## The Schistosomiasis Manual

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A guide for the rapid identification of communities with a high prevalence of urinary schistosomiasis

For:-

District Health Management teams, Disease Control Programme Managers and Community Health Workers

#### **PREFACE**

This manual is intended for use by schistosomiasis control programmes for targeting *S.haematobium* at national, regional or district level. It provides a step by step guide for implementing a rapid and inexpensive method of identifying communities with a high prevalence of, and morbidity due to, urinary schistosomiasis. The assumption is that control programmes planning interventions will generally need to identify the communities with the highest prevalence and morbidity rates, so that available resources can be concentrated where they are most needed.

The aim of this Guide is to introduce a powerful tool which control programmes can use as a first stage in the control process. It does not discuss the organization of subsequent control strategies or activities. A French version of the Guide is also being prepared.

The Guide is based on work that was initially conducted by the Swiss Tropical Institute in Tanzania <sup>1,2</sup>, and then repeated in seven other African countries by the "Red Urine" Study Group <sup>3</sup>.

The authors of this Guide would like to acknowledge their debt to all the research workers who participated in the earlier studies. Their combined experience made this publication possible.

## **CONTENTS**

		A RAPID IDENTIFICATION METHOD FOR COMMUNITIES WITH A HIGH PREVALENCE OF URINARY SCHISTOSOMIASIS	
1.1.	INTRO	DUCTION  1.1.1 Outline of the problem 1.1.2 The rapid assessment method 1.1.3 The basis of the method 1.1.4 The reliability of the method 1.1.5 Limitations to the use of the method	1 1 1 2 3 3
1.2	ТНЕ Q	UESTIONNAIRE SURVEY AS A FIRST STEP IN CONTROL 1.2.1 Selection of communities for control measures 1.2.2 A note on possible control measures 1.2.3 Case-detection by teachers	4 4 5 5
SECT	ION 2: H	OW TO USE THE METHOD	
2.1	OVER	VIEW	6
2.2	SELEC	TION OF AREAS FOR SURVEY: SOURCES OF INFORMATION	7
2.3	THE Q	UESTIONNAIRE 2.3.1 Introduction 2.3.2 Essential elements 2.3.3 Language and comprehension 2.3.4 Pre-testing	8 8 9 10 11
2.4	ORGA	2.4.1 General 2.4.2 Discussions with district level authorities 2.4.3 Information and instructions for Head Teachers 2.4.4 Instructions for class teachers 2.4.5 Implementation	12 12 14 15 16
2.5	DATA	ANALYSIS AND PRESENTATION OF RESULTS	18
2.6	DETER	MINATION OF A CUT-OFF VALUE (OPTIONAL)	22
SECT	ION 3: V	ALIDATION OF THE METHOD	
3.1	POSSIE	BLE REASONS FOR CARRYING OUT FURTHER VALIDATION	23
3.2	VALID	ATION OF THE METHOD: OUTLINE OF PROCEDURE	24
SECT	ION 4: E	XTENSIONS OF THE METHOD	
4.1	RANKI	NG PRIORITY PROBLEMS	25
4.2	FURTH	ER ANALYSIS; THE INFLUENCE OF GENDER	26
4.3	EXTEN	SION OF THE APPROACH TO OTHER DISEASES	26
REFE APPE	RENCES NDIX	1.Example of a children's questionnaire (Tanzania) 2.Example of a map 3.Example of a Head Teachers' questionnaire (Tanzania)	27 28 29 30

## SECTION 1. A RAPID IDENTIFICATION METHOD FOR COMMUNITIES WITH A HIGH PREVALENCE OF URINARY SCHISTOSOMIASIS

#### 1.1 INTRODUCTION

#### 1.1.1 Outline of the Problem

At least 200 million people, in 74 countries, are infected with schistosomiasis and at least 600 million are at risk of infection<sup>4</sup>. People can be infected by five schistosome species, but only three are found on the African continent. *Schistosoma haematobium*, the cause of urinary schistosomiasis, is present in 44 African countries, while *S. intercalatum* and *S. mansoni* are endemic in 10 and 40 countries respectively. These infections show marked differences within and between countries in their distribution, prevalence and intensity of infection, as well as in the resulting morbidity.

Transmission of schistosomiasis is focal - it tends to be concentrated in particular areas, because it depends on particular features of the environment, like the water-bodies people use, and the presence of the snail species that are the intermediate hosts. Therefore neighbouring areas may have very different rates of infection <sup>5</sup>. In most countries in Africa, little is known in detail about the status and epidemiology of schistosomiasis infection in large areas of endemic regions <sup>1</sup>.

This lack of detailed knowledge can be a problem for control programmes. Where resources are limited, it is clear that they should be concentrated in the areas where they are most needed - that is, in those communities where the risk of infection is highest.

Identifying communities where schistosomiasis has a high prevalence - where a considerable percentage of the people are infected - can be done by carrying out an extensive epidemiological survey, using urine filtration or other tests, but this is expensive and time-consuming. A quick way of finding out which communities should be given priority when interventions are planned is therefore needed.

#### 1.1.2 The Rapid Assessment Method

This Guide describes a rapid and inexpensive method that can be used for a first assessment to determine which communities in an area have a high risk of *S.haematobium* infection. It is intended to give practical information about using the method. Those who want to know more details about the ideas behind the procedure, and the way it has been tested, can find further information in other publications <sup>1-3,6</sup>.

The procedure is based on using simple questionnaires to find out how frequent schistosomiasis is in a community. The questionnaires are sent to primary schools, and the teachers are asked to interview school-children, asking them whether they have had schistosomiasis, or whether they have had blood in their urine. The children answer "yes" or "no", and the percentage of children answering "yes" will show clearly whether there is a lot of urinary schistosomiasis, or whether it is not a major problem.

The questionnaire method described here is only a first step in a control programme. It is not designed to pick out which individuals should be treated, only to indicate which communities are most in need of intervention. Decisions about the second step - the actual carrying-out of

control measures - will have to be made taking into consideration the local situation and resources.

#### 1.1.3 The basis of the method

The questionnaire method is based on the fact that schistosomiasis is a chronic disease, and one symptom is the appearance of blood in the urine (haematuria). This is a symptom children will be able to observe easily, and will tend to remember. Since it is not a symptom of other common diseases in children, haematuria is a clear sign of urinary schistosomiasis. In addition, in most places where *S.haematobium* infection is prevalent, people recognise it as a disease. There is a special word for it in many vernacular languages, and children will understand a question like "Did you have schistosomiasis?"

The school is an appropriate unit on which to base a survey of schistosomiasis prevalence. On the whole, when the disease exists in a community, the children of school age will have the highest infection rates, and the percentage of infected children will give a very good idea of the overall prevalence.

There are many practical advantages in carrying out a survey through the school system. Firstly, teachers are competent to carry out the interviews and fill in the questionnaires, and there will be an administrative structure through which forms can be delivered and collected. Secondly, in most countries there is a very dense network of primary schools, covering places where there are no permanent health facilities. Thus a lot of information can be collected in a short time at a relatively low cost.

These are not the only advantages of doing such a survey through the school system. The activity can help to strengthen efforts towards health education. Furthermore, because it is based on the community, the survey will arouse interest in the problem, so that when control measures are carried out people will be more likely to support and sustain them.

It is possible to combine the questionnaire for the children with others to be filled in by teachers and other well-informed people. These can show what people see as priorities for their community in health and other fields. Such information is useful not only for schistosomiasis control, but for everybody who needs to know how communities perceive priorities in health. This is discussed further in Section 4.1.

#### 1.1.4 The reliability of the method

The method of using questionnaires to find out about the prevalence of urinary schistosomiasis has been carefully tested by comparing the results with the results of standard methods using urine filtration or testing for haematuria in 7 African countries <sup>3</sup>. The results showed that the method has a very good capacity to detect high-risk schools and to rule out low-risk schools (a high "negative predictive value"). This means that communities identified as having a low prevalence can safely be set aside, and resources for intervention concentrated on other communities, without the risk that many infected people will remain untreated. The process of "validation" of the method is discussed in Section 3.

The testing phase also showed that the approach using questionnaires distributed through the school system worked well; return times were short (usually 1 month) and return rates were excellent (80-100%).

#### 1.1.5 Limitations to the use of the method

The method has been shown to be reliable, feasible and cost-effective in many countries. But before deciding to use it, programme managers should be aware of the possible limitations.

- The method works best where there is a dense network of schools, and an infrastructure that can be used for the distribution and collection of the questionnaires.
- The results obtained with school-children may not always be typical for the whole community. The results may not even give a true picture of the situation in the 9-15 year-old group, if a lot of the children of this age are not in school, or where one sex is badly under-represented. Extrapolation of the results to the whole community should only be done after a careful review of the school enrolment and the overall socio-cultural and epidemiological situation in the area.
- The methodology does not identify which child is infected. If this information is required, it will have to be obtained in a second step, using conventional diagnostic methods.
- True prevalence is usually underestimated because the method relies on recall, and those who are only mildly infected may not recall having had haematuria or schistosomiasis. However, since the purpose of the method is to **rank** communities, this underestimation is likely to be the same everywhere.
- In some countries, girls and boys may perceive the disease differently, or give different answers to questions about it. This is discussed in Section 4.2.

## 1.2 THE QUESTIONNAIRE SURVEY AS A FIRST STEP IN CONTROL

The questionnaire approach is appropriate as a first step, when a decision has already been made to launch a programme for schistosomiasis control. At a low cost, it will enable low-risk areas to be identified and set aside, and resources concentrated on areas of high risk. It also has the advantage that it can arouse interest in the disease in the community, so that the subsequent control measures may be better supported and sustained.

The approach can be used as a fast and cost-effective way of **ranking** communities according to the prevalence of infection. This ranking list will provide a basis for making decisions about which communities require intervention, and where the control measures should be carried out first. Priority-setting will be affected by many considerations <sup>7</sup>, and this Guide does not go into details of all aspects. However, some points that need to be considered when the survey is being planned are discussed briefly below.

## 1.2.1 Selection of communities for control measures

At this stage, there are two possibilities:

- a. Decide how many schools or communities can be treated with the resources at your disposal, and simply provide treatment in as many schools as possible, beginning at the top of the ranking list with the highest-risk schools and working down as far as possible.
- **b.** Decide on a "cut-off point" or "threshold of intervention". Control measures will be carried out in all the schools where the rate of infection is higher than this threshold level (for example, in all schools with more than 30% infected children). The cut-off level chosen will depend on how endemic urinary schistosomiasis is. In a country where the disease is hyperendemic, the cut-off may be at 50%, whereas in an area of lower overall prevalence, the cut-off may be lower.

Cut-off points are commonly defined in terms of the prevalence of infection as determined by biomedical testing (e.g. 50% of children with haematuria). If the questionnaire procedure is being used for screening, it will be necessary to define a cut-off in terms of the percentage of positive answers in the questionnaires. To do this, it will be necessary to find out the relationship between the percentage of positive answers and the prevalence as measured by biomedical testing. This can be done by carrying out biomedical testing in some of the schools where questionnaire interviews have been carried out. It will then be possible to calculate the percentage of positive answers ("positivity rate") that corresponds to a given prevalence of infection. This is discussed further in Section 2.6.

#### 1.2.2 A note on possible control measures

Once the target schools (or communities) have been selected, the actual nature of the intervention will have to be decided upon according to the local situation, and on the basis of calculations of comparative costs.

Again, there are two main options:

#### a. Mass treatment

In many situations, the simplest procedure will be to follow the questionnaire survey by mass treatment in schools or communities identified as being at high risk.

#### b. Selective treatment

An alternative which may be more cost-effective in some situations is to treat only the infected children. This will require a second step, in which the infected individuals are identified with a specific diagnostic test (such as reagent-sticks to detect haematuria) and then treated. This case-finding could be carried out by teachers.

#### 1.2.3 Case-detection by teachers

Experience in several countries during the testing of the questionnaire method showed that case-finding could be reliably carried out by schoolteachers, using dip-sticks to test for haematuria. The teachers learned to use this technique after a short period of training. Their results were accurate, and they did not have problems with handling urine samples <sup>1,3</sup>.

This procedure could help to relieve pressure on the health services. Teachers could prepare lists of infected children and organize their treatment, either by a health worker coming to the school or in the local health facility.

#### **SECTION 2.**

#### HOW TO USE THE METHOD

## 2.1 OVERVIEW Details are discussed in Sections 2.2 - 2.6

It is assumed that those wishing to use this methodology have already developed a control strategy, or are in the process of developing one.

- 1 Determine which areas (districts, regions) are to be surveyed.
- 2 Prepare a questionnaire adapted to the local situation.

#### 3 Organization

- Contact the regional and district health and education authorities in charge of the areas to be surveyed, and brief them on the purpose and methodology of the study.
- In consultation with the relevant authorities, identify the person at district level who will coordinate the activities.
- Obtain information about the schools in the district. Discuss the method of distribution and collection of questionnaires.
- Prepare a budget and reach agreement on financing.
- Set agreed target dates for distribution, completion and return of questionnaires.

All schools in the selected area should be included. All children in one class from each of three grades or standards covering the age-group 9 - 15 should be interviewed.

#### 4 Implementation

Produce sufficient copies of questionnaires and instructions. Forward them to district authorities for transmission to Head Teachers.
 Keep in touch with the responsible person in the district during the survey.
 Collect completed questionnaires from the district authorities.

**OPTIONAL**. Carry out biomedical testing in a sample of schools. This is ONLY necessary if a cut-off value is to be calculated or validation is needed (1.2.1;2.6;3).

#### 5 Results

- Analyse the data; rank communities according to rate of positive answers, and summarise the results in tables and maps.
- Feed the information into the next stage of the control programme, and provide feedback for all government authorities, school staff and others who were involved in the survey.

## SECTION 2. DETAILED INFORMATION ABOUT THE DIFFERENT STEPS

## 2.2 SELECTION OF AREAS FOR SURVEY: SOURCES OF INFORMATION

Schistosomiasis only occurs in certain types of environment, so some areas, such as highlands or very dry regions, will not need to be considered. However, among those regions where schistosomiasis might occur, a choice of priority areas for surveys will have to be made. The following sources may help:

#### A Health statistics

These may be available on a district or hospital basis, and can provide relevant information. For example, districts which report schistosomiasis as one of the top 10 causes of morbidity should receive a higher priority for survey than those that rarely report the infection.

## Possible problems with using health statistics

- In many countries health statistics are not uniformly reported by health facilities.
- Data from large referral centres may include patients who come long distances for treatment.

#### **B** Other sources

Where health statistics are not available demographic, ecological and historical information may assist in identifying areas for survey:

- Transmission of schistosomiasis is associated with frequent contact with water; freshwater fishing villages and places with irrigation schemes are examples of areas that should be selected.
- Densely populated areas where water is abundant are likely to have high transmission rates. (However, there can be intense transmission in small isolated communities as well).
- A review of historical data may reveal areas once known to have schistosomiasis, or may
  provide information about where vector snails have been found. A good starting point is
  the Atlas of the global distribution of schistosomiasis.<sup>8</sup>

#### AN IMPORTANT REMINDER:

Transmission of schistosomiasis is focal, therefore even in neighbouring communities there may be substantial differences in the prevalence of infection and morbidity. Therefore:

Once an area has been selected for survey, all schools in the area should be included.

#### 2.3. THE QUESTIONNAIRE

#### 2.3.1 Introduction

A sample questionnaire is given in Appendix 1.

The aim of the questionnaire is to identify communities at high risk for urinary schistosomiasis. However:

Teachers and pupils should not know that schistosomiasis is what you are interested in, or the answers may be biased.

People may be influenced by ideas they already have about schistosomiasis being a problem in the area, or they might be tempted to select children for interview who they think might have schistosomiasis.

Therefore, the questionnaire should not be focussed on schistosomiasis but on health and development problems of school children and their communities. Nothing on the forms or covering letter (including headings, instructions etc) should refer to schistosomiasis. The questions relevant to schistosomiasis are part of a list of several diseases and symptoms.

The questionnaire in Appendix 1 is the form that has been tested and shown to work. Therefore its basic format should **not** be modified. However, some adaptation will be required to make the questionnaire clear and understandable in the setting in which it will be used.

Necessary modifications may include:

- translation into local languages (see Section 2.3.3),
- changes in the lists of symptoms and diseases to include those most common in your area, if these are different from those in the original questionnaire. Symptoms and diseases should be ones children can be expected to recall.

If any other modifications are made, the new version will have to be validated.

This means that for some schools the results will have to be checked against other testing methods (see Section 3)

#### 2.3.2 The questionnaire: essential elements

See example in Appendix 1

- 1 <u>Brief instructions</u> on how to fill in the questionnaire.

  (More detailed instructions for the teacher should also be attached to the questionnaire form or sent in a covering letter; see Section 2.4.4.)
- 2 Spaces for the <u>name of the school</u> and the <u>class</u>.
- 3 Spaces to record age and sex of each child interviewed.
- 4 Question 1. Symptoms experienced in the last 2 weeks.

The teacher asks, "Did you experience (abdominal pain, blood in stool, blood in urine, coughing, diarrhoea, fever, headache, itching) during the last 2 weeks?"

The answer "Yes" "No, "Don't know" is entered on the form as a tick, a zero or a dash. (These symbols will have to be coded for computer analysis if this is used).

5 Question 2. Diseases experienced in the last 2 weeks.

(Abdominal problems, diarrhoea, helminths, malaria, respiratory infections, schistosomiasis, skin diseases).

6 Teacher's name and signature. The date of the interview.

#### **NOTES**

1. Space for answers. It is very important that all the children in each selected class should be interviewed. (Otherwise the teacher may start selecting children, e.g. those who look sick, or interview more of one sex than another).

The form must have enough space for the largest possible class, or more copies must be given to the teacher.

The questionnaire in Appendix 1 had space for 35 interviews, and more space on the back.

- 2. Division into symptoms and diseases. Questions are asked about both symptoms and diseases in order to check for consistency. The proportion of positive answers to having had "blood in the urine" should be relatively similar to that of children saying they had schistosomiasis in the last 2 weeks. If it is not, the situation may have to be further investigated (see Sections 2.5 and 4.3)
- 3. Recall period. The studies that validated the method used a "recall period" of 2-4 weeks, and 2 weeks is suggested here. However, there are workers who feel that 1 week is better. Provided that all questionnaires in a given survey are identical, 1 week could also be used.

#### 2.3.3 The questionnaire: language and comprehension.

#### Language and translation

It is vital that questions be understood by both teachers and pupils, so they must be in a language they understand. In Africa, teachers usually understand English or French well, but the pupils often do not.

The **interviews with pupils** should be conducted in the language they normally speak at home (or at least one they are really familiar with). This means that the questionnaire must be translated into the local language or languages, before it is sent out to the schools.

Teachers must not translate the questions as they interview the children, because each person is likely to translate them slightly differently.

The questions must be read out as written on the questionnaire.

If the questionnaire cannot be translated into the local language the children should be interviewed in the original language of the questionnaire.

## Comprehension

Even if the questions are in a language the children understand, they have to be carefully worded to make sure the children understand what is meant.

- There may be different local words for the symptom "urinating blood" or "blood in the urine" and the disease "schistosomiasis" (there are also places where the name "bilharzia" is better known). Talk to people who know the local culture about this.
- Other problems in understanding may arise and result in misleading results. For example, in some places "urinating blood" is so common among adolescent boys that it is considered a normal part of growing up and not a disease symptom. In other places it was found that it was better to ask "Did you have red urine?" than "Did you have blood in your urine?", because the latter is considered to be a symptom of STDs (sexually transmitted diseases) and therefore something to be concealed. Again, this must be discussed with local people.
- There is sometimes confusion when asking children to recall a past event. If the teachers think the children may not understand "in the last 2 weeks" they should be told to make it clear by mentioning a local or school event the children will remember, e.g. "since last market day", "since the football match".

## 2.3.4 The questionnaire: pre-testing

Pre-testing the questionnaire is essential to ensure that it will collect the information intended, and reduce confusion that may arise during its use.

- 1 Have the questionnaires translated back into English from the local languages by someone <u>not</u> involved in the adaptation of the questionnaire.
  - This is to ensure that what is presented in the local languages is indeed what was meant in the English version.
- 2 Send sample questionnaires to a few schools that will not be included in the actual survey, to see how well they work.
- 3 Talk to the teachers and other interested parties and discuss whether improvements can be made.
- 4 Modify the questionnaires accordingly.

#### 2.4 ORGANIZATION OF THE SURVEY

#### 2.4.1 General

The questionnaire approach needs to be carried out at a level that has an infrastructure that groups all primary schools in the area, but is still as close as possible to the community. In many countries this will be the **district** level.

A schematic diagram of the authorities involved, and how the questionnaires might be routed to schools, is shown in Figure 1.

#### **PROCEDURE**

Discuss the intentions of the survey, and the procedure, with all the people who will be involved in the survey. This kind of survey necessitates collaboration between the health and the education sectors. The translation of the questionnaire could well be done with the help of the education authorities. The authorities involved will usually include;

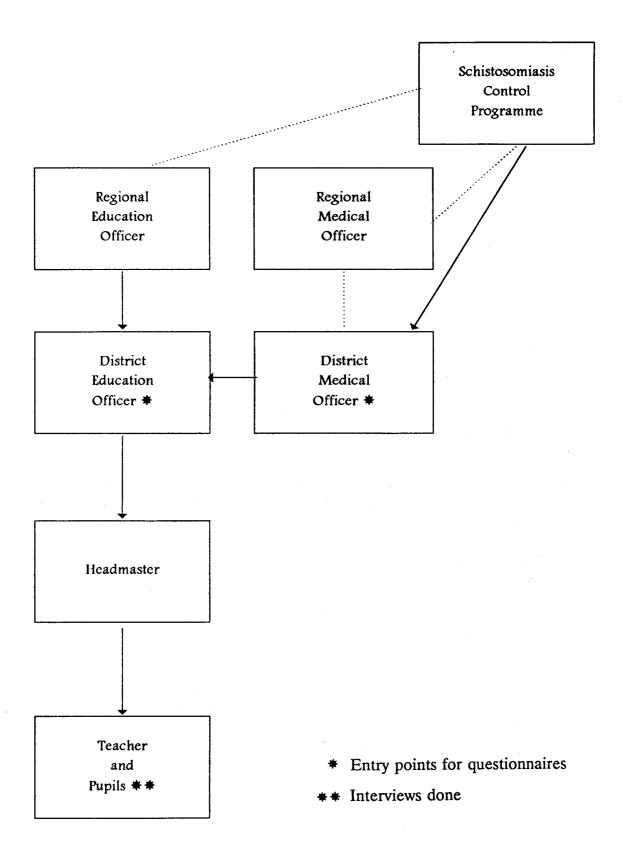
- The Regional Medical Officer (RMO).
- The Regional Education Officer (REO), who supervises education activities in the region and from whom permission needs to be sought for schools to participate in the survey.
- The District Medical Officer (DMO) and District Health Management Team (DHMT), who will be responsible for the survey in the district and liaise with district education authorities on the distribution of questionnaires.
- The District Education Officer (DEO), who will distribute the questionnaires to teachers and ensure their timely return.

Preliminary contacts can be made informally but it is important to communicate formally in writing with the various collaborating officers and thereby secure their official agreement to participate in the surveys.

Discussions with regional authorities can be general, explaining the reasoning behind the questionnaire approach and the intent of the survey.

Discussions with district authorities must be more detailed (see 2.4.2).

Figure 1. Routes for distribution of questionnaires



#### 2.4.2 Discussions with district level authorities

These discussions must be detailed and specific.

The DEO, DMO and DHMT should be told that the intent of the survey is to determine which communities in the area are at high risk for urinary schistosomiasis, and the mechanics of the survey should be explained to them.

They should also be told that to avoid biasing the results, the teachers should <u>not</u> know that the survey is directed at schistosomiasis. All teachers (including the Head Teachers) should simply be told that the survey is to find out about health and development problems affecting school children and their communities.

#### STEPS TO BE TAKEN

- 1 Agree, in consultation with the DMO and DEO, on:
  - main lines of responsibility for the conduct of the survey;
  - who in the DHMT will coordinate the survey in the district.
- 2 Prepare specific instructions for Head Teachers and the teachers who will conduct the interviews (see Sections 2.4.3, 2.4.4).
- 3 Obtain details of the number of schools in the district from the DEO. (Where possible, the number of children per class should also be obtained so that an adequate number of questionnaire forms can be sent to the selected schools).
- Work out and agree on the best **means for distributing** the questionnaires to schools. (In 7 African countries distribution and collection through the salaries vehicle worked well).
- 5 Determine the costs of the survey for the district and reach agreement on who will meet them.
- 6 Set agreed target dates for distribution, completion and return of questionnaires. Various points should be considered:
  - The questionnaire surveys should be done during the school year. Schedule survey dates that do not conflict with other school activities such as examinations!
  - Mobility is easier during the dry season where possible, avoid the rainy season.
  - Four to six weeks is usually sufficient for the questionnaires to be returned to district authorities. This will depend on the local situation.

#### 2.4.3 Information and instructions for Head Teachers

A letter or circular will need to be prepared for the Head Teachers, explaining that the survey is being carried out, requesting their cooperation, and providing specific instructions. The example below shows the information that must be included:

Remember that nothing in the letter should indicate that the survey is about schistosomiasis!

#### SAMPLE LETTER

From: The District Education Officer, M---- District.

To: Head Teachers, all Primary Schools in M---- District.

Survey of health and development problems of school children.

We should appreciate your help in the above survey.

Please ask the teacher of one class in each of the 3 grades/standards ...., ...., ....\* to interview all the pupils in the class and write the results on the questionnaire form. We enclose .... questionnaires with instructions for the teachers. There is one spare copy.

#### At each school, interviews should be completed in one day.

Please give the teachers a copy of the instructions, and enough questionnaire forms for all the children in the class. It is important that the teachers should follow the instructions carefully so that we can compare the results for different schools:

- a. All pupils in the selected classroom should be interviewed. (It is important that children should not be selected for interview because they appear to be sick. This will give a false picture of the situation.)
- b. Each pupil must be interviewed alone. It is advisable to call the pupils for interview one by one into an empty classroom.
- c. Pupils already interviewed should not discuss their interviews with those waiting to be interviewed.
- d. The teacher should not alter children's answers, even where they appear to be contradictory.

Questionnaires should be filled in within two weeks and sent back to this office as quickly as possible \*\*.

Thank you for your help.

X.X.Z. . . . .

#### **District Education Officer**

Notes \* Specify the classes according to the local system.

They should cover the age-range 9 - 15 (e.g. Standards 2, 4 and 6).

\*\* Precise instructions about return of questionnaires may be useful, e.g. "by post" or "they will be collected by ....."

#### 2.4.4 Instructions for class teachers

Instructions should be attached to each questionnaire or sent with a covering letter.

## Survey of health and development problems of school children.

#### INSTRUCTIONS FOR TEACHERS

- 1. Write the number of boys and girls enrolled in the class on the questionnaire form.
- 2. Read all the questions first to make sure you understand them before filling in the answers.
- 3. Interview all the children in the class.

  Each pupil must be interviewed alone. It is advisable to call the pupils for interview one by one into an empty classroom. Those already interviewed should not mix with those about to be interviewed.
- 4. There are two main questions on this form that your pupils are to be asked. The first is about 8 symptoms of diseases and the second is about 8 diseases.
- 5. As you start the interview, please fill in the section on age and sex of the pupil you are about to interview.
- 6. Please ask each selected pupil "Have you experienced any of these symptom(s) during the last 2 weeks?", and then read the list. Then do the same with "Have you had any of these diseases during the last 2 weeks?"

Answers should be written in the boxes as follows:

Yes =  $[\sqrt{}]$ , No = [0]

Don't know [-] (if the pupil cannot answer or remember)

# READ OUT EACH QUESTION AS IT IS WRITTEN ON THE QUESTIONNAIRE. PLEASE DO NOT TRANSLATE THE QUESTIONS DURING THE INTERVIEW.

**Note**: for younger children "during the last 2 weeks" may cause difficulties. You could refer to a local or school event that took place 2 weeks ago, e.g. "Since last market day"; "Since the football match". If you decide to do this, make sure that all the teachers in your school <u>always</u> ask the question the same way!

7. The interviewing of all the pupils in each class **MUST** be completed on the same day. Please do not alter any answer given by a pupil even if it seems contradictory to what the pupil said earlier.

#### 2.4.5 Implementation

1 **Produce** sufficient copies of questionnaires and instructions.

**Supply questionnaires** to the District Authorities for distribution, as previousy agreed (Figure 1).

- **During the survey: maintain contact** with the person responsible for the survey at district level, to follow progress, and resolve issues that may arise.
- 3 After the survey: collect completed questionnaires from district authorities for data processing.

#### 4 When the results are available:

- Feed the information into the next stage of the control programme.
- Provide feedback for all government authorities, school staff and others who were involved in the survey.

**Note:** If biomedical testing is to be carried out in a sample of schools (2.6; 3), this must be planned to take place shortly after the interviews. It may involve sending special teams to the schools, or organizing workshops to train teachers to do the testing, and collecting and checking their results.

#### 2.5 DATA ANALYSIS and PRESENTATION OF RESULTS

Data analysis can be done at district level or by the Schistosomiasis Control Programme.

#### STEP 1. Record and calculate the results for each school.

A suitable form is given in Table 1, with a space for each class.

1 For each question, "blood in urine" and "schistosomiasis", write down for each class:

Number of children interviewed Number giving positive answers P

"Don't know" is treated as "no"

#### 2 Re-check

that the numbers agree with what the teacher has noted on each questionnaire.

#### 3 Calculate

the percentage of positive answers for each class and for the whole school.

### % of positive answers

P x 100 number of positive answers N divided by number of children interviewed, multiplied by 100.

#### 4 Check

to see if the percentages of positive answers for the two questions are similar.

Note: If the percentages of positive answers are not similar (i.e. if the difference between the final percentages is more than 5 - 10), this indicates that some further investigations may be needed. There are various possibilities - they will depend on the local epidemiological situation and culture. Experience collected in other studies suggests:

- If more children answer "Yes" to the question "Did you have schistosomiasis?" than say "Yes" to having had blood in urine, this might mean that intestinal schistosomiasis (S.mansoni infection) exists in this area as well as urinary schistosomiasis (see Section 4.3).
- If a lot of children have observed blood in their urine but answer "Don't know" to the question about schistosomiasis, it may mean that they have the disease but do not recognise it as such in some languages there is no word for schistosomiasis, perhaps because people have not previously been exposed to it.

Table 1. Form for reporting survey results for each school

School:		District:	Date:		
Column 1	Column 2	Column 3	Column 4	Column 5	Column 6
Class	Number interviewed	No. positive for "blood in Urine"	Percent (%) "blood"	No. positive for "schistosomiasis"	Percent (%) "schisto"
			-		
Total					

Example: To calculate the percentage of positive answers for having had schistosomiasis.

(No. positive for "schistosomiasis"/Number interviewed) x 100 = % positive (positivity rate)

i.e.

Column 5 x 100 = Positivity (%) Column 2

#### **DATA ANALYSIS continued**

#### STEP 2. Compile results for all survey sites (schools)

Record the percentage of positive answers for each school on a summary form (Table 2).

#### STEP 3. Show which communities are most at risk

#### 1 Prepare a ranking-list

Use the percentage of positive answers for having schistosomiasis, recorded in Table 2, to rank the schools. (For the school with the highest percentage write "1" in column 3, for the next school write "2", etc...)

Make a new list in which the schools are arranged in order of rank.

#### 2 Make area or district maps

Maps showing the prevalence of positive answers for each school will show whether there are clusters of high prevalence communities. An example is given in Appendix 2.

The map could show different rates of positive answers by using different colours or symbols,

e.g. positive answers: 50% or more \*

35% - 49% +

below 35% o

Table 2. Summary form for school positivity rates

District:		Date:	
School	Percentage +ve "blood in Urine"	Percentage +ve "schistosomiasis"	Rank*
		,	
		·	
			1

<sup>\*</sup>The rank should be based on the percentage of positive answers to the question "Did you have schistosomiasis?"

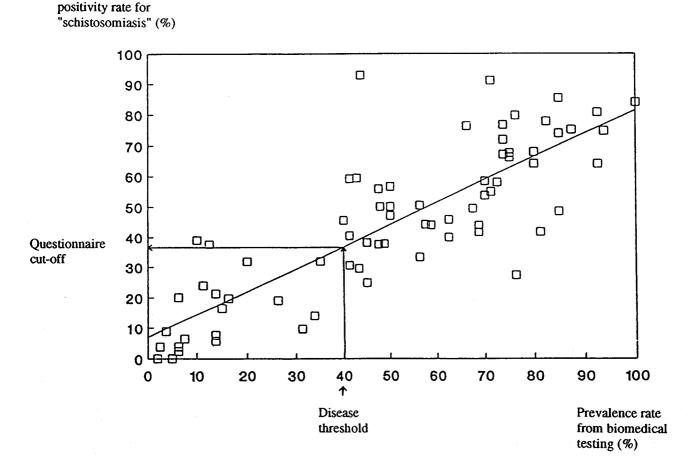
## 2.6 DETERMINATION OF A CUT-OFF VALUE (OPTIONAL)

The first step is to carry out biomedical testing in a sample of schools. At least 60 schools should be randomly selected. The same children or classes should be interviewed using the questionnaires, and screened for *S. haematobium* infection by testing for blood in urine using reagent strips, or by another biomedical method. (The procedure is essentially the same as that for validation of the method, Section 3).

If reagent strips are used, the testing can be carried out by the teachers, after they have been shown how to use the method in a short training-workshop. This procedure has been found to be satisfactory in several African countries<sup>3</sup>.

The questionnaire cut-off point can be determined by plotting a graph of %positive answers against %prevalence by biomedical testing (Fig.2). Taking a pre-determined "disease threshold", the percentage of positive answers corresponding to that disease level can be found. This will define the cut-off point in terms of the questionnaire survey; that is, the threshold above which a school will be described as "positive" on the basis of the questionnaire results (Section 1.2.1).

Figure 2. Relationship between disease threshold and questionnaire cut-off value.



Questionnaire

#### SECTION 3. VALIDATION OF THE METHOD

The "indirect interview" approach using questionnaires, as described in this manual, is a method for diagnosing urinary schistosomiasis at community level. It is based on the hypothesis that if communities are ranked according to the percentage of positive answers to the questions "Did you have blood in your urine?" or "Did you have schistosomiasis?", the rank-order will be the same as that obtained by ranking them according to the actual prevalence of schistosomiasis. Like every new technique, the questionnaire approach first had to be validated to check that this hypothesis is true, by comparing the results for the new approach with those obtained with standard tests.

The "questionnaire" method for determining communities at high risk for urinary schistosomiasis was validated in eight African countries; Cameroon, Congo, Ethiopia, Malawi, Tanzania, Zaire, Zambia and Zimbabwe <sup>1,3</sup>. The prevalence of urinary schistosomiasis obtained using the questionnaire survey was compared with the prevalence obtained using urine filtration and/or testing for haematuria with chemical reagent strips.

In all but one country (Ethiopia) the method was found to work well for "community diagnosis". It was shown to have a very high negative predictive value, so that it is safe to use it to identify communities with a low prevalence, so that they can be excluded from the first phases of a control programme and resources concentrated elsewhere. (A few communities with only moderate or low prevalences may not be excluded, because the questionnaires do not have 100% accuracy. But including a few communities which do not really need intervention is less dangerous than missing some that do.)

The validation procedure and results have been described in a detailed report<sup>3</sup>.

N.B. The questionnaire method has not been validated as a tool to identify individuals for treatment, and should not replace other diagnostic tests for that purpose.

#### 3.1 POSSIBLE REASONS FOR CARRYING OUT FURTHER VALIDATION

It is not necessary to validate the questionnaire approach before using it, since it has already been shown in a number of settings that there is a consistent correlation between the results obtained and those of biomedical tests. There are, however, some situations where further validation will be needed, or might be useful:

- When significant changes have been made to the questionnaire. Only the questions given in this guide have been validated.
- Where the endemic setting is very different from those already investigated.
- Where health authorities are not convinced about the usefulness of the method, validation might provide stronger arguments. However, it should be sufficient to refer to the results of the studies already carried out.

#### 3.2 VALIDATION OF THE METHOD: OUTLINE OF PROCEDURE

#### **Procedure**

At least 60 schools should be randomly selected. The same children or classes should be interviewed using the questionnaires, and screened for haematuria or S. haematobium infection.

Reagent strips to test for blood in urine are recommended for the screening process, since they reflect the morbidity due to *S.haematobium* infection better than parasitological techniques do. In 5 countries where the "indirect approach" was validated, teachers were asked to do the testing. Their results using reagent strips correlated well with those for urine filtration, as well as with a history of schistosomiasis, and were as accurate as those obtained by biomedical teams.

#### Results

- 1 Plot a graph as in Figure 2 (Section 2.6) to compare the results obtained with the questionnaires (the percentage of children saying they had had schistosomiasis) with the prevalence of infection as determined by biomedical testing. The points should be grouped around a straight line. If they are not, this is an indication that in this particular situation the questionnaire approach does not work. For example, the levels of haematuria might generally be so low that children do not notice the symptom, or the procedure might not have been well understood.
- 2 Calculate the diagnostic efficiency of the questionnaire approach (the sensitivity and specificity, and the positive and negative predictive values).

The first step is to set the cut-off point; the **high-risk limit** or **intervention threshold** (see Sections 1.2.1; 2.6). This is the haematuria rate or parasitological prevalence at which a school is defined as "positive" - that is, where the prevalence is high enough to justify control measures. It is then possible to determine the questionnaire threshold which is equivalent to this prevalence, and to calculate the diagnostic efficiency of the questionnaire in identifying which schools are in the positive category.

The calculation of diagnostic efficiency has been described in detail elsewhere <sup>1</sup>.

Validation is not a pre-condition for using the questionnaire approach.

It simply gives more refined criteria, where necessary, for its use in a particular endemic area.

#### **SECTION 4. EXTENSIONS OF THE METHOD**

#### 4.1 A FURTHER USE OF QUESTIONNAIRES; RANKING PRIORITY PROBLEMS

The consequences of schistosomiasis infection in terms of health status and morbidity have been described <sup>5</sup> and new tools for assessing morbidity continue to be developed <sup>9</sup>. However, less is known about how the individual in an endemic setting perceives the infection and consequent disease, and how the problem is viewed in relation to other problems in the community. Where people are aware of a problem they may be in a better position to participate in the solving of that problem.

In the African countries where questionnaires were tested for rapid assessment of schistosomiasis, a questionnaire was also sent at the same time to Head Teachers, and sometimes other members of the community like party leaders. There is an example of such a questionnaire in Appendix 3. These were "self-administered" questionnaires, and the objective was to find out how these key informants perceived schistosomiasis and its relationship to other health problems in the community. The informants were asked to rank six common diseases and six common symptoms, and name six health problems in the community to which they would give priority for control. The responses were variable within and between countries, but in general where schistosomiasis was of relatively high prevalence, informants also gave schistosomiasis a high rank. Moreover, the rank teachers gave to schistosomiasis was significantly associated with the proportion of children reporting a history of schistosomiasis.

The sample questionnaire in Appendix 3 might have to be modified for use in other places. For example, the lists of symptoms and conditions would have to be adapted to the local epidemiological situation.

The results of earlier studies <sup>3</sup> showed that the children's questionnaire is a more powerful tool for diagnosis of high-prevalence communities than the Head Teachers' questionnaire. However, questionnaires filled in by Head Teachers and other key informants can provide information of a different kind, by showing how people in the community perceive schistosomiasis in relation to various other health problems. Such information is also important for control programmes, because when the members of a community are conscious of a problem they are more likely to support and sustain intervention measures.

The questionnaires will provide information as to which communities perceive urinary schistosomiasis as a problem. But in addition, the answers can provide information about other health problems. This information should not remain with the schistosomiasis control programme, but be shared with other health workers, and with those responsible for planning the overall health policy of the district.

#### 4.2 FURTHER ANALYSIS; THE INFLUENCE OF GENDER

Girls and boys may have different perceptions of having schistosomiasis. The possibility that gender may affect the conclusions from the survey was investigated in three countries (Cameroon, Malawi and Zaire) during the "7-country study" 3

The results indicated that there were differences. Girls answered "No" to the question "Did you have blood in your urine" more often than would have been expected on the basis of the true prevalence of infection. This might have been due to the level of infection being lower among girls, so that haematuria was less easily seen. It may also simply be easier for men and boys to observe blood in their urine. However, there is evidence from other studies that in some places, for cultural reasons, older girls do not want to admit to having blood in their urine <sup>3</sup>.

The questionnaires provide information about the sex of the pupils. Therefore the results could be analyzed separately by sex in order to find out how important gender-differences really are.

#### 4.3 EXTENSION OF THE APPROACH TO OTHER DISEASES

There is already some evidence that the questionnaire approach may also work for intestinal schistosomiasis <sup>3</sup>. The approach is currently being tested more extensively for infection with <u>S.mansoni</u> and for other types of helminths.

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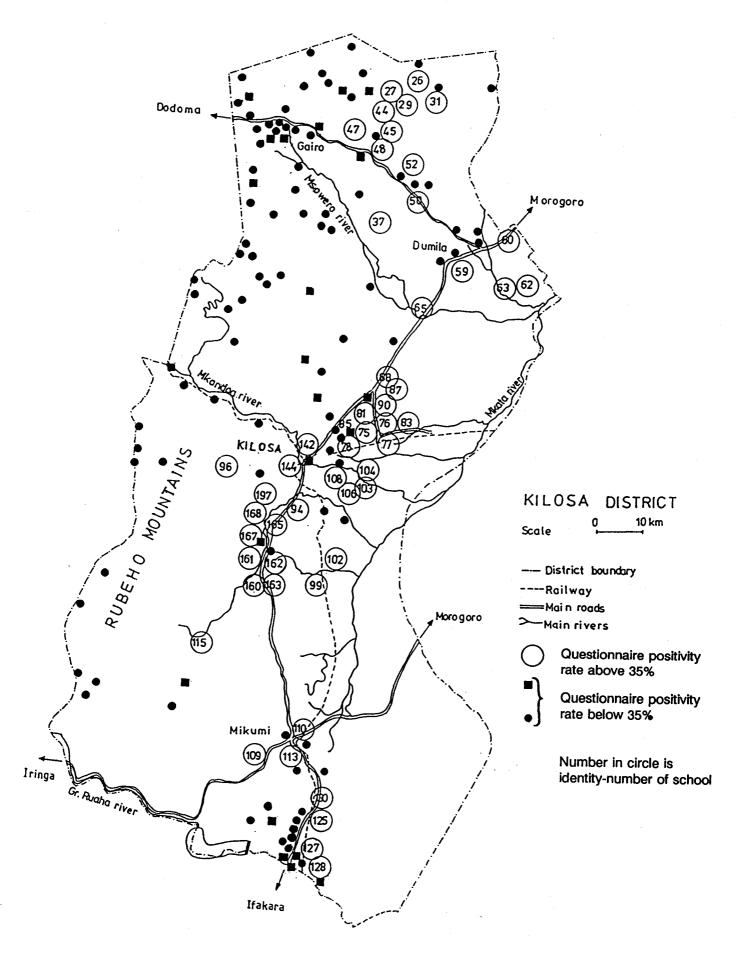
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Acta Tropica 51, Special Issue

	HEALTH RESEARCH IN PRIMARY SCHOOLS OF THE KILOSA DISTRICT - DISTRICT EDUCATION OFFICE	
	Questionnaire 2: Questions concerning the health of pupils	
	Explanation: Put a mark V for "yes" or a o for "no" and a dash — if the child does not remember or can not answer. You have to answer the following questions. Each box is for only one child. If the boxes are not enough on one page, use the back. Return this sheet to the Headteacher. Thank you!	
	Name of school	
	Pupils 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35	
	Age Age	
	Sex (H/F)	
	Question 1: Which of the following symptoms did you experience during the last month?  Put a mark [7] or a [ -] in the boxes in front of corresponding symptoms.	
	Coughing	
Ц	Itching	
	Headache	
1	Abdominal pain	
Ц		
Ш	Blood In Stool	
	Question 2: Which of the following diseases did you experience during the last month?  Put a mark of or a of or a finithe boxes in front of the corresponding symptoms.	
L	. Halaria	
Ц	01 arrinoea	
	Skin diseases	
	Eye diseases	
<u></u>	Respiratory infect.	
U	Violence	
╚	· Abdominal problems	
		٦

## APPENDIX 2 Example of a map



	HEALTH SITUATION IN THE SCHOOLS OF THE KILOSA DISTRICT  QUESTIONNELLE 1: To be filled in by the Headteacher  Renk 6	The purpose of this questionnaire is to assess the health situation in the schoolchildren of the Kilosa District. There are two questionnaires to fill important.  The first is this one, to be answered and fillad by the headteachers.  In. The first is this one, to be answered and fillad by the headteachers.  In. The first is this one, to be answered and fillad by the headteachers.  In. The first is the answered and fillad by the headteachers.  In. The first is the answered one fillad by the headteachers.  In. The first is the answered one fillad by the headteachers.  In. The first is the answered one fillad by the headteachers.  In. The first is the answered one fillad by the headteachers.  In. The first is the beautiful fillad by the headteachers.  In. The first is the forms to the forms to the District Education Office, before Auvert 12.  Name to a fill does are return the forms to the District Education Office, before Auvert 12.	Name of school:  Ward:  Ward:	Rank 4  Among the following list of symptoms, please choose the 6  Among the following list of symptoms, please choose the 7  Among the following list of symptoms, please choose the 7  Among the following list of symptoms, please choose the 7  Among the following list of symptoms, please choose the 7  Among the following list of their list of symptoms, please choose the following list of their list of symptoms and the following list of their list of symptoms and the following list of their list of symptoms and the following list of their list of symptoms and the following list of their list of symptoms and the following list of their list of symptoms and the following list of their list of symptoms and the following list of their list of symptoms and the following list of their list of symptoms and the following list of their list of symptoms and their list of symptoms and their list of symptoms and the followin	Thenk you for your help I District Education Officer Kilose District, Kilose.
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