

## Border parasites: schistosomiasis control among Uganda's fisherfolk

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It is recognized that the control of schistosomiasis in Uganda requires a focus on fisherfolk. Large numbers suffer from this water-borne parasitic disease; notably along the shores of lakes Albert and Victoria and along the River Nile. Since 2004, a policy has been adopted of providing drugs, free of charge, to all those at risk. The strategy has been reported to be successful, but closer investigation reveals serious problems. This paper draws upon long-term research undertaken at three locations in northwestern and southeastern Uganda. It highlights consequences of not engaging with the day to day realities of fisherfolk livelihoods; attributable, in part, to the fact that so many fisherfolk live and work in places located at the country's international borders, and to a related tendency to treat them as "feckless" and "ungovernable". Endeavours to roll out treatment end up being haphazard, erratic and location-specific. In some places, concerted efforts have been made to treat fisherfolk; but there is no effective monitoring, and it is difficult to gauge what proportion have actually swallowed the tablets. In other places, fisherfolk are, in practice, largely ignored, or are actively harassed in ways that make treatment almost impossible. At all sites, the current reliance upon resident "community" drug distributors or staff based at static clinics and schools was found to be flawed.

**Keywords:** Uganda; fisherfolk; fishermen; neglected tropical diseases; schistosomiasis; disease control

### Introduction

Hundreds of thousands of poor people in sub-Saharan Africa eke out a living by undertaking small-scale fishing and fishing-related activities. Many live for much (or all) of their time in isolated and largely overlooked places, located in borderlands for the obvious reason that lakes and rivers frequently divide neighbouring countries. This is strikingly the case in Uganda, where the huge expanses of Lake Albert and Lake Victoria are located on borders with the Democratic Republic of Congo (DRC), Tanzania and Kenya, and where the White Nile spreads wide along the border with southern Sudan.<sup>1</sup> Mobility is a feature of life among those who fish. It often involves movement across borders, and, for fishermen, considerable periods staying at remote camps or even out on the water. They often arrive at mainland locations with quantities of fish to sell, only to disappear again. Friends and relatives

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frequently visit them at their camps, sometimes with a view to buying slightly larger quantities of fish, which they then sell at markets on the mainland. The fish are often processed, by smoking or sun-drying, and, in some cases, they are taken further afield by local traders for sale in the bigger towns. Profits from these kinds of activities are not large, but, in local terms, they are perceived to be considerable, simply because most of the more permanently resident populations have no reliable source of income at all.

Fishermen and their associates are less constrained than farmers. They are alleged to take what they want, consume resources, but manage to avoid taxes, the vicissitudes of state control, the oppression of armed groups and the scrutiny of police. Drunken fishermen are a common sight on market days, feeding a perception, particularly among those knowing little of their way of life, that fishermen have more money than sense, and that they are too independent for their own good, irresponsible and immoral. They can, therefore, be a focus of considerable denigration, stemming from a mixture of envy and resentment. Those associated with them, including the women engaged in local fish-processing and drying, as well as those directly involved in marketing can also be tainted. Accusations of prostitution and criminality abound, as well as rumours about the spreading of sexually transmitted infections.

In the last few years, a group of analysts have highlighted a paucity of research focused on these fishing populations. They have used the heterogeneous term “fisherfolk” to draw attention to a range of people whose livelihoods depend, to varying degrees, on the “capture, processing or trade of fish”.<sup>2</sup> As Westaway, Seeley and Allison point out, fisherfolk in Uganda are characterized as “feckless risk takers with a reckless attitude”.<sup>3</sup> They are perceived by outsiders to lack networks of trust and to wreak social havoc,<sup>4</sup> with district officials often referring to them as “ungovernable”.

Stereotypes aside, it is increasingly recognized that their economic, political, geographic and social exclusion ensures that they are the least likely to access biomedical care.<sup>5</sup> In particular, it has been argued that they rarely benefit from interventions seeking to control the transmission of HIV/AIDS. This makes them both acutely vulnerable to, and a potential source of, infection.<sup>6</sup> The oversight is especially surprising when it is recalled that the first recorded African cases of HIV/AIDS infection were noted among a group of Ugandan fishermen from Kasensero on the shores of Lake Victoria in 1982/3.<sup>7</sup> Nevertheless, fisherfolk have certainly been neglected, as much by researchers as by policy makers. With the few notable exceptions cited above, and a few more cited below, literature dealing with Ugandan fisherfolk is noticeable by its absence, perhaps indicating that negative views about them extend to those choosing sites for fieldwork, including anthropologists.

This paper presents findings drawn from research carried out in different border regions of Uganda since 2005.<sup>8</sup> It differs from previous publications about health issues among Ugandan fisherfolk in that it is neither focused on HIV/AIDS, nor restricted to the study of fisherfolk on Lake Victoria. It draws comparisons between fisherfolk of southern Uganda and those of the north, and focuses on the water-borne, parasitic disease, schistosomiasis (which is more popularly known as bilharzia). The fishermen, local fish processors and traders of Uganda’s borders, people who are themselves castigated as “parasitic”, are some of the most likely people to be infected with these parasites. At one level, this obvious point is widely recognized. Fishermen and their families are commonly mentioned as a specific

target group in policy documents outlining strategies to control schistosomiasis. Yet there is an on-going tendency to ignore the realities of fisherfolk livelihoods. As noted elsewhere, it is neglected people who are infected with neglected tropical diseases (NTDs) such as schistosomiasis, and this political fact cannot be wished away.<sup>9</sup> Structures of marginalization and sometimes outright hostility, let alone a basic lack of information, limit the efficacy of well meant assistance efforts, even when it is putatively aimed in their direction.

Since the early 2000s, programmes involving the mass distribution of drugs have been established in Uganda with the intention of controlling, and in some cases eradicating, a range of NTDs – notably schistosomiasis, soil-transmitted helminths, onchocerciasis and lymphatic filariasis. These top-down, biomedical programmes have been funded by a range of international donors, including the Bill and Melinda Gates Foundation, the Carter Center, USAID and the UK Department for International Development. They have all involved the distribution of drugs, free of charge, to adults and children living in areas where the diseases are endemic. Initially, they were run side by side; but it was not long before it was argued that in areas of co-endemicity it would be more economical to treat several diseases simultaneously. A National Control Programme for the Integrated Control of NTDs was thus established in 2007, linking together the established programmes for dealing with specific diseases.

Schistosomiasis has been a primary target throughout this time. The drug of choice, praziquantel, has been distributed with a view to treating at least 75% of schoolchildren and adults living in those parts of Uganda where schistosomiasis is endemic. Working closely with the Schistosomiasis Control Initiative (which is based at Imperial College, London and undertakes similar work in other parts of sub-Saharan Africa), the programme has relied upon a combination of locally resident volunteers to treat their neighbours and primary school teachers to treat their pupils. The drugs are passed to these “community” drug distributors and teachers by staff working at a district level within the Ugandan Ministry of Health. Ethical concerns, it is argued, do not arise as the tablets are deemed to be safe, and it is much more cost-effective to treat everyone than to treat positive cases of infection after individual testing. Although re-infection is likely in the absence of attempts to kill the snail vector; it is thought that the numbers of people infected can be reduced by distributing drugs to everyone on an annual or bi-annual basis. In addition, repeated treatment is expected to have the beneficial effect of containing the worst aspects of infection by reducing the worm burden in infected individuals and, therefore, reducing the likelihood of developing serious symptoms.

Positive results have been reported,<sup>10</sup> but our detailed analysis from multiple field sites has demonstrated that the programme has not, and cannot, be rolled out in a uniform way across the country. We have also found that in several places the mass distribution of tablets has run into unforeseen difficulties, and that treatment coverage has been exaggerated.<sup>11</sup> A concern raised about our findings by, among others, a senior official in the Ugandan Ministry of Health in a personal communication, is that they are biased because our investigations have been too orientated towards populations living near international borders. It is an odd criticism, given that the vast majority of those infected with schistosomiasis in Uganda are known to live along the shores of the country’s great lakes. It reflects a view expressed by many officials that border people are mostly migrants and that many are not proper citizens at all. It also helps explain why published data on the

control of schistosomiasis in Uganda, even those appearing in reputable medical journals, can be so profoundly flawed.

### **Schistosomiasis among Ugandan fishing populations**

Poor people working in fishing, fish processing and fish trading in Uganda are vulnerable to becoming infected with either *Schistosoma haematobium* or *Schistosoma mansoni*. These two species have similar life-cycles involving an aquatic snail intermediate host, the human definitive host and their mutual presence in a common environment where transmission occurs, typically the slow moving water of lakes and rivers where fisherfolk live and work. The signs and symptoms of *S.haematobium* and *S.mansoni* vary. The former has a visible symptom of reddish urine (haematuria), especially among school children. This symptom is uncommon in adults, but the parasite may cause serious internal damage to the kidneys as well as fibrosis of the bladder and ureter, with bladder cancer occurring in more advanced cases. By contrast, infection with *S.mansoni* does not necessarily generate visible signs and symptoms, even in children. Most of those infected are unaware of their condition. Nevertheless, over time, the disease can lead to gross swelling of the spleen and liver, blood in the stool, diarrhoea and, in advanced cases, the vomiting of blood. Both forms of schistosomiasis are also linked to a loss of energy and to general malaise which may often be explained by those infected with reference to other factors, sometimes with specific localized associations (such as ideas about witchcraft or other afflictions with non-biomedical aetiologies). A challenge for treatment control programmes is that tablets need to be taken before serious symptoms develop. It is a particular problem in the case of *S.mansoni* as it is possible to be infected for a considerable period of time before visible signs of infection develop.

This paper is concerned with *S.mansoni* among fisherfolk living in northwestern and southeastern Uganda. It is known to be endemic at all the study sites chosen, although epidemiological data monitoring changing patterns of infection before and after the mass distribution of drugs is very limited. A detailed critique of this literature, as well as the literature assessing social responses to treatment, has been presented elsewhere.<sup>12</sup> Here, a few examples will suffice to highlight the paucity of information. They also reflect the way epidemiological assessments have focused on children rather than adults, with reliance upon monitoring cohorts of children and rapid mapping methods. Both approaches have serious limitations.

The cohort approach involved testing and re-testing the same group of children at selected schools over a four-year period. Children were tested six months after each annual round of treatment and, if they were found to be positive, they were re-treated. The results showed declining rates of infection and intensity of infection (i.e. worm burden) among those studied.<sup>13</sup> It cannot be assumed, however, that these children are representative of all children at the schools they were attending – not least because they were being given the opportunity to be treated twice a year instead of once a year. A further limitation with relying upon cohort studies is that they are biased towards individuals of long-term and stable residency. They are, therefore, an inadequate method for assessing infection among the families of fishermen and other mobile populations. This fact is evidenced by the high drop-out rates from the cohorts, which eventually resulted in the research project being abandoned. Nevertheless, much has been made of the data generated in the initial years of the study, 2003–06, without referring to these difficulties.

Indeed, French et al. recently published a paper entitled “Observed reductions in *Schistosoma mansoni* transmission from large-scale administration of praziquantel in Uganda: a mathematical modelling study”.<sup>14</sup> The paper argues that the declining rates of infection found in the cohort study cited above can be used to estimate declining rates of re-infection. It then goes on to suggest that this will result in a reduction of transmission in “the community” as a whole. Whatever the theoretical merits of the mathematical model, the fundamental flaws of the data set render the conclusions speculative. Nevertheless, the paper gives the impression that the potential achievements discussed have occurred in reality, and concludes that the results indicate that the mass drug administration programme developed by staff from the Schistosomiasis Control Initiative (SCI) is a useful model for others to follow.

Rapid mapping approaches have produced similarly problematic findings. One much cited example uses LOT Quality Assurance Sampling.<sup>15</sup> Again, Ugandan school children were the primary focus. Twenty four schools were sampled in each study district and 15 children were tested for *S.mansoni* in each school. The data were then mapped using GPS readings for each school. In a subsequent paper, Brooker et al.<sup>16</sup> compared these results with data that was collected two years later. The comparison indicated a significant decline at some sites following mass drug administration. The lead researcher himself would not claim that the small and restricted sample groups used in these studies was a reliable basis for assessing changing patterns of infection in Uganda overall. The research was intended to be indicative of the very high rates of infection found in some locations, and to highlight what might be achieved if sustained mass treatment of the whole population occurred in endemic areas. The claim made on the SCI website that LOT Quality Assurance Sampling and mapping indicates there is a “realistic chance of bringing bilharzia infection in Uganda to below an intensity level at which it is a major public health problem” is thus not tenable.<sup>17</sup> More recently, research undertaken by Standley et al.,<sup>18</sup> involving staff from SCI, demonstrated an additional problem. It found that the type of test used to diagnose *S.mansoni* with LOT Quality sampling produces different results from other methods in the same population, and that it is inappropriate to assess changing patterns of infection by relying on one method alone. Sensibly, the overly optimistic statement on the SCI website has now been removed.

In short, while there have been some high quality studies at particular sites in Uganda, their findings are limited and the subject of debate. The far-reaching claims about widespread drug take-up in some publications are little more than over-optimistic assertions. Also, while it is undoubtedly the case that millions of tablets have arrived in the country, it is quite another thing to know if those most in need of them have actually swallowed them. Research on this crucial topic, as noted elsewhere,<sup>19</sup> is largely absent. In this context, it is appropriate and important to pose the following question: is it the case that fishermen and those that work closely with them, probably the very people most vulnerable to acquiring schistosomiasis, are being treated?

### **Fieldsites and methods**

Research was undertaken in northwestern and southeastern Uganda between 2005 and 2009. In northwestern Uganda, research took place in Panyimur sub-county,

Nebbi district and Dufile sub-county, Moyo district. Panyimur sub-county is located on the northern shores of Lake Albert and borders the DRC, while Dufile sub-county is located on the River Nile and shares a border with southern Sudan. In southeastern Uganda, research took place in Lumino sub-county, Busia district and Banda and Sigulu sub-counties, Bugiri district. Lumino sub-county shares a border with Kenya and some of the villages in the sub-county are located on the shores of Lake Victoria. Banda sub-county borders Bugiri district and it, too, has villages located on the shores of Lake Victoria. Research in Sigulu sub-county took place on the islands of Sigulu and Lolwe.

Ethnographic research was undertaken at all research sites. Insights emerging from participant observation with fishermen and others involved in local fish processing and marketing, as well as political figureheads, local healers (spirit mediums, herbalists), village elders, health care providers, school teachers and soldiers informed the design of surveys. These surveys recorded the proportion of adults who received drugs for the treatment of schistosomiasis, soil-transmitted helminths and, where relevant, lymphatic filariasis and onchocerciasis. Close attention was paid to understanding the rationale for accepting, missing, avoiding or openly rejecting treatment among fishermen as well as other adults living at the selected study sites. With the exception of research undertaken in Sigulu sub-county, Bugiri district, surveys were administered with a random sample of at least 10% of households at each location. In Sigulu sub-county, a random sample of at least 5% of households was undertaken at selected locations.

Wherever possible, data recording the take-up of drugs in Ministry of Health registers for NTDs and data monitoring changing patterns of infection for NTDs were analysed alongside the ethnographic and survey data collected above. Inevitably, there were some variations in the combination of methods employed between sites. These are detailed below in relation to the main characteristics of the three study areas. Each area is discussed in turn, highlighting the political and economic context in which fishing occurs and the multiple ways in which this influences the mass drug administration programme for fisherfolk. Evidence from our research is combined with any available parasitological and epidemiological data to assess the relationship between the disease control programme and changing patterns of infection.

### **Dufile sub-county, bordering southern Sudan**

The majority of people living in Dufile sub-county are Madi and the main language spoken is Ma'di. There are, however, a few people from other ethnic groups including Acholi, and Lugbara. In 2008, data used by the Ministry of Health to calculate the number of drugs to allocate to adults and children for the treatment of NTDs suggested that the total population was 25,577. However, this figure was affected by the number of Madi from Sudan who were living in the sub-county at the time. It was probably inflated, because food relief was being provided by the World Food Programme to all reported residents.

The Madi have a long history of moving back and forth across the northern Uganda and southern Sudan border. This is partly because there are Madi populations on both sides of the border, and a boundary was created for administrative convenience by colonial governments at the time of the First World War. In recent decades, political instability has prompted population movement in

both directions. In the 1960s, Madi families moved south to avoid Sudan's first civil war; in the 1970s they returned following the peace agreement; and by the end of the decade, they were accompanied by thousands of Ugandan Madi, in response to the Tanzanian invasion of Uganda and the return to power of Milton Obote. Further instability ensued in southern Sudan with the formation of the Sudanese People's Liberation Army (SPLA) and attacks on refugee settlements. From 1986, both Ugandan and Sudanese Madi fled south. Attacks in Uganda by the Lords' Resistance Army and other groups sustained high levels of insecurity, but there has been a drift back to southern Sudan since 2005 with the signing of the Comprehensive Peace Agreement. The biggest Madi town in southern Sudan is Nimule. It is just over the border from Dufile. Madi from Uganda go there to trade, and to benefit from economic opportunities created by the emergence of a new state with access to international aid and oil revenues. There is continuous movement back and forth, and no significant border monitoring by government officials on either side of the international boundary. Those that travel the short distance from Dufile to Nimule go by canoe, and they usually do so to sell fish.

Madi families living near the Nile are involved in agricultural production, especially in the rich soil that becomes available when the river waters are low in the dry season. Saleable crops such as pumpkins, maize and sugar cane are grown. However, fishing and fish processing is also undertaken by all families. In this respect, the whole population might be considered to be fisherfolk, with involvement in fishing ranging from the use of small nets and lines from the shore to days and nights spent away at fishing camps or out on the water. Many homes also have family members who live semi-permanently on islands in the river. Here, too, farming occurs, but fishing and fish processing predominates.

Among the Madi of the Metu highlands or those living away from the Nile in neighbouring Adjumani district, the riverine Madi have always been viewed as a bit different, and rather difficult to deal with. Their consumption of alcohol is often mentioned, and certain fishing camps are notorious. Young women are advised not to go there unaccompanied. In the 1980s and 1990s, liquor known as *waragi* was distilled locally in many homes, and sold to the fishermen at landing sites in the mornings. This source of income has been undermined, in large part, by the availability of small sachets of cheap manufactured *waragi*; but the sight of inebriated fishermen is no less common. District officials in the bigger towns, some of whom come from other parts of Uganda, sometimes express frustration with the population in a way that is not dissimilar to those noted by researchers in the south of the country. The inaccessibility of the main fishing grounds in the Nile and the ready access to southern Sudan make it hard to introduce regulations, or even to find out how many people are living in the area. Nevertheless, it should be stressed, the riverine Madi and their fishermen are closely connected with families living further away through extended patrilineal and affinal relations. It may be that some of those making money from fish will occasionally drink too much in public places, but many are also paying the medical costs and school fees of their relatives. In spite of the fact that the schools are poorly resourced, there is a strong commitment to education and maintaining children at school for as long as possible.

As a group, then, they are less socially excluded than might initially be apparent. This can be attributed, in part, to the fact that the Madi on both sides of the border are Roman Catholic and, historically, the priests have had, and continue to have, considerable moral authority. Their positive engagement with education contributes

to on-going enthusiasm for education among the Madi. There is another factor too: the lowlands near the River Nile are prone to sleeping sickness (African trypanosomiasis). Since colonial times there have been campaigns to control the disease. This has sometimes involved aggressive treatment of those infected and even the enforced movement of villages. As recently as the late 1980s, an epidemic was contained with assistance from Médecins Sans Frontières. As a result, Madi populations are perhaps rather more willing to respond to vertical medical interventions than other Ugandan populations.

Research exploring social responses to the mass drug administration programme took place against this background. It built upon long-term participant observation fieldwork undertaken in Moyo district by one of the authors, Tim Allen, in the 1980s and 1990s.<sup>20</sup> During this period he lived near Laropi trading centre in Dufile sub-county. Much of this research focused on health and healing among populations living on or close to the Uganda/Sudan border; and it informed the design of semi-structured interviews undertaken in 2008 and 2009. A total of 72 semi-structured interviews were undertaken in five villages and two trading centres in the sub-county in August–September 2008; and a further 94 semi-structured interviews were undertaken in July–September 2009. In addition, three months participant observation was undertaken in the sub-county from June to August 2009 including hundreds of open-ended, unstructured interviews.

It also proved possible to carry out a small amount of parasitological research during August 2009, in collaboration with the vector control officer of Moyo District. This took place at one fishing camp (Ulua) and two islands (Utudrigbwulu and Siria). The number of people inhabiting these fishing sites varies throughout the year. For example, an estimated 120 people were thought to use the island of Siria, around 10 of whom stayed permanently. Fresh stool samples were analysed from 31 individuals for *S.mansoni* and soil-transmitted helminths such as ascaris, hookworm and trichuris trichiura.

It is important to note that both the landing sites and fishing communities vary along this stretch of the river with respect to accessibility, infrastructure and facilities. Some, including Siria fishing camp and Ulua fishing camp, are at the end of roads or tracks that can only be reached on foot; whereas others, including Utudrigbwulu fishing camp, have concrete buildings and areas for cleaning the fish, with waste channels for the dirty water. There are few, if any, functioning latrines or boreholes at the majority of the landing sites. Occasionally, people have tried to drill boreholes, but without success; and the latrines that have been built usually collapse. Moreover, the village boreholes and latrines are too far for the fishermen to return to while they are out on the river. A consequence is that they defecate in or close to the river; and, if they are infected, they can contribute to the cycle of transmission.

Interviews confirmed that fishermen spend anything from a few days to three months on the river away from their family and home village. They stay at the landing sites or fishing camps and islands, as daily movement back and forth to the village would be too much. Depending on the time of year, they may then spend one to two weeks at home before returning to the river. Accommodation at the landing sites and fishing camps varies too. It ranges from sleeping on the river in canoes, to sleeping outside on the land, to papyrus walled shelters, to permanent houses. At some of the more permanent fishing camps, mosquito nets are hung by those who own them. On one rocky island where there is no shelter, the fishermen have built

raised platforms to sleep on. At night, they light a fire underneath the platforms so that the smoke will deter the mosquitoes.

There is a lot of movement between the fishing grounds, and between the fishing grounds and the villages. The fishermen move between the fishing grounds depending on the catch, and from the village to the river. Some women move daily between the village and the fishing grounds. They bring firewood and food items, and they collect fish and money from the men. Other women stay at the fishing grounds, smoking fish and cultivating. Elderly men, who cannot fish anymore, also move back and forth to the fishing grounds, helping to fetch and carry items – including one who had lost the end of his fingers from leprosy. With so much daily movement between the villages and fishing grounds, especially among women, news and information travels back and forth easily. As previously noted, there is also a great deal of cross-border trade. Pa-anjala landing site is where people generally depart and arrive from Nimule. In addition to fish, women regularly travel to Nimule to sell products such as mangoes, vegetables, tomatoes and papyrus mats. The financial benefits are significant. At the trading centres of Dufile sub-county in 2009, a bunch of five fish could be sold for 5000 Ugandan shillings, but in Sudan a single fish could be sold for the equivalent of 3000 to 4000 Ugandan shillings.

There are numerous rules and regulations that fishing authorities have tried to introduce. These include regulations on the type and size of fishing nets to be used and license fees for canoes. To keep a canoe at the landing site, a yearly license fee of about 20,000 Ugandan shillings has to be paid. While this can be made back in a day's fishing (or at least a week), it causes some tension between the fishermen and the fishing authorities. To quote a 32 year old fisherman:

We are not given education about fishing, we just learn from friends. How can you punish those that don't have the education and don't know the regulations? There is no school to acquire the knowledge of fishing, we just use our own memory and learn from each other. The fishing authorities are very good at fining you, but not at educating you.

Other regulations include the fact that fish are no longer supposed to be sold at the riverside and fishermen have to sell their fish at a designated market area, where a 10% fee is levied. However, the fishing authorities struggle to impose these regulations. Many landing sites are narrow, muddy and crowded with canoes and the vegetation along the banks of the river is dense. This not only makes it is easy for fishermen to hide, but it is also difficult for an outsider to know who owns which canoe. Moreover, some landing sites are impossible to monitor without a boat, an outboard engine and fuel, all of which are generally unavailable.

### ***Schistosomiasis control among fisherfolk of Dufile sub-county***

Analysis of data from the 10% randomly selected sample of people living in five villages and two trading centres showed that the uptake of drugs varied widely between locations, as well as over time. In 2007, for example, the uptake of drugs was reported to be 17% in Paubu, 38% in Pakonira East, 0% in Olia West, 17% in Pakaa West, 33% in Laropi, 88% in Dufile and 17% in Panjala. In 2008, the uptake increased considerably in some villages and declined in others. That is, uptake was reported to be 100% in Paubu, 92% in Pakonira East, 90% in Olia West, 50% in

Pakaa West, 33% in Laropi, 15% in Dufile and 5% in Panjala. The overall average uptake in these seven villages was 41% in 2007 and 55% in 2008.

Fisherfolk in all these villages expressed concern about the rationale for mass treatment in the absence of parasitological testing as well as concerns about possible side-effects. There were complaints that some of those taking the tablets had felt sick, a symptom that is probably linked to them having had a heavy infection. Elsewhere in Uganda, people have sometimes refused to accept treatment, and rumours have circulated about the “true” motives for handing them out free of charge.<sup>21</sup> In Dufile, this was rarely found to be the case. For reasons already mentioned, the Madi are remarkably open to biomedical interventions, and mass drug distribution is no exception. Instead, variations in reported uptake within and between villages are attributable to the effects of recent forced displacements and on-going insecurity, rather than resistance or rejection. Local population mobility is also a factor, as well as the residence of many fisherfolk for extensive periods at remote fishing grounds.

With respect to mobility, it is important to note that the established protocol for the National Control Programme for the Integrated Control of Neglected Tropical Diseases involves the mass distribution of drugs through primary schools and unpaid drug distributors living in villages. It does not currently involve distributing drugs to any of the fishermen based at the islands in the Nile or at other fishing camps and landing sites. No procedures were put in place to reach these groups. In 2008, partly in recognition of the fact that fishing populations needed specific targeting, a policy was adopted of only distributing drugs in locations close to the Nile. Nonetheless, endeavours to access the most vulnerable fisherfolk were not attempted. When this was pointed out to district medical staff, they readily accepted that this was a problem; but they had not been required to ensure that drug take-up by these groups had occurred, and they had no effective means of accessing the islands and remote fishing camps to assess the situation. Basically, the arrangements put in place to roll out treatment invited those involved in implementation to overlook large numbers of people involved in fishing, many of whom, by the nature of their work, are vulnerable to infection.

While the apparent exclusion of fisherfolk is cause for concern, it is hard to gauge the precise effects this has had on the overall prevalence of infection. In common with other parts of Uganda, data documenting changing patterns of infection in Dufile sub-county is both sparse and muddled. According to data collected by staff from the Ministry of Health (with the assistance of colleagues from SCI), the prevalence of *S.mansoni* among children sampled at two schools in Dufile and Laropi trading centres was 5.3% and 1.6% in 2003. However, the prevalence was 40.4% among adults in Laropi in the same year. These data were collected prior to the mass distribution of drugs for the treatment of *S.mansoni* and, defying patterns usually reported by epidemiologists, suggest that the prevalence of *S.mansoni* was high among adults and low among children from the same location. The situation is complicated by the fact that the prevalence rose to 9.6% among children in Laropi one year after treatment but fell to 5.6% among adults from Laropi. With no information available on the number of children and adults sampled, or any follow-up data to assess what has happened since then, it is difficult to comment other than to suggest that these rates might be indicative of relatively low rates of infection, given the amount of time some local people spend in slow moving water.

Recognizing that schistosomiasis might present a serious health problem among apparently untreated fisherfolk based on the islands, the district vector control

officer for Moyo district collaborated with our team in a small-scale parasitological survey in 2009. As far as we are aware, this was the first time that such testing had occurred. Surprisingly, there was only one case of *S.mansoni* and one case of trichuris trichuria. While these fisherfolk did not receive treatment in the round of mass drug administration that occurred in 2008, 97% of them stated that they had received treatment at least once since the establishment of the mass treatment programme in Moyo district in 2004. It is, therefore, possible that the low levels of infection reflect the beneficial impact of treatment, even though the fisherfolk on the islands were omitted from community-based and school distribution. By one means or another, they were able to access praziquantel tablets and they swallowed them. In some instances, the volunteer drug distributors had kept back tablets for them or given an additional allocation to their families. There are indications from immunological research that treatments with praziquantel may confer a degree of resistance to re-infection in some groups.<sup>22</sup> These immunological findings are still a matter of debate,<sup>23</sup> but they could be a factor. Other reasons for the low rate of infection on the Nile islands might be that the local ecology did not encourage the snail vector of schistosomiasis to thrive, or possibly the parasitological data collected was too limited to deduce the level of infection among those sampled. In any case, the finding is very interesting, and highlights the need for further systematic investigation.

### **Panyimur sub-county, bordering the DRC**

An estimated 26,000 people live in Panyimur sub-county. In common with Dufile sub-county, accurate demographic data does not exist. There is, for example, a considerable discrepancy between the number of households and family members recorded by local council officials and the number of households and individuals that were registered by the drug distributors for the treatment for schistosomiasis. In the villages where this was investigated, the drug distribution registers contained between 24% and 46% more names per village than those registered with local council officials.

The majority of people living in Panyimur sub-county are usually referred to as Alur, but there are, in addition, some Acholi, Lendu, Lugbara and Kebu. Also, the Alur living close to Lake Albert are sometimes categorized as a distinct ethnic group. Traditionally, they did not recognize the ritual or political authority of upland Alur *rwodi* (chiefs). The current *rwot* of Panyimur still makes the point that his people are really Jonam, and are not like other Alur. The term Jonam means “people of the lake” in the Lwo language, and emphasizes the different way of life between the shore dwellers and the farmers in the hills to the north. The distinction is no longer precise due to influxes of migrants from other locations. However, there is still some tension between the Jonam and the upland Alur, and this continues to inform commonly expressed attitudes by district officials based in the town of Nebbi. Although there are bitter complaints about fish stocks dwindling as a result of the large-scale commercial fishing occurring elsewhere in Lake Albert, even today, a Jonam identity remains a quintessential “fisherfolk” identity. Cultivation of cassava, cotton, groundnuts, sorghum, maize and simsim occurs in plots located away from the shore line, but many “people of the lake” remain reluctant farmers. Border trading is more appealing.

Panyimur sub-county shares an international boundary with the DRC and there is a visible military presence close to the border and around the trading centre

(ostensibly to prevent unwanted threats from Congo). However, there are several Jonam/Alur villages located either side of the border, and there is considerable inter-marriage between them. Not surprisingly, then, they consider each other to be “brothers” and, in many respects, their social and historical connections with each other are much stronger than their connection with their respective governments. In this respect, it is not dissimilar from the relationships that exist between the Ugandan and Sudanese Madi. Scores of Congolese children cross the border every day to attend school in Uganda, and hundreds of Congolese travel to the town of Panyimur by foot, truck or boat to buy and sell fish, grain and other products in the large market held every Monday.

The weekly market also provides an important focal point for cross-border trade between southern Sudan and Uganda, as well as Panyimur and other parts of Nebbi district, Hoima and Arua districts. The purchase and sale of fish is an important aspect of this trade. As northwestern Uganda becomes more settled, an increasing amount of trade is developing between Panyimur and the capital city, Kampala. It is now only six hours away by bus and there is a direct bus once a week. It leaves the day after market day, Tuesday, and returns the following Friday. Many traders arrive the night before and stay in small lodgings or “hotels” in Panyimur. However, the majority sleep in their trucks, in their boats, or in the doorways of boarded-up shops or in the open air. There are hardly any latrines available to them, so defecation in or near the lake is inevitable.

Endeavours to document the number of fishermen and fish traders who were coming to Panyimur from the DRC or other parts of Lake Albert proved futile. No records are kept and there was no practical way of documenting how many boats or people were moored at the numerous landing sites around Panyimur Trading Centre without causing great suspicion. It was, however, possible to acquire an understanding, albeit partial, of the lives of fishing families resident or partially resident in Panyimur sub-county while making a detailed assessment of the take-up of drugs for *S.mansoni* throughout the sub-county.

Participant observation fieldwork was undertaken in the sub-county from May to September 2005, July to September 2008 and August 2009. Semi-structured interviews were also undertaken in 15 of the 49 villages that make up Panyimur sub-county in 2008. This involved taking a 10% random sample of adults that were registered by staff from the Ministry of Health in the registers documenting the uptake of drugs for the treatment of *S.mansoni* in 2004. In common with research undertaken in Dufile sub-county, these interviews explored social responses to the roll-out of mass treatment for schistosomiasis and soil-transmitted helminths. The 2004 registers for Panyimur were particularly useful, because, unlike other registers found in Panyimur and elsewhere, they provided a list of all adults on a village by village basis, irrespective of whether or not they had received treatment.

With mobility a central feature of so many peoples’ lives on the Uganda/DRC border, an endeavour was made to document the nature and extent of movement among people residing in Panyimur sub-county, and the multiple ways in which movement influenced current strategies to contain the spread of NTDs. The following five villages were selected for this part of the study: Singla Central, Dei B, Afhoda, Awulu and Lwala. These villages are located in very different parts of the sub-county. That is, Dei B is located on the border between Uganda and the DRC whereas Singla Central refers to the densely populated trading area within Panyimur. The busy weekly market is located here. Awulu lies between Singla Central and Dei B

on the shores of Lake Albert, whereas Afhoda lies to the west of Singla Central, and Lwala is located in the hills rising up from the lake.

Each village has a dedicated Ministry of Health register documenting the uptake of drugs among adults for the treatment of NTDs in 2007. A 5% random sample of names was taken from each register and this yielded approximately 50 names from each register. The names were then cross-checked with the household register kept by the local council chairman (LC1) for each village. Every effort was made to elicit accurate information about the occupations, age, place of birth and travel patterns of those people on the list. On those occasions where the relevant people could not be contacted, discussions occurred with the local council chairman as well as relatives, neighbours and friends to try and elicit the necessary information. A final component of the study of mobility involved the collection and analysis of fresh stool samples from a random sample of 120 traders attending the weekly market.

### ***Schistosomiasis control among fisherfolk of Panyimur sub-county***

The quality of the 2004 drug distribution registers in Panyimur sub-county facilitated analysis of repeated drug take-up by named individuals. An endeavour was made to assess the proportion of adults who were re-treated for *S.mansoni* in 2007, compared to 2005 and 2004. It was possible to compare the uptake of drugs over a four-year period (involving three rounds of mass distribution). By comparing recorded distributions with information from the 10% random sample of adults in 15 of the 49 villages that constitute the sub-county, it became apparent that the majority of the 595 adults interviewed received treatment in 2004 (65%), but the percentage of adults that were re-treated fell in 2005 (37%) and 2007 (42%). In fact, large numbers of people rejected treatment in 2005 and 2007. There were numerous reasons for this, including widespread questioning of the rationale for mass treatment and fears that the drug, praziquantel, could lead to infertility and even death. There was also widespread concern about the side-effects linked to treatment. In addition, the dearth of adequate health education and reliance upon unpaid volunteers to distribute the drugs proved problematic. Others simply missed treatment because they were unaware that the drug was being distributed.

It remains to be asked if those families largely specializing in fishing and fishing related activities were included in these distributions. Follow-up work with a 5% random sample of names elicited from the 2007 Ministry of Health registers for five villages confirmed that a large percentage of the adult population are mobile, including many of those who appear in drug distribution registers. Using a definition of mobility whereby a person was classified as mobile if they regularly spent more than one night a week away from home, it emerged that Singla Central had the highest proportion of drug recipients (46%) who were "mobile" and Dei B had the second highest proportion of mobile persons (33%) taking the drugs. These findings are not surprising. The weekly market is located in Singla Central so it is a focal point for trading; and Dei B is located on the Congolese border so people frequently move back and forth across the border to buy and exchange goods, including drugs from the mass treatment programmes. The other villages surveyed, Lwala, Afhoda and Awulu, had slightly lower proportions of mobile people receiving the drugs, at 30%, 28% and 24% respectively.

Thus, a significant number of people receiving drugs were mobile in 2007. They were recognized by resident drug distributors as fellow residents, even if they were

known to be away from home regularly. Many of these mobile people were confirmed to be heavily involved in fishing. In Awulu, 60% of mobile drug recipients were confirmed to be more or less full-time fishermen. The corresponding figures for Singla Central and Dei B, where there are many traders, were found to be 38% and 17% respectively. In Lwala and Afodha, they were 25% and 23%. The results suggest that many fisherfolk are being assisted by the drug distribution programme, notwithstanding the acute problems that have arisen overall in Panyimur.

The rejection of treatment by many of those offered drugs in Panyimur, as well as the intense pattern of fishing, fish processing and border trading at the edge of the lake, would suggest that if the prevalence of schistosomiasis had been affected by mass drug administration, almost immediate re-infection, or at least re-exposure, would be likely. In common with Dufile sub-county, the available epidemiological data is limited, but recorded rates of re-infection among school children are high throughout the sub-county. In July 2008, re-infection levels reported by the Ministry of Health at Panyimur Primary School were 54%, at Nyakagei Primary School they were 84% and at Boro Primary School they were 60%.

A strong link between these disappointing results and border movements along the lake were confirmed by our own investigations. Analysis of stool samples from a random sample of 120 traders attending market day in August 2009, suggested that more than 90% were infected with *S.mansoni*, and the small number that were not infected with *S.mansoni*, were infected with soil-transmitted helminths such as hookworm and ascaris. Importantly, those who were not infected with *S.mansoni* were almost entirely from Ugandan locations, and while they may have rejected treatment in some rounds of distribution, all said they had taken praziquantel at least once since 2004. Most of those who were found to be positive arrived in the market in boats from the DRC, and the remainder came overland from southern Sudan (the DRC, like Sudan, has no schistosomiasis control programme). Given the fact that these traders sleep overnight in Panyimur market place, without access to latrines, it is little wonder that children who receive treatment in local schools are re-infected. However, it may be very significant that the Ugandan traders tested were negative. As noted above, some recent parasitological and immunology research has suggested that there may be a degree of resistance to re-infection with *S.mansoni* among adults who have taken praziquantel.<sup>24</sup> It has also been argued that resistance of this kind does not occur in children.<sup>25</sup> While recognizing that these are matters of debate among scientists, and also that our parasitological findings from both Panyimur and Dufile are not adequately rigorous to draw firm conclusions, the results do tend to indicate that praziquantel may indeed have a not yet fully understood protective function for adults, but not for children.

### **Lumino sub-county and neighbouring locations near the Kenyan Border**

The third area of research focused on Lumino sub-county, Busia district. We were encouraged to assess the situation in Busia by staff at the Ugandan Ministry of Health because it was perceived to be a “model” district. Whatever the problems emerging elsewhere, treatment was said to be working well here.

Lumino is located in southeastern Uganda with the Kenyan border to the east and Lake Victoria to the south. The sub-county has an estimated population of 20,067, with the majority of people identifying themselves as Samia and speaking Lusamia. While there have been political tensions at the border with Kenya, the

kinds of insecurity that have affected Panyimur and Dufile sub-counties has been absent. There has been no armed opposition to President Museveni in this part of the country. Indeed Busia, like other parts of southern Uganda, has been part of the government's political power base. However, the emergence of opposition party support has been an issue in recent years.

Busia town itself is a lively place. It is located at the most important land-border crossing on the tarmac road running from Kampala towards Nairobi and Mombasa. Not surprisingly, there is a great deal of trading going on. In this respect, too, the contrast with our other research areas is significant. The border is far more rigorously administered and controlled than those with southern Sudan or the DRC. Moreover, the populations living on either side are roughly equivalent in terms of economic well-being. They may not be affluent, but health and education services are significantly better than those available in northern parts of the country, there are a variety of income sources, and salaried employment is more of a possibility.

There is informal trade out on the lake, but it occurs on a less intensive scale than that described for Dufile and Panyimur. Some of the islands have government customs officials permanently stationed on them. Also, the lack of general demand for commodities on one side of the border compared with the other means that smuggling is mostly connected with avoidance of official taxation. It is, therefore, explicitly criminalized. Doubtless, there are profits that can be made when it is done on a large scale, with rumours circulating about border officials doing it themselves; but those most likely to be arrested are fisherfolk attempting to supplement their small-scale fishing activities.

Over the past few years, Lumino sub-county has benefited from considerable economic investment by government agencies and private companies, with the fishing industry being a direct recipient of economic assistance. In particular, a state-of-the-art fish processing plant has been constructed on the shores of Lake Victoria as well as a high-grade landing site and market. The new plant exports fish to Europe. In 2009, new tarmac roads linking landing sites at Manjanji and Maduwa to Busia were under construction.

Running alongside these developments has been an endeavour by government officials, in conjunction with the Beach Management Unit<sup>26</sup> to develop an ecologically sound approach to fishing. This has taken various forms and includes attempts not only to restrict access to Lake Victoria, but also to ensure that those fishing in the lake do not use nets that will catch small and immature fish. The vigilant enforcement of new rules and regulations has had a profound impact on the lives of fishermen and their families in Busia district. In 2007, for example, the Manjanji/Maduwa Beach Management Unit approved licenses for 766 fishermen, fishmongers or bariahs (fish porters). By 2009, the number of people renewing their licenses fell to 114 as the cost became prohibitively high. That is, the cost of acquiring new, appropriately sized nets and fulfilling a range of other requirements requested by the Beach Management Unit including registration, and the purchase of life jackets and health checks increased to a total of 595,000 Ugandan shillings. To put this in perspective, a fisherman with an "old sized" net paid 8000–18,000 Ugandan shillings for his net and typically fished without a life jacket (as life jackets cost about 40,000 Ugandan shillings to purchase). The amount they earn inevitably varies from day to day, and typically ranges from 2000–10,000 Ugandan shillings; but it can occasionally be as much as 50,000 Ugandan shillings. By way of contrast, farm labourers earn approximately 1500–3000 Ugandan shillings a day.

The majority of people willing and able to respond to the new regulations and to cover the costs incurred were either members of the Beach Management Unit, their close relatives or locally powerful individuals. To quote a local council chairman: “many people cannot afford the gear and are losing their livelihoods. But it is as always. The rich will remain rich and the poor will remain poor.” Similarly, a registered fisherman, reflecting on the spiralling costs said: “life is harder now. People were expecting to get more money but actually income has decreased. Before I could make 10,000 a day but now I come home with only about 2,000 because the equipment is so expensive.”

The social ramifications of the ecological fishing policy are difficult to quantify, because so many people have migrated from the area and are difficult to trace. However, discussions with current residents confirmed that the population living close to the landing sites had declined dramatically, with some estimates being as high as two-thirds. This, in turn, was said to have had a major effect on market trading in the area. Moreover, some of those formally involved in fishing and fish processing were now said to be concentrating on subsistence farming with a consequent loss in income and livelihood diversity. Others were said to have moved either to neighbouring districts with less vigilant Beach Management Units (such as Banda sub-county, Bugiri district) or to some of the islands in Lake Victoria where, again, there are few endeavours to regulate fishing activities (such migration was confirmed in our research, see below for further details).

Follow-up work with a 5% sample of the 766 fishermen who were registered with the Beach Management Unit from 2004 to 2007 enumerated the effects of some of these new procedures. Only two out of 37 fishermen sampled were able to secure a license under the new regulations; nine others were either fishing (illegally) or involved in the trading of fish in Lumino sub-county; seven were reported to have moved to islands in Lake Victoria so that they could continue fishing; six were said to be “mobile” with their livelihoods being reported as “unclear”; three had moved from the area to seek an alternative livelihood in farming; a further three were engaged in agricultural work in their existing villages; nothing was known about the whereabouts of four; and the remaining three had either died, fallen sick or “retired”. Such levels of population movement obviously have important implications for those seeking to distribute drugs for the treatment of schistosomiasis.

In common with other research sites, endeavours to document the impact of these changes on the uptake of drugs involved undertaking participant observation fieldwork and surveys. The latter involved taking a 10% random sample of households in 24 of the 64 villages that constitute Lumino sub-county. Semi-structured interviews were then undertaken with adults at their houses. In addition, 223 open-ended, unstructured interviews were carried out with a range of people including fishermen, local fish processors, political figureheads, labourers, healers and Ministry of Health officials across the sub-county. Selected schools were visited too. Wherever possible, the school drug distribution registers were analysed alongside information emerging from interviews with teachers.

Further research was subsequently undertaken in neighbouring Bugiri district to assess the effects of out-migration of fisherfolk. This involved doing semi-structured interviews with a 5% sample of adults at two landing sites in Banda sub-county and five locations in Sigulu sub-county. The landing sites in Banda sub-county were Busiro Beach and Lugalla Beach. The population is very mobile with the local council chairman (LC1) at Busiro Beach suggesting there were around 350 rented

huts and 30 permanent houses. An estimated 80 fishermen were registered and a further 200 people were engaged in fishing-related activities. The second landing site, Lugalla Beach, is a busy trading centre. It has a population of around 5000 with approximately 200 households. Sigulu Island is the largest island in Bugiri idistrict. It has approximately 20 villages and the fieldsites were the villages of Buwube, Buyima and Sikinga landing site. It takes around 40 minutes by boat to reach the island from the mainland by motorboat. Lolwe Island lies further from the mainland and the boat journey takes about two hours. The two fieldsites selected here were: Singila A and Kandege Village. The island has a new jetty and a fish processing factory. Both islands have limited access to clean water and sanitation facilities.

### ***Schistosomiasis control among fisherfolk of Lumino sub-county***

The self-reported uptake of drugs among adults in Lumino indicated that 64% received praziquantel in 2009 and 67% received the drugs in 2008. This information is based on the 10% sample of randomly selected households from 24 of the 64 villages that make up the sub-county. These are relatively high levels of drug uptake, at least compared to the other areas investigated in the north of Uganda. Moreover, according to the Ministry of Health, the prevalence of *S.mansoni* has declined among school children at all schools at which testing occurred. In 2003, for example, the reported prevalence in Manjanji, Maduwa, Budimo, Buloosi and Bwaniha schools was 24%, 41%, 82%, 52% and 74%, but it fell to 2%, 12%, 2%, 43% and 41% respectively in 2007.

The situation is, however, much more complex than that conveyed by these data. To begin with, the reported decline in the prevalence of *S.mansoni* among school children is rather difficult to interpret as data collected by staff from the Ministry of Health also suggest that the prevalence of *S.mansoni* increased among adults at Maduwa and stabilized among adults at Buloosi. That is, the prevalence of *S.mansoni* increased in Maduwa from 9% in 2004 to 14% in 2007, while the prevalence of *S.mansoni* in Buloosi was reported to be 20% in 2004 and 19% in 2007. No parasitological data was collected from Manjanji, Budimo or Bwaniha, but from the available data it remains far from clear why the prevalence of *S.mansoni* would decline among children but increase or stabilize among adults.

An additional complication is that it is impossible to gauge what proportion of school children were treated for *S.mansoni* in any one year. By way of illustration, eight schools were visited in Lumino sub-county in 2009. A total of 6518 children were registered at these schools, with 2567 (39%) of them receiving treatment for *S.mansoni* and soil-transmitted helminths. However, the uptake of drugs is likely to be higher than that suggested by these data as it is probable that the number of children enrolled at primary schools has been inflated by head teachers in the hope of securing a larger grant from the Ugandan Ministry of Education (as the budget for each school is affected by the number of children formally enrolled at the start of the academic year). Unfortunately, none of the schools had a daily register so it was impossible to gauge what proportion of school children enrolled at the start of the academic year attended school on a regular basis, nor therefore the proportion of school children that received treatment for *S.mansoni* and soil-transmitted helminths.

While the partial nature of routine data makes it extremely difficult to interpret the overall impact of rolling out free drugs among adults and children living in relatively stable and settled villages in Lumino sub-county, there is evidence that

other factors have contributed to declining or stabilizing rates of infection. One of these is that district officials have made a real effort to enforce existing public health legislation and to clean up beach landing sites and the lake shore more generally. This has included, for example, the enforcement of a 5000 shilling fine for any household that does not have a pit latrine, as well as a 5000 shilling fine for anyone caught urinating or defecating in the lake and a 3000 shilling fine for anyone caught bathing in the water.

Other issues relating to the control of *S.mansoni* are connected with the assault on fisherfolk livelihoods associated with the promotion of ecological fishing by the Ugandan government. This has exacerbated the marginality already experienced by fisherfolk, as the enforcement of a set of policies has fostered out-migration from Busia district to neighbouring districts, where endeavours to control access to Lake Victoria are less stringent, or forced people into other kinds of livelihoods. As previously mentioned, most registered fishermen had their licenses revoked in 2007 and fishing in the vicinity of the landing sites became tightly controlled by the Beach Management Unit. This significantly reduced the number of people accessing the lake on a regular basis, but it also had ramifications for the population as a whole as large numbers of adults used to be involved, if not in fishing, then fish processing and/or the provision of services to fishermen at landing sites. Although it was impossible to acquire detailed empirical data with the time and resources available, long-term residents noted that the total number of people living close to the landing sites had dropped dramatically in recent years.

The absence of people along the shoreline of Lake Victoria in Busia district raises the question of what happened to all those fishermen who had their licenses revoked. Was it possible that they had simply moved to the neighbouring district, Bugiri, or to some of the islands in the lake? If so, were they receiving free drugs for the treatment of schistosomiasis and soil-transmitted helminths at these locations? Was it possible that they were actually exporting *S.mansoni* to neighbouring populations and districts?

Open-ended interviews suggested that some of those who used to rely upon fishing were now engaged in agriculture and other activities. However, it was impossible to ascertain how many of those who had previously been involved in fishing activities were still resident in Busia and it was repeatedly stated that large numbers of people had migrated. While district officials tended to emphasize migration to Kenya, others recounted details of people moving to islands in Lake Victoria or to beach landing sites in neighbouring Bugiri district. Evidence supporting the latter view includes the fact that 58% of those people interviewed in villages in Bugiri district said they had moved to the sub-county, with 61% of migrants coming from Busia district. Similarly, in-migration was confirmed on Sigulu Island and Lolwe Island. In Singila A on Lolwe Island, for example, the number of fishermen has increased from 328 to 1000 since the imposition of restrictions in 2007. Similar patterns were observed in other villages on both islands, with household survey data suggesting that only 43% of all those interviewed had been born on one of the islands while 53% had migrated from the mainland – 28% from Kenya and almost all the remainder from Busia district.

The analysis of household survey data from five villages in Banda sub-county and five villages in Sigulu sub-county, Bugiri district also suggested that fisherfolk moving to these sub-counties from Busia district, along with “fisherfolk” already resident in these sub-counties, were less likely to receive treatment for *S.mansoni*.

By way of illustration, the uptake of praziquantel and albendazole among adults at the 10 selected villages was 43% in 2007 and 34% in 2008. Moreover, 93% of those who did not take the drug in 2008 reported that they had no idea that free drugs were distributed that year. To make matters worse, no drugs were distributed to adults in the following year, because the District Vector Control Officer was ill. No-one was appointed to replace him, and the whole programme ground to a halt.<sup>27</sup>

The migration of large numbers of fisherfolk from Busia district to Banda and Sigulu sub-counties in Bugiri sheds light on the higher prevalence of *S.mansoni* reported by staff from the Ministry of Health in this district. That is, the prevalence of *S.mansoni* among adults was reported to be 46% in Banda sub-county in Bugiri district (personal communication with vector control officer).<sup>28</sup> However, this is by no means the only reason for the higher recorded prevalence. Other explanations include the fact that 18 of the 39 villages in Bugiri district are located on the lake shore and water and sanitation facilities are very limited as the soil is often too light to support pit latrines and the water from bore holes is much too salty to drink. There have also been no attempts to enforce by-laws that will help to interrupt the life-cycle of schistosomiasis and soil-transmitted helminths; and there are, undoubtedly, unique challenges to reducing the transmission of *S.mansoni* and soil-transmitted helminths among fisherfolk on the islands. In Sigulu sub-county, for example, there are 142 inhabited islands. The expenditure required to cover the cost of fuel to even reach these islands is considerable. Nevertheless, they need to be overcome as 98% of adults in the sub-county reported that they had not received any treatment in the last two years and some of those that had received treatment had been made to pay local councils for the drugs. Investigation of the clinic on the biggest island, Sigulu, revealed that there were five large unopened tins of praziquantel tablets, suggesting that the picture is much more complex than overcoming logistical and budgetary constraints.

## Conclusions

The term “fisherfolk” embraces a rather amorphous and highly varied category as it includes people who fish for others, people who fish occasionally and people who seek their livelihood almost entirely from fishing with no supplements from agricultural production. While the political, economic and social contexts in which livelihoods based on small-scale fishing varies considerably within Uganda, fisherfolk is nonetheless a useful broad category. Whatever the marked differences between groups, it seems that in all parts of Uganda, local fishermen and those connected with them are viewed with suspicion by officials; and they are often resented or disparaged by less mobile residents involved predominantly in agriculture. Partly as a result, they are often overlooked by aid and health care programmes. Similarly hostile attitudes and a lack of support prevail with respect to many of those involved in border smuggling activities; although some groups or networks of traders in commodities such as fuel have successfully established mechanisms to protect and enhance their livelihoods by co-opting local government officials, police and soldiers where necessary.<sup>29</sup> While fisherfolk may attempt to act in a similar way, they have not been very successful at any of the locations studied. A further point is that when there is investment in the fishing industry, it is almost exclusively aimed at larger-scale exploitation of fish stocks, professionalization of fishermen or other schemes that systematically exclude small-scale fishing, processing and marketing. In other

words, it deliberately undermines the livelihoods of fisherfolk rather than encourages or assists them. To what extent is the effort to control schistosomiasis among fisherfolk in Uganda an exception to all of this? Are they receiving treatment? Are rates of infection declining? The straightforward answer is that the evidence is not as robust as it ought to be, but in so far as it has been possible to assess current processes, results are far from uniform.

Of the three areas studied, mass drug administration has probably been most effective in Dufile sub-county. Dufile shares a border with southern Sudan, a country which currently lacks a National Control Programme for the control of schistosomiasis and other NTDs. However, migration patterns in the sub-county have been outwards in recent years and the Ugandan programme for the integrated control of NTDs has thus not been affected by the regular influx of Sudanese migrants infected with parasites. Moreover, all Sudanese residing in Uganda have been offered the tablets in schools and villages; and the majority of Ugandan Madi adults, including fishermen and those associated with them, have received treatment at some point. This reflects a general receptiveness to biomedical interventions among Madi people, which is not restricted to mass drug administration. In short, the combination of out-migration and availability of tablets to fisherfolk and riverine residents seems to have had a positive effect. Epidemiological data are largely unavailable, but there are indications that rates of infection are currently low, even among fisherfolk resident on islands in the Nile.

The situation is rather different in Panyimur sub-county. The sub-county shares a border with the DRC. In common with southern Sudan, there is no national programme seeking to control schistosomiasis, but hundreds of fisherfolk move backwards and forwards across the Congolese–Ugandan border to buy and sell fish and other products at the weekly market in Panyimur. Almost all the Congolese migrants coming into Panyimur were found to be positive for *S.mansoni*, and soil-transmitted helminths. These migrants contribute to the on-going transmission in this part of Uganda.

The overall self-reported uptake of drugs among adults in Panyimur was slightly lower than that reported in Dufile sub-county. Nevertheless, fishermen and other adults with mobile lifestyles have not been excluded from the programme by the community drug distributors. In other words, while mobility and fisherfolk lifestyles contributed to the low uptake of drugs in the successive rounds of distribution, the primary reason for low uptake relates to widespread questioning of the rationale for distributing free treatment, including suspicion, fear and anxiety about the “real” motivations of government officials running the disease control programme. The combination of in-migration by heavily infected Congolese with a low uptake of drugs among adults explains the high re-infection rates noted among school children. However, most resident adults report having taken praziquantel at least once, including full-time fishermen. This may well provide them with a degree of protection from the serious symptoms that can arise from infection with *S.mansoni*.

The situation in Lumino sub-county, southeastern Uganda is different again. Lumino shares a border with Kenya, a country that like Sudan and the DRC does not currently have a national control programme for schistosomiasis or other NTDs. The movement of fishermen across the border may have some effects on the prevalence, but those recorded indicate that they are low. Several factors combine to explain this: first, the uptake of drugs is relatively high among residents, including those currently working at the landing sites and who are fishing from bases in the

district. Second, there is a political commitment to develop ecological fishing and to clean up the areas near the new fish processing factory. Expensive new fishing licenses are now required, and various compliance procedures are imposed that prevent defecation and bathing at the lake shore. As a result, a small fishing elite has been established that is closely connected with the authorities, while the vast majority of fisherfolk have been forced to migrate to other places, primarily in Bugiri district, including islands in the lake, where drug distribution has largely failed and where rates of infection appear to be high.

Far from being a model district for the success of the disease control programme, evidence from Lumino and neighbouring locations illustrates how counter productive policies can be for the very populations most in need of treatment. Approaches towards poor fisherfolk here are depressingly similar to those described in the literature relating to HIV/AIDS, all of which similarly deal with groups working in Lake Victoria.<sup>30</sup> This suggests that the institutionalized exclusion of the poor fisherfolk highlighted is partly a southern Ugandan problem. It is, at least for the time being, less systematic and pervasive in the northwest. In other words, there has not yet been a vigorous strategy of establishing a formalized and regulated local fishing industry based on professional fishermen, and linked to the systematic exclusion of the mass of fisherfolk.

Another factor to consider when interpreting findings from the three study areas is that northwestern Uganda has experienced protracted political and economic marginalization, and this has fostered a general sense of solidarity, linking fishermen and farmers in their resentment. It is hard to assess the localized implications of this point, not least because there are signs that the situation is changing. In Panyimur, for example, resistance to mass drug administration in 2005 was explicitly linked to concerns about the intentions of President Museveni's government. By 2009, attitudes had become less homogenous, with several credible local activists even campaigning on behalf of the President's "Movement" faction. In part, this can be attributed to the government's decision to support the extraction of oil from Lake Albert and a growing expectation that such investment will help bring putatively beneficial new developments to this part of the country. If that happens, then the problems faced by the former fisherfolk of Busia may be replicated. Moves are already underway to "improve" the landing sites around Lake Albert and, while writing this paper, a research assistant rang from Panyimur to say that new restrictions on fishing in Lake Albert were being implemented, not dissimilar to those introduced in the southeast to restrict fishing activities in Lake Victoria. It is possible, then, that increased investment in the area will have similar effects, and will force large numbers of fisherfolk to continue their activities across the border in the DRC, where rates of infection with *S.mansoni* are very high.

In sum, fisherfolk ought to be a primary focus for schistosomiasis control in Uganda, but, in practice, endeavours to treat them have been haphazard, erratic and location specific. In some instances, efforts have been made to reach them and ensure that they are offered tablets, but there is no effective monitoring, and it is difficult to gauge what proportion of fisherfolk have swallowed the tablets. In other instances, they are largely ignored, actively harassed or excluded. In Uganda, the fact that the majority of fisherfolk secure a livelihood near, and often across, international borders compounds disparaging attitudes that prevail against them, especially among government officials. When praziquantel tablets and other medicines reach them, it is due to their links with mainland villagers and whether or not they have personal

relationships with the volunteers and primary school teachers handing out the tablets. All of this highlights a rather crucial point: the current reliance upon “community” drug distributors, or staff based at static clinics and schools, to regularly treat the majority of fisherfolk and other peripatetic border populations is flawed. An engagement with the realities of fisherfolk and other border livelihoods is a prerequisite for moving forward. Sadly, prejudice militates against such action.

### **Ethical clearance and acknowledgements**

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### **Notes**

1. Southern Sudan became the Republic of South Sudan on July 14, 2011.
2. McPherson, “Health Service Delivery and other HIV/AIDS Related Interventions in the Fisheries Sector in Sub-Saharan Africa,” 6.
3. Westaway, Seeley, and Allison, “Feckless and Reckless or Forebearing and Resourceful?,” 663.
4. Tanzam and Bishop-Sambrook, “The Dynamics of HIV/AIDS in Small Scale Fishing Communities in Uganda”; Kher, “Review of Social Science Literature on Risk and Vulnerability to HIV/AIDS among Fishing Communities in Sub-Saharan Africa.”
5. Kher, “Review of Social Science Literature on Risk and Vulnerability to HIV/AIDS among Fishing Communities in Sub-Saharan Africa.”
6. Grellier et al., “The Impact of HIV/AIDS on Fishing Communities in Uganda”; Kher, “Review of Social Science Literature on Risk and Vulnerability to HIV/AIDS among Fishing Communities in Sub-Saharan Africa”; Kissling et al., “Fisherfolk Are among Groups Most at Risk of HIV”; Seeley and Allison, “Overcoming Barriers to Delivery of Effective Health Services for Fisherfolk”; Seeley, Tumwekwase, and Grosskurth, “Fishing for a Living but Catching HIV”; Westaway, Seeley, and Allison, “Feckless and Reckless or Forebearing and Resourceful?”
7. Allen, “AIDS and Evidence.”
8. The findings presented in this paper are part of a research programme led by the two lead authors, Melissa Parker and Tim Allen, in East Africa from 2005. The other named authors are post-graduate students who worked alongside the lead authors in the field for a period of one to three months either in 2008 or 2009. They were undertaking fieldwork for their MSc dissertations and/or preparing doctorate research proposals.
9. Parker, Allen, and Hastings, “Resisting Control of Neglected Tropical Diseases.”
10. See, for example, Kabatereine et al., “The Control of Schistosomiasis and Soil-transmitted Helminths in East Africa”; Zhang et al., “Parasitological Impact of 2-year Preventive Chemotherapy on Schistosomiasis and Soil-transmitted Helminthiasis in Uganda”; RTI International, “Neglected Tropical Disease Program, Uganda.”

11. Parker, Allen, and Hastings, "Resisting Control of Neglected Tropical Diseases"; Parker and Allen, "Does Mass Drug Administration for the Integrated Treatment of Neglected Tropical Diseases Really Work?"; Allen and Parker, "The 'Other Diseases' of the Millennium Development Goals."
12. Parker and Allen, "Does Mass Drug Administration for the Integrated Treatment of Neglected Tropical Diseases Really Work?"; Allen and Parker, "The 'Other Diseases' of the Millennium Development Goals."
13. Kabatereine et al., "Impact of a National Helminth Control Programme on Infection and Morbidity in Ugandan Schoolchildren."
14. French et al., "Observed Reductions in *Schistosoma mansoni* Transmission from Large-scale Administration of Praziquantel in Uganda."
15. Brooker et al., "Rapid Assessment of *Schistosoma* Mansonii: The Validity, Applicability and Cost-effectiveness of the LOT Quality Assurance Sampling Method in Uganda."
16. Brooker et al., "Rapid Mapping of Schistosomiasis and Other Neglected Tropical Diseases in the Context of Integrated Control Programmes in Africa."
17. www.SCI.org.uk (accessed on November 15, 2008).
18. Standley et al., "Epidemiology and Control of Intestinal Schistosomiasis on the Sesse Islands, Uganda."
19. Parker and Allen, "Does Mass Drug Administration for the Integrated Treatment of Neglected Tropical Diseases Really Work?"; Allen and Parker, "The 'Other Diseases' of the Millennium Development Goals."
20. Allen, "Coming Home"; Allen, "The Quest for Therapy in Moyo District"; Allen, "Upheaval, Affliction and Health"; Allen, "The Violence of Healing"; Allen, *Trial Justice*.
21. Parker, Allen, and Hastings, "Resisting Control of Neglected Tropical Diseases."
22. See, for example, research undertaken by: Dunne et al., "Applied and Basic Research on the Epidemiology, Morbidity, and Immunology of Schistosomiasis in Fishing Communities on Lake Albert, Uganda"; Satti et al., "Specific Immunoglobulin Measurements Related to Exposure and Resistance to *Schistosoma* Mansonii Infection in Sudanese Canal Cleaners"; Karanja et al., "Resistance to Reinfection with *Schistosoma* Mansonii in Occupationally Exposed Adults and Effect of HIV-1 Co-infection on Susceptibility to Schistosomiasis."

There are some indications that immunity to infection can develop as a result of high levels of IgE antibody levels following chemotherapeutic treatment (Dunne et al. "Immunity after Treatment of Human Schistosomiasis"; Satti et al., "Specific Immunoglobulin Measurements Related to Exposure and Resistance to *Schistosoma* Mansonii Infection in Sudanese Canal Cleaners"; Karanja et al., "Resistance to Reinfection with *Schistosoma* Mansonii in Occupationally Exposed Adults and Effect of HIV-1 Co-infection on Susceptibility to Schistosomiasis"). However, it has been suggested that resistance of this kind does not occur in children (Walter et al., "Increased Human IgE Induced by Killing *Schistosoma* Mansonii in Vivo is Associated with Pretreatment Th2 Cytokine Responsiveness to Worm Antigens"). Also, Hagen et al. ("Human IgE, IgG4 and Resistance to Reinfection with *Schistosoma* Haematobium") have argued that praziquantel may actually have the opposite effect: treatment can lead to high levels of IgG4 antibodies and susceptibility to re-infection; and Pinot de Moira et al. ("Analysis of Complex Patterns of Human Exposure and Immunity to Schistosomiasis Mansonii") have suggested that observed ethnic and sex-related variations in rates of re-infection with *S. mansoni* can be attributed to exposure to infection rather than immunological responses following treatment. They have also shown that age-related differences in re-infection are linked to the balance between IgE and IgG4 antibodies which, in turn, is positively related to resistance to re-infection. Overall, these remain hotly contested matters of debate among immunologists and parasitologists.

23. Hagen et al., "Human IgE, IgG4 and Resistance to Reinfection with *Schistosoma* Haematobium"; Pinot de Moira et al., "Analysis of Complex Patterns of Human Exposure and Immunity to Schistosomiasis Mansonii."
24. Dunne et al., "Immunity after Treatment of Human Schistosomiasis"; Satti et al., "Specific Immunoglobulin Measurements Related to Exposure and Resistance to *Schistosoma* Mansonii Infection in Sudanese Canal Cleaners."; Karanja et al., "Resistance

- to Reinfection with *Schistosoma Mansoni* in Occupationally Exposed Adults and Effect of HIV-1 Co-infection on Susceptibility to Schistosomiasis.”
25. Walter et al., “Increased Human IgE Induced by Killing *Schistosoma Mansoni* in Vivo is Associated with Pretreatment Th2 Cytokine Responsiveness to Worm Antigens.”
  26. Beach Management Units were created in 2003 in Uganda. They register fisherfolk throughout the country and take responsibility for enforcing fishing policies that have been agreed among East Africa countries. Their influence varies throughout Uganda and they have a strong presence in Busia district.
  27. While these figures are much lower than that reported for neighbouring Busia district, the majority of adults (73%) reported that they had received drugs for *S.mansoni* and soil-transmitted helminths, with 31% of them saying they had taken praziquantel once since 2004 and 42% saying they had taken it more than once.
  28. Interestingly, data collected by Pinot de Moira and colleagues in Mayuge district, the district which lies immediately to the west of Bugiri district, revealed a high rate of re-infection for *S.mansoni* among selected primary school children. That is, 94% were positive for *S.mansoni* before mass treatment and 93% were re-infected 12 months later. The intensity of infection, as measured by geometric mean egg counts, was similarly unaffected with the GM egg count being 172.73 among children sampled immediately before treatment and 103.04, 12 months after treatment (personal communication with Pinot de Moira, September 2011.)
  29. See, for example Flynn and Titeca, “Trading in the Twilight between State and Society” and Titeca, “Tycoons and Contraband.”
  30. For example: Grellier et al., “The Impact of HIV/AIDS on Fishing Communities in Uganda”; Kher, “Review of Social Science Literature on Risk and Vulnerability to HIV/AIDS among Fishing Communities in sub-Saharan Africa”; Kissling et al., “Fisherfolk Are among Groups Most at Risk of HIV”; Seeley and Allison, “Overcoming Barriers to Delivery of Effective Health Services for Fisherfolk”; Seeley et al., “Fishing for a Living but Catching HIV”; Westaway, Seeley, and Allison, “Feckless and Reckless or Forebearing and Resourceful?”

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