USD / km ² | % |
| External resources | | | | | | |
| Transport* | 547.7 | 77.7 | 22.9 | 30.4 | 22.4 | 31.6 |
| Staff | 121.3 | 17.2 | 9.2 | 12.2 | 24.0 | 33.6 |
| Equipment* | 17.7 | 2.5 | 35.7 | 47.2 | 24.8 | 34.8 |
| Refreshments | 4.8 | 0.7 | 1.9 | 2.5 | 0.0 | 0.0 |
| Sub-total | 691.5 | 98.1 | 69.7 | 92.2 | 71.2 | 100.0 |
| Internal resources | | | | | | |
| Staff | 12.0 | 1.7 | 5.4 | 7.2 | | |
| Equipment | 0.6 | 0.1 | 0.1 | 0.1 | | |
| Gifts & refreshments | 0.8 | 0.1 | 0.4 | 0.5 | | |
| Sub-total | 13.4 | 1.9 | 5.9 | 7.8 | 0.0 | 0.0 |
| Total | 704.9 | 100.0 | 75.6 | 100.0 | 71.2 | 100.0 |

Source: The costs for action research are based on Tables 5.1 and 5.2 above, for the community scheme on Tables 5.3 and 5.4 and for local government on the data presented in Shaw et al. [49], adjusted so as to exclude the preliminary survey and monitoring costs.

Note: * These transport costs and equipment costs are not strictly comparable, as for the community scheme, the transport cost was based on a motorbike only and for the local government scheme various forms of transport are used and the daily mileage was 30% of that required for the community scheme and a 2.3 times higher trap density was used in the community-based scheme – see discussion in main text.

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