Sleeping sickness surveillance: an essential step towards elimination

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Summary
In the last decades, with little or no surveillance sleeping sickness has returned to alarming levels comparable to the early twentieth century. Sixty million people are considered at risk but only 3–4 million are under surveillance, yielding some 45 000 new cases annually. It is estimated that at least 300 000–500 000 people are presently infected. Despite the almost universal presence of the vector in sub-Saharan Africa and the existence of an animal parasite reservoir, it is technically feasible to control and eliminate the disease as a public health problem. The authors describe, step-by-step, a surveillance method based on the epidemiological status of the village and using several approaches ranging from passive to active surveillance. Co-ordinated by the WHO, such surveillance has been incepted in several countries. Epidemiological data is spatially linked to the village, whose geographical co-ordinates are collected using a Global Positioning Systems (GPS). Information is transmitted to WHO through internet. Data analysis and mapping is carried out using Geographical Information System (GIS) software and thematic maps are generated to illustrate epidemiological status. Examples from Central African Republic (CAR), Cameroon and Gabon illustrate the process and mapping.

keywords human African trypanosomiasis; sleeping sickness surveillance, GPS, GIS, HAT-epidemiological mapping

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Introduction
The return of ancient communicable diseases such as sleeping sickness (Cattand 1988; Van Nieuwenhove 1992) is a growing concern. In industrialized countries, where communicable disease mortality has greatly decreased over the past century, the concern is to prevent diseases from entering. In developing countries, it is to detect communicable disease outbreaks early to stop their spread and potential impact on population dynamics and the local economy (Budd 1999). One means of addressing these objectives is through strong surveillance systems. In view of the disparity among national systems, partnerships in global surveillance are a logical starting point in this area of common commitment. Rapidly developing communication systems provide the opportunity to reinforce and expand networking for better and more timely information sharing. In recent years, alarms over emerging and re-emerging diseases have resulted in a number of national and international initiatives to improve surveillance and control of communicable diseases.

Surveillance
The principle of surveillance
Epidemiological surveillance consists in observing disease occurrence within a given population (Thacker & Berkelman 1988). It is defined as the ongoing systematic collection, collation, analysis, and regular interpretation of sanitary information for the description and continuous observation of a disease (Thacker et al. 1988). The end of the chain of activities comprising the surveillance process provides information essential for the planning, execution
and evaluation of public health. The goal is to improve prevention and control of diseases. Thus the timely delivery of information to those who can act on it is an essential component of surveillance (Orenstein & Bernier 1990).

Sleeping sickness surveillance approaches

There are four implementation approaches, each having its advantages and disadvantages, to epidemiological surveillance of sleeping sickness. They can be used individually or in combination. It is generally considered more effective to combine two or more of them.

The fixed health post-surveillance approach is often called ‘passive surveillance’, although the term passive is not suited for a willful action, as there is strong awareness of case-finding. Patients who spontaneously seek medical assistance in dispensaries or health centres are examined for specific signs and symptoms. If infection is suspected, the patient is referred to a specialized centre for diagnosis and treatment. Such an approach alone is insufficient to control sleeping sickness, which has an extended asymptomatic pre-clinical course, making it difficult to diagnose at an early stage, when it is most dangerous for the community.

The sentinel surveillance approach is restricted to carefully selected health centres or hospitals. Reporting is similar to that of fixed post semiactive surveillance. The limited geographical coverage of such surveillance generally provides a major bias in terms of knowledge in disease distribution. But the technical case-finding methods can be highly sophisticated because human and financial resources are concentrated in a few places. In sentinel surveillance, any occurrence of the disease is immediately shared with decision-makers. This approach is well suited for the surveillance of particular events such as drug resistance.

The active surveillance approach consists of mobile teams actively searching for the disease among a given population. This is the only approach suitable for a disease with an extended asymptomatic pre-clinical course such as *gambiense* trypanosomiasis. Active surveillance can deal with one or several diseases. Methods used for diagnosis can be more or less elaborate. The feasibility of a multidisease integrated active surveillance approach depends on the available logistics. Active surveillance is generally exhaustive within a pre-determined geographical area considered at risk.

WHO’s role in disease surveillance

In 1995, the World Health Assembly expressed their concern in a resolution, urging all WHO member states to strengthen surveillance for infectious diseases to promptly detect re-emerging infectious diseases and identify new ones. The World Health Assembly recognized that the success of this resolution depends on the ability to obtain information on infectious diseases and the willingness to communicate this information nationally and internationally. Improved detection and surveillance, moreover, will lead to better prioritizing of public health efforts. In 1984, WHO launched a programme entitled ‘Trypanosomiasis prevention and control in the framework of primary health care’, with the aim of promoting sleeping sickness surveillance and control activities by providing expertise for the planning, establishment, maintenance and fine-tuning of field activities. Subsequently, WHO enhanced its co-ordinating role and strongly promoted networking (WHO 1987). Finally, in 1999, a Surveillance Support Office was established in Yaounde, Cameroon, to assist endemic countries in developing and implementing a solid surveillance system. While WHO does not assume the responsibilities of national authorities, it provides the technical support and international co-ordination required to facilitate collaboration between national programmes in endemic countries (WHO 1998).

Sleeping sickness

Human African trypanosomiasis or sleeping sickness is a parasitic disease caused by a unicellular parasite, the *trypanosome*. It is transmitted to man through the bite of the blood-sucking tsetse fly *Glossina*. Two forms of the disease occur, due to two distinct subspecies of trypanosomes: *Trypanosoma brucei gambiense* and *T.b. rhodesiense*. Both forms will evolve into a central nervous system infection and, without treatment, cause death. *Trypanosoma brucei rhodesiense* causes an acute infection lasting from a few weeks to a few months. This form of the disease...
prevails in eastern and southern Africa. Infections caused by \textit{T. b. gambiense} are chronic, lasting for years, with a latent period which may be several years long before the patient shows any major clinical signs. Infections caused by \textit{T. b. gambiense} are typically found in Western and Central Africa. This difference in clinical expression of the two forms dictates the surveillance approach to be used (WHO 1999).

The impact of sleeping sickness in terms of public health lies not in the annual incidence, but in its potential for the development of explosive epidemics causing thousands of deaths. If incidence alone is considered, the disease appears as a minor health problem compared with other parasitic diseases like malaria and helminthic infections. However, because of its severity, a single case in a family will affect all members (Kuzoe 1989). Outbreaks not only affect families but also place a major burden on the whole community by reducing the labour force, interrupting agricultural activities, disrupting the local economy and jeopardizing food security. In the past, many thousands of people have died during large-scale epidemics. If the Disability Adjusted Life Year (DALY) figures (i.e. loss of healthy life years by premature mortality and disability) are considered, the social and economic impact of trypanosomiasis ranks third behind malaria and schistosomiasis in sub-Saharan Africa (A. Moore, personal communication). The number of deaths due to Human African Trypanosomiasis (HAT) each year is estimated at 100 000. Populations fleeing sleeping sickness leave behind them vast deserted regions (Ekwanzala 1996). A comparable exodus due to a disease can only be found in regions with river blindness, caused by the filarial \textit{Onchocerca volvulus}. Dissemination of sleeping sickness can be effectively prevented by regular surveillance of the population at risk, including diagnosis and treatment, and in certain areas, by controlling the tsetse fly population.

The epidemiology of sleeping sickness is characterized by its occurrence in discreet foci. Over time the geographical extent of foci changes significantly, because of environmental changes favouring or hindering the fly’s multiplication, density and dissemination (Leak 1999). Flare-ups often occur within larger endemic areas. This peculiarity requires tailoring surveillance and control to curb transmission and spread of the disease. Without surveillance and control, the disease will amplify until the human population is decimated or until the last survivors abandon the affected area for fear of infection (Ekwanzala 1996).

Sleeping sickness-endemic areas receive their names from local geographical features such as valleys, rivers, villages or towns (i.e. Sinfra focus in Cote d’Ivoire, Busoga focus in Uganda, the Couloir focus in the Republic of Congo, the Lambwe Valley focus in Kenya, etc.). Constant changes in the epidemiological status and geographical extent of sleeping sickness foci render analysis of their evolution extremely difficult. Surveillance and control reports rarely provide adequate detail: While positive results are given, reports often omit negative ones. Generally, the figures cannot be associated with a constant geographical area or to a defined population. Appropriate and coherent implementation of control activities cannot take place without detailed knowledge of disease distribution and intensity. Consequently, it became evident that a suitable epidemiological surveillance method, which would provide precise and standardized information of the disease occurrence and extent was needed (WHO 1986).

**Surveillance method development**

A surveillance system must answer a need, which in sleeping sickness concerns avoiding the occurrence of a deadly epidemic. The system must be useful, simple, sensitive, specific, adaptable, reactive and acceptable. Thus it must be a compromise between ‘ideal’ and ‘operational’. It must be efficient and cost-effective, taking into account field constraints and available means. Bearing these parameters and the need of a consistent system in mind, a geographical standard unit was required for reporting. With the advent of Global Positioning Systems (GPS) and computer based Geographical Information Systems (GIS), it became evident that, from an operational point of view, villages and hamlets would be the most appropriate reporting unit. This is opposed to the classical concept of reporting prevalence of whole endemic or epidemic areas. By obtaining the spatial co-ordinates of villages and hamlets, they can be unequivocally identified and all information of interest to the epidemiologist and other staff responsible to control diseases could then be attached to this clearly identified geographical ‘unit’.

In areas where disease control activities were ongoing, the surveillance system would use the observations made during operations: case search, diagnosis and treatment, vector control. The data collected would then be analysed to evaluate control operations; thus surveillance is also a monitoring tool. In areas without control operations, a minimal amount of data would be collected to assess the epidemiological situation. It is no longer a simple observation of ongoing activities, but an activity of its own. The analytical results would then provide the information necessary to identify the resurgence of the disease and its epidemiological trend; thus surveillance is a warning tool.
Constructing the surveillance system

The construction of a surveillance system starts with specifying its expected functions and qualities. The list is exhaustive and disregards any existing or expected constraints at first; it matches the need of an ‘ideal’ system. Each item is then described, detailing implications and expected constraints. Next, the list is adjusted to ensure usefulness of each item, taking into account unsurmountable limitations and constraints. The coherence of the system is then verified and the technical steps and procedures of each element are carefully set out. Further adjustments take account of difficulties encountered during the descriptive phase of the technical and procedural steps. This process is repeated until the system becomes as simple, effective and acceptable to end-users as possible.

Ultimately the epidemiological surveillance will aim at obtaining annual minimal information on the epidemiological situation in each village located in any given endemic zone or area at risk. Specific objectives of the

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**Figure 1** Map showing villages with known co-ordinates in an area at risk and villages with known epidemiological status in micro-foci under control. + endemic village, ○ disease-free village, ● village of unknown epidemiological status.

**Figure 2** Map showing additional villages with geographical co-ordinates in risk area.
system are to identify all villages situated in endemic or at-risk areas, to accurately describe disease spread, assess surveillance coverage, determine the epidemiological intensity of the disease and establish the epidemiological profile of each endemic area, and finally, analyse the data obtained to identify the dynamics of disease development in time and space. Surveillance should not be confused with the notion of active or passive case-finding surveys or campaigns, which are part of control.

Organization of surveillance

There are two sleeping sickness surveillance levels: qualitative and quantitative. At the first level, villages in

Figure 3 Map showing villages previously endemic for sleeping sickness (previous 4 years). Thus in addition to the three signs found in Figure 1, a ▲ will indicate villages previously endemic for the disease.

Figure 4 Map showing villages and their epidemiological status grouped into different operational endemic and risk areas.
any area under surveillance are classified either endemic or free of the disease; at the second level, endemic villages are classified by the intensity of their endemicity. Information necessary to classify villages qualitatively and quantitatively can be acquired separately or concomitantly.

### Sleeping sickness case definition

The following definitions have been adopted for surveillance purposes: any person harbouring trypanosomes in any body fluid is considered infected. Any person with suggestive clinical signs and symptoms or with a
positive serological test result without parasitological confirmation is suspected to be infected. Seronegative people living in endemic areas where conditions for transmission are met, despite the possibility of false negativity of the test, are considered free of the disease, but at risk.

**Figure 7** Distribution and extent of risk areas based on the 259 present and former sleeping sickness foci on the African continent.

**Figure 8** Number of new cases between 1950 and 1999 in Central African Republic showing the notable increase of cases in the last 10 years.
First-level or basic surveillance

Minimal disease information is collected from all villages in the area concerned. The geographical coverage must be as wide as possible. Villages are classified into four groups: endemic, suspect, free of sleeping sickness, and of unknown epidemiological status. Endemic villages are those where one or more cases have been identified during the current year, or, if no data are available for the current year, where cases were found during the previous 4 years. These villages will retain their status until confirmed or invalidated by an exhaustive case search. Villages free of sleeping sickness are those where a serological survey took place and no seropositive individuals were identified, whereas suspect villages are those in which a serological survey has disclosed seropositive individuals but none could be parasitologically confirmed. The identification of a parasitologically positive individual will place the village among endemic villages. Villages of unknown epidemiological status are those for which no information is available for the past 5 years (current year + 4 previous years).

A group of endemic villages defines an area at risk, called a focus for practical purposes. An area comprising suspect villages only (with unconfirmed seropositive cases) is defined as a high-risk area. An area with villages free of sleeping sickness (with no cases or suspects) is a nonendemic area. Suspected areas are those where sleeping sickness occurred in the past. Areas encompassing villages of unknown epidemiological status provide the limit of the surveillance coverage. Any village previously classified free of sleeping sickness will become endemic if a case is identified and will form a new focus or will be attached to a neighbouring one. Any changes in the epidemiological status of a village will be immediately notified to national health authorities regardless of the intensity of the disease.

Figure 9 Distribution of risk areas in Central African Republic based on distribution of cases by villages in the last 10 years.
The quality of a surveillance system is determined by the extent of its coverage and the amount of useful epidemiological information it makes available. The objective is reached when there are no more villages without information for any particular year. In endemic areas, information is elicited through the usual activities of control programmes, in nonendemic areas it is acquired through specific surveillance activities.

In certain endemic areas, existing information permits identification of the village of origin of patients diagnosed and treated during the current or previous years. Villages can thus be classified on this basis. Epidemiological information from areas where no activities have taken place is gathered in the simplest and least expensive way to obtain the minimal information necessary to classify villages. Minimal surveillance includes testing a proportion of the population by immunological methods such as the microcard agglutination trypanosomiasis test (micro-CATT) on dried blood samples collected on filter paper. The samples are analysed in a laboratory; positive samples from a village with or without specific individual information on the patients themselves will allow to classify this village ‘suspect’. Surveillance information using serology should be collected each year. While serology has its

![Figure 10](imageurl) Map illustrating the outcome of surveillance in the Nola area.

![Figure 11](imageurl) Evolution of number of reported cases in Cameroon in the past 10 years. In the past 5 years the number of cases has not been alarming. Recrudescence is observed in 1998 and 1999.
limitations due to inevitable false reactions, changes in seroprevalence rates are highly significant.

**Second-level surveillance**

This type of surveillance initially addresses areas highly suspected or known to be endemic and then extends to other risk areas. The process will identify, localize and classify surveyed villages, providing decision-makers with prevalence figures, apparent incidence and the extent and epidemiological profile of the area. All data collected in the field by mobile teams and from patient files in treatment centres are fed into the GIS database. One of the major difficulties in the collection of retrospective data is to ensure that the information is effectively associated to spatially defined villages.

**Implementation of surveillance, step by step**

Step 1: In a defined area the mobile team systematically records the geographical co-ordinates of all villages through which they travel while doing a selective survey for control purposes (Figure 1). Each village is then rated as: (1) a village with geographical co-ordinates only, no survey performed, mapped as a black dot; (2) a village where the case-finding survey yielded positive results, mapped as a cross; (3) a village where the survey yielded negative results, mapped as a small circle. Next, several endemic villages are grouped to form discrete areas, a so-called focus. The mapping codes can vary depending on the programme manager’s choice. Different colour dots to illustrate village status are also very common.

The map drawn up in step 1 does not show all villages and hamlets in the considered risk area as they have not all been visited by the team. In step 2, a special team is sent to those villages to record geographical co-ordinates (Figure 2). Village co-ordinates can also be extrapolated from an existing map when available. These ‘new’ villages also are represented by black dots on the background map, indicating that spatial information for a village is available.
but that its epidemiological status is unknown. Such a map allows evaluating the extent of surveillance.

Step 3 is analytical. The exact origin of patients is determined from survey documents of the previous 4 years. If a patient originated from an endemic village, the map does not change; but if a patient originates from a negative village or from a village of unknown status, the village is then re-mapped as a triangle (Figure 3). Triangles illustrate ‘previously endemic’ villages with cases during the past 4 years.

For practical purposes, the villages represented by a triangle are considered endemic. Thus a cross can replace triangles on the map and surveillance areas are defined by roughly circling groups of endemic and previously endemic villages in step 4 (Figure 4). These areas may include villages of unknown status if this is justified by their proximity to endemic villages. Surveillance activities shall then endeavour to ascertain the epidemiological status for the current year of all the villages in these areas.

In step 5, depending on the number and density of endemic villages and other pertinent information, a decision is taken where in the overall area, control operations should be established (Figure 5). If only a number of areas are selected for control, surveillance will be sustained in the other areas. The decision is made on the basis of disease suspicion, and human and financial resources. Priority is given to areas most likely to have the highest prevalence. In the situation illustrated in Figure 5, the decision was taken to implement exhaustive case-finding in area 1 and to treat all patients. Concurrently, in this same area, an exhaustive list of the villages was drawn up with their epidemiological status. In areas 2, 3 and 4 it was decided to sustain serological surveillance to determine village epidemiological status. Suspect villages were then mapped as an equal sign, which revealed that some of these areas would require control activities. It was further decided that control operations would start as soon as possible, based on the availability of the necessary resources.

Figure 13 Status of villages in the Mbam area of Cameroon.
During case-finding or serological surveys, in addition to geographical co-ordinates, information on village population, name, health facilities, water sources, etc. is verified and, where necessary, corrected or completed. Ultimately, all villages and hamlets in the area are mapped and assigned an epidemiological status.

Step 6, again, is an analytical process to determine the extent of the focus. Where justified, foci are grouped together to form a wider area. As the surveillance system is expected to function as an alarm, a buffer zone is further drawn around the focus and surveillance extended to this area (Figure 6). Should any one village in the buffer zone become suspect at any time, the size of the focus is increased accordingly and appropriate action taken to stop the spread of disease. Control and surveillance activities are subsequently sustained throughout the focus. Initially the buffer zone is determined depending on area history, vector, population density, environmental factors, people’s behaviour and a number of other factors known to influence transmission.

The surveillance tool is considered effective when all six steps have been achieved and activities are sustained. Each village is evaluated once a year. The data collected are analysed and maps brought up-to-date to illustrate disease prevalence, new cases, stage of the disease, etc. Once surveillance has been implemented in all foci and areas at risk throughout an endemic country, it becomes useful to decision-makers for planning national control activities.

**Disease distribution and risk areas**

Sleeping sickness being focal, it concerns only part of the population in 36 African countries. Sixty million people are estimated to be at risk of infection in some 259 discrete known areas (Figure 7), but not more than

![Figure 14](image-url)
3–4 million people are under surveillance. At least 300 000 individuals are believed to be infected, but only 10–15% diagnosed and treated. In the Democratic Republic of Congo (DRC), where 10 000 new cases were diagnosed each year in the late 1980s, surveillance and control activities ceased after the withdrawal of external technical and financial aid because of political problems. After 4 years with little or no activities, the national programme resumed surveillance and control, and the number of reported cases rose to 30 000, but it is estimated that at least 150 000 individuals have the disease. In Uganda an outbreak in 1986 produced more than 4000 cases. In Angola, the number of cases rose sixfold after operations were interrupted during the war and social upheavals. In 1999, for the first time in the history of the disease, urban and peri-urban transmission was reported in Kinshasa, DRC and Luanda, Angola (reported in respective 1999 National Sleeping Sickness Control Programme Annual Reports). More than 40 000 new cases were reported in both 1998 and 1999 throughout Africa. While each national programme in endemic countries had their successes and failures, surveillance followed by adequate control interventions remained erratic. Field interventions are prompted by emergencies rather than prevention. Figure 7 illustrates the distribution and extent of the 259 sleeping sickness-endemic and at-risk areas as evaluated at the end of 1999. In some instances the surveillance system has been extremely successful in alerting local health authorities to the growing public health problem and helped implement interventions to curb development of the disease. In a few countries, control operations could be established before the disease had reached epidemic levels, which are difficult and costly to manage.

Sleeping sickness has been known to exist in the Central African Republic (CAR) since the beginning of the twentieth century. Three areas are known to be endemic (Figure 9), but in the early 1960s, the disease was thought

![Figure 15](image-url)
to have been eliminated. The sporadic cases which still occurred were believed to be epidemiological ‘accidents’ without great consequences on the general evolution of the disease, and the risk of an epidemic was not seriously considered by health authorities. In the early 1970s, however, cases became more frequent and could no longer be considered sporadic. Informal reports from the old eastern Obo focus and from the western Nola area seemed to indicate that the disease was spreading. It was rumoured that thousands of sick individuals in the north-west were thought to be sleeping sickness cases. A survey in 1982 in the old Ouham focus partially confirmed this (Figure 8), raising some concern among health authorities. However, after some 20 years of wait-and-see policy, available expertise, human resources, material and equipment were insufficient to properly evaluate and manage the situation. Upon request by national authorities, the French Government and WHO re-enforced the national programme, a plan of action was worked out, training took place, financial means were made available and activities implemented. But the process was slow. By 1998, the number of cases had soared to more than 1000 (Figure 9), while surveillance and control activities were further reinforced. The first results of surveillance mapped in 1999 showed major gaps (Figure 10).

In Cameroon, several sleeping sickness epidemics killed many thousands in the early twentieth century, with the last epidemic occurring in the late 1970s and early 1980s. In 1983, at the peak of the flare-up, more than 3000 patients were diagnosed and treated. Control operations, which were then reinforced with the introduction of serology to facilitate exhaustive population surveys and vector control using traps and screens, ultimately waned with the decrease in number of cases. From 1993 to 1997, less than 20 cases were passively diagnosed each year (Figure 11). In 1998, surveys in the context of research projects disclosed a relatively important number of new cases. Surveillance was partially implemented in several areas and results mapped (Figure 12). Each of the areas considered at risk (Figure 13) is now being screened to assess the epidemiological situation, which so far has not yet extended to even mapping all villages, pointing to the insufficiency of the existing surveillance system.

In Gabon, several areas have been known to be endemic in the past (Figure 14). In recent years the number of reported cases has not been particularly high, but persisting foci are irritating. In 1993–95, after surveillance was implemented in the focus of the ‘Estuaire’ near Libreville and northwards towards the Equatorial Guinea focus of Cogo, some 100 cases were diagnosed each year (Figure 15). Eventually the number of cases was substantially reduced and surveillance abandoned. In 1999, a survey in that same area disclosed some 38 cases – not yet a major public health problem, but the risk of an epidemic remains. The environment is particularly suitable for transmission, as tsetse flies are universally present on the territory. There is a high risk for the disease to spread because of the common practice of the Estuaire population to travel inland for trade.

**Conclusion**

The outcome of surveillance provides information for action. It serves to monitor the disease trend, estimate the size of a health problem and detect early outbreaks. It also allows for the evaluation of the impact of preventive measures and control interventions. Surveillance monitors progress toward programme objectives.

**References**


